Exploring Experiences of Informal Caregivers with Hospital Care at Home for patients with Heart Failure

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Abstract

Title Exploring Experiences of Informal Caregivers with Hospital Care at Home

Background Hospital care at home is a nurse-led program for patients with deteriorated heart failure with continuous intravenous medication. Informal caregivers of patients with heart failure are known to experience problems with their own well-being, having insufficient support and have lack of knowledge. These may increase during the program. However, the experiences of informal caregivers with hospital care at home are yet unknown.

Aim The study aims to explore the experiences with hospital care at home of the informal caregivers of patients who were enrolled in the hospital care at home program for deteriorated heart failure.

Method A generic explorative qualitative study was conducted, with use of semi-structured interviews of informal caregivers. Data were analyzed using thematic analysis by Braun and Clarke.

Results During the analysis of the ten interviews five themes emerged: 1)Motivations for hospital at home, where informal caregivers saw it as their task as significant other, 2)Process of the program, where informal caregivers lacked information, 3)Mental load for informal caregiver, 4)Persevere hospital at home program and 5)Context, where home situation and patient characteristics influenced the burden of informal caregivers.

Conclusion Informal caregivers had doubts about safety by lacking information about the program. Their home situation and the patient characteristics influenced the burden of the informal caregivers. However, they saw it as their task as significant other to take the role of informal caregiver during the program.

Implications of key findings It is recommended to investigate how informal caregivers can be educated about the program. Also, health professionals involved in the program need to be aware of the context of the informal caregiver and patient in order to arrange a sufficient support system.

Keywords Informal Caregivers, Hospital based Home Care Services, Heart Failure, Nursing, Experiences

Nederlandse samenvatting

Titel Verkenning van ervaringen van mantelzorgers met ziekenhuiszorg thuis

Achtergrond Ziekenhuiszorg thuis is een door verpleegkundigen geleid programma voor patiënten met een verslechtering van hartfalen met continue intraveneuze medicatie. Van mantelzorgers van patiënten met hartfalen is bekend dat ze problemen ondervinden met hun eigen welzijn, onvoldoende ondersteuning ervaren en gebrek aan kennis hebben. Deze problemen kunnen tijdens het programma ziekenhuiszorg thuis toenemen. De ervaringen van mantelzorgers met ziekenhuiszorg thuis zijn echter nog niet bekend.

Doel/onderzoeksvraag Het doel van de studie is om de ervaringen met ziekenhuiszorg thuis te onderzoeken van de mantelzorgers van patiënten die werden behandeld door ziekenhuiszorg thuis voor verslechterd hartfalen.

Methode Het betreft een generiek verkennend kwalitatief onderzoek, waarbij gebruik is gemaakt van tien semigestructureerde interviews van de mantelzorgers die met thematische analyse van Braun en Clarke zijn geanalyseerd.

Resultaten Tijdens de analyse van de tien interviews kwamen vijf thema's naar voren: Motivatie voor ziekenhuiszorg thuis, waar mantelzorgers vonden dat het hun taak was, Proces, waar mantelzorgers onvoldoende informatie over ziekenhuiszorg thuis hadden, Mentale belasting van de mantelzorger, Volhouden van ziekenhuiszorg thuis en Context, waar de thuissituatie en patiëntkarakteristieken de belasting van de mantelzorgers beïnvloedden.

Conclusie Mantelzorgers twijfelden aan de veiligheid door een gebrek aan informatie over ziekenhuiszorg thuis. Hun thuissituatie en patiëntkenmerken hebben de belasting van de mantelzorgers beïnvloed. Ze zagen het echter als hun belangrijke taak om de rol van mantelzorger op zich te nemen tijdens ziekenhuiszorg thuis.

Aanbevelingen Het wordt aanbevolen om te onderzoeken hoe mantelzorgers beter kunnen worden voorgelicht over ziekenhuiszorg thuis. Ook moeten zorgprofessionals die bij ziekenhuiszorg thuis betrokken zijn op de hoogte zijn van de context van de mantelzorger en de patiënt om toereikende ondersteuning voor hen te kunnen organiseren.

Sleutelwoorden mantelzorgers, ziekenhuiszorg thuis, hartfalen, verpleging, ervaringen

Introduction

Heart failure is a common condition with high morbidity and a one-year mortality of 25-35%(1-3). Heart failure is a syndrome with various symptoms such as shortness of breath, edema and fatigue, caused by dysfunction of the heart(3). The incidence and prevalence are the highest for older patients(4). More than 16% of people over 80 years have been diagnosed with heart failure worldwide(3). Deteriorations, when patients experience a worsening of symptoms, occur regularly(5) with frequent indication for hospital admission(6). After admission, 22-30% experience readmission within one year(3). Hospital admissions are associated with long stay(7), delirium, falls, infections(8,9) and high costs(10). Therefore, it has been suggested that hospital care at home (HaH), also known as hospital based home care services, would be a better(11) and more cost-effective(12) alternative for patients.

HaH is a nurse led program, where specialized intensive or cardiac care nurses from the hospital, visit patients with an indication for hospital admission for deteriorated heart failure at home on a daily basis. Patients receive continuous intravenous medication, also known as home infusion therapy(13). The need for intravenous medication is an indication to receive HaH. Specialized nurses take blood samples for laboratory testing, do physical examinations and assess whether more information is needed or wanted about the disease, diet or medication.

The experiences of informal caregivers (IC; significant others) in the HaH program for deteriorated heart failure are yet unknown. The availability of ICs during HaH may increase quality of life of patients with heart failure(14,15). However, it is shown in France that ICs experience several problems in providing care for patients with heart failure, including performing multifaceted roles, maintaining their own well-being on physical, emotional, social, spiritual and financial dimensions, performing caregiving with inadequate knowledge and having insufficient caregiver support(16). During HaH, ICs must be available for the patient during the treatment. This leads to a decrease of their freedom and more responsibilities. Patients rely on their IC during the day, instead of nurses, when they have a regular hospital admission. These factors increase the impact on the daily lives of ICs(17,18) and may worsen problems they already experience(16). Also, not being in the hospital may cause feelings of unsafety for the IC(19), caused by not having a medical team on a ‘call button’ away. It is seen in local practice that when ICs cannot handle the extra care, patients end up in the hospital after all. Literature shows limited knowledge of experiences of ICs of patients with deteriorated heart failure with regular hospital admission(20,21) and no knowledge of experiences with the HaH program.

Lately there have been suggestions to increase HaH for more patient groups. Health insurances and the Dutch Healthcare Authority support initiatives of hospitals providing HaH.

The experiences of ICs of patients who received this treatment can help to develop other nurse-led programs for HaH. Therefore, in order to improve the HaH program, tailor it to the experiences of ICs and reduce hospital admissions caused by overburden of ICs, the experiences of ICs need to be explored.

Objectives

The objective of the study was to explore the experiences with hospital care at home of informal caregivers of patients who were enrolled in the HaH program for deteriorated heart failure.

Method

Design, Population, domain and Setting

This study had a generic qualitative explorative design. Semi structured interviews were conducted and a thematic analysis was used(22). COREQ (Consolidated criteria for reporting qualitative research) was used to report this study(24).

ICs were included from the population of patients who were enrolled in the HaH program for deteriorated heart failure of a tertiary hospital in the Netherlands. The purposive samples, performed to create a wide variety in the sample, were based on stage of heart failure, earlier hospital admission and comorbidities of the patient, relation to the patient and age and gender of both patient and IC. In order to be eligible for the study, the patient must have been enrolled in the HaH in the last 6 months. ICs who had medical diagnosed cognitive impairments or did not fluently speak and read Dutch were excluded. The interviews were conducted in February and March 2020 in the homes of the ICs and were audiotaped with a voice recorder.

Data collection

All participants were called by nurses of the HaH program, to get consent for approach by the researcher. The researcher then called the ICs for further information about the study and to make an appointment for a face to face interview or an interview by telephone (Figure 1). The main topic during the semi-structured interviews was the broad experiences of the IC. This main topic was further explored with the following topics (Appendix A): Upsides, Downsides, Feelings of safety, Burden of caregivers, Differences with regular hospital admissions. These topics were based on relevant literature and experiences with the current practice in the HaH program(19-21). The topic list was tested during the first interview and evaluated with two researchers (EN and LG), resulting in adding two questions regarding the process of the HaH program. Memos on behavior, emotions and relevant events were made during and after the interview. The sample size was based on saturation, defined as no emerging of new information on the last two interviews(25). After eight interviews, only one new code emerged from the data. After 10 interviews saturation was reached, as no new codes emerged from the last two interviews.

[Insert Figure 1]

Member checking

Member checking helped to assess the researchers interpretation and understanding of the data(26). A narrative summary of the interview, made by the researcher, was sent to eight participants, as two of the participants did not want to do a member check. The participants had no additional comments on the narrative summaries.

Data analysis

All interviews were transcribed verbatim by the executive researcher within seven days after the interview, so the researcher could recall the interview. Memos were used to provide additional information during transcription and coding. After reading and re-reading the transcripts of the interviews, codes were created using NVivo software for qualitative analysis by the executive researcher. After four interviews, axial coding was performed to create categories. At last, when categories were defined for all interviews, selective coding was applied, to find core concepts that could answer the research question(22,23). Codes, categories and themes were discussed in the research group to create rigour. The total process of analysing was an iterative process where constant comparison took place.

Ethical considerations

The investigation conforms with the principles outlined in the Declaration of Helsinki(27) and with the Medical Research Involving Human Subjects Act. The study protocol was assessed by the Medical Ethics Commission of the tertiary hospital with the HaH program. The Commission provided a waiver of consent to perform the study. The General Data Protection Regulation (AVG) was applied in the data handling. ICs could use the time between the phone call from the researcher and the interview to reconsider their participation in the research. Before all interviews, informed consent was signed by the researcher and the IC.

Results

A total of ten ICs were contacted, three male, seven female (Table 1), none refused. Eight interviews were conducted at the home of the ICs, two by telephone. One IC insisted on the presence of the partner during the interview. The mean duration of the interviews was 37 minutes. The patients were enrolled in the HaH program between October 2019 and

February 2020. After analysis, five themes emerged regarding experiences of ICs with the HaH program: Motivations for HaH Program, Process, Mental Load, Perseverance HaH Program and Context (Figure 2). The codebook is available in Appendix B.

[Insert Table 1 and Figure 2]

Motivations for HaH program

At the start of the interviews many ICs immediately talked about their wishes and preferences choosing the HaH program, the experienced benefits of HaH and their role as IC during HaH.

Wishes and preferences choosing HaH program

The majority of the ICs had a strong wish to let the patient enroll in the HaH program. Others followed the wish of the patient. Even when the patient resisted against regular hospital admission and would rather avoid treatment.

> *He never would have stayed in the hospital. He just would not have done it.(I1)*

> *I'd rather have her here than in the hospital, for herself, too.(I2)*

All ICs gave the preference to HaH in the future, after their experiences with HaH. Only when the doctors say it is safe and their own health allows it.

> *The last time we asked ourselves if she could enroll in the HaH program again. Because that was so good before.(I4)*

Experienced benefits HaH program

Compared to hospital admission, HaH was seen as a treatment which brings more rest in the lives of the patient and IC. Not only by fulfilling the wish of the patient, but also with benefits like less travel time, being in your own environment, no visiting hours, better sleep and more privacy for the patient.

> *..In the hospital she sleeps less...it is often early and restless on the ward.(I7)*

..But when she wanted a cup of tea, go to the bathroom or read the newspaper, all of that was much easier… And at home it is much easier for a caregiver to have a quick look.(I10)

ICs were very satisfied that nurses had more time for the patient, and for them. They got involved in the communication during the home visits, as nurses have all focus on one patient and IC at a time.

What struck me is that they took so much time for us, including me. I really liked that.(I3)

Role IC

ICs saw it as their natural task to take the role of IC during the HaH program. There was an increase of regular tasks such as cooking, doing chores and getting groceries. But also more caregiving tasks as helping getting the intravenous catheter (IV) through the clothes and helping showering. Despite these extra tasks, ICs could not imagine saying no to their significant other.

I'm married to him, so if I can take care of him, I'll take care of him.(I6)

I cannot imagine saying: admit yourself in the hospital, because I don't have time supporting you during the HaH program.(I1)

ICs had the feeling they could be of value to the other during HaH, by doing these extra tasks.

Here I can help her, with showering or whatever. I can help her in all sorts of ways.(I2)

Process

ICs had experiences with the start and end of the HaH program, but also in switching between hospital admission and the HaH program.

Start HaH program

Most ICs lacked knowledge about the HaH program which would have helped to take control in arranging the right care at the right time and even start the treatment sooner.

I didn’t know about the HaH program, and when I heard about it, I thought: genius, I should have known this earlier.(I1)

The waiting time at the emergency department before enrolling in the HaH program was a strongly mentioned hindering factor.

You wait in the emergency department for 3 hours. I think that is the only disadvantage.(I5)

However, some ICs experienced the start of HaH without a visit to the Emergency Unit and found that very satisfying.

When I call, they come right to our house. We do not have to come to the hospital anymore. That is well organized.(I2)

Switch between hospital admission and HaH program

ICs experienced a switch between hospital admission and HaH. They were not prepared to go home with the patient and worries arose. They wanted to take care of practical things, but also needed time to process all the information to feel safe to take the patient home.

Like, oh shit, he's going home, he's got an IV, who's going to take care of him? How come you have to be hospitalized one minute and then go home the next.(I1)

..he could go home right away, but I said no, wait a minute, I have to take care of transport, I still have to do that. I said stay until tomorrow, then I'll pick you up tomorrow.(I6)

End HaH program

Some ICs expected the end of the program, while others did not. Expectations about the end of the program were related to the duration of the program. Some patients were only treated for a few days and recovered quickly, while other patients were treated for two weeks and ICs could prepare themselves for the end of the program.

But suddenly he was disconnected and had to do it alone.(I1)

It was fine to end the treatment.. She also noticed at this moment .. the weight is stable.(I7)

ICs experienced at the end of the program uncertainties about the future of the patients with heart failure. During the program there was the safety of daily checks by skilled nurses. When the program was over, some felt they just had to wait until the patient needed another treatment.

We hope that she can make it with a treatment once a year or once every six months… well, it is just going right until it is going wrong. Then we ask for medical help.(I7)

Mental Load

Most of the participants mentioned worrying, safety and their feelings as important parts of their experience with the HaH program.

Worrying

During HaH, many ICs worried about the patient falling and death. But also how the first night would go and if the treatment works. ICs tended to arrange extra care during the night for their own peace of mind.

I'm worried about him falling … and that he is lying there.(I1)

The first night he was home alone .. I found very difficult. What if something goes wrong .. my brother stayed for the night, just to be sure.(I1)

The worrying about falling and death was not only present during HaH, but also during hospital admissions and during daily life.

In the hospital they can also fall. … that makes no difference.(I10)

The doctor said he was very ill, … I thought, soon I will be here all by myself.(I6)

Safety

All ICs experienced safety during HaH. The main reasons for feeling safe were the daily checkups by the nurses and the own support system of the patient.

Yes, I felt safe. And if something is wrong, I can always ask the neighbors.(I6)

Everything was examined… and we had homecare... and we as family take turns in stepping by. And the neighbors had a key.(I8)

ICs were well instructed by the HaH nurses to use an emergency telephone number, which was quickly answered when needed.

..the phone was immediately answered. Not that you panic like what should I do now.(I8)

Also, being in their own environment, where some made some changes in the homes to increase safety and trust in the doctors decisions contributed to the feeling of safety.

I don't think the hospital would have sent him home otherwise.(I9)

Feelings

ICs had different feelings about HaH. Some felt relieved to fulfill the wish of the patient to stay home, others felt powerless and out of control because the patient needed another treatment.

There is nothing I can do about the process. You're on the sidelines there. You cannot do more.(I2)

The worries were more now, but I went to him with a happier feeling.(I1)

Some ICs did not feel powerless at all and experienced they were more in control during the HaH program, in comparison with a hospital admission.

You get more insight in the treatment... Now you could see what was happening and they explained what they were doing.(I10)

Perseverance HaH program

Burden of the IC, Problems during the HaH program and Clarity influenced ICs to preserve the HaH program.

Burden IC

ICs experienced burden at different levels. Some had the same regular daily rhythm, while others felt HaH time consuming. Some even said HaH gave less burden than a regular hospital admission.

> *If I had to express it in percentages, the burden during home treatment is more than 50% lower than during hospital admission.(I5)*

ICs who experienced extra burden, could only keep that up for a couple of weeks.

> *Well I must say if you have to do that for weeks or months... it took two weeks all together, that is doable.(I8)*

Problems

A few ICs recalled any problems during HaH: insufficient results of the medication, kidney failure and going in to the palliative phase. Regular telephone communication with the cardiologist helped to persevere the HaH program.

> *The treatment didn't work fast enough. There were regular calls with the cardiologist and medications were adjusted several times.(I4)*

Clarity

ICs felt supported in persevering HaH by the clarity of the program. Knowing it would take days or weeks instead of months helped them.

> *You know it's been a few days. If they tell you well, this is going to be long, this will take six weeks, then you will think very differently.(I5)*

Also, the impact on the daily lives was reduced by the clarity and punctuality of the nurses of the HaH program.

> *They agreed on a time and came at that time... They were here according to their agreement.(I3)*

Context

Home situation and patient characteristics influenced the experiences of the IC.

Home situation

Some ICs lived with the patient and their family in the same home or street, while other ICs had busy jobs and their own family to take care of besides the patient in the HaH program. ICs tried their best to make sure that the patient and their family did not suffer under the HaH program, instead they sacrificed their me-time. This finding is connected with perseverance, where knowledge about the duration helped them to preserve the HaH program.

I don't think my family suffered. I was there when they needed me. But me-time was gone.(I1)

Characteristics patient and heart failure

Most patients were independent or there was sufficient home care. One patient was diagnosed with dementia, which brought a higher burden for the IC in comparison with an independent patient. The ability of the patient to ask for help when needed and knowledge about their illness makes it easier for ICs to cope with the patient.

For years she wrote down her weight every day.(I7)

He did not want to be confronted with the hospital, he did not find himself sick enough.(I1)

Discussion

This qualitative study identified broad experiences of ICs with the HaH program. During the analysis of the ten interviews five themes emerged: Motivation for HaH Program, Process, Mental Load, Persevere HaH Program and Context. This study had three main findings. First, at the start of the HaH program, ICs lacked information to have full confidence in the safety of the program. Second, the home situation of the IC and patient characteristics influenced the burden of the IC during HaH. And finally, ICs saw it as their task as significant other to take the role as IC during the HaH program.

At the start of the HaH program, ICs doubted the safety of the HaH program. Some had to switch between the thought of hospital admission and the HaH program. One of the reasons for this switch was unfamiliarity with the program and not knowing if it is safe, as mostly, the option of going home was unexpected and ICs were not prepared. In this decision making process, communication is key. Nurses need to engage in a conversation about preferences with both the patient and the IC (28). Also, the way you communicate influences the process of decision-making, where knowledge about treatment and care is essential(29). In this study, ICs also gained trust in the HaH program by getting involved and informed by the HaH nurses.

The home situation of the IC and patient characteristics influenced the burden of the IC during HaH. This was comparable with other studies were also the degree of dependency on the IC and the time the patients need was related to the impact the HaH program has for ICs(17-18). In addition, this study found a relation between the higher burden of ICs and persevering the HaH program.

Despite the doubts and burden of the ICs, they saw it as their task as significant other to take the role as IC during the HaH program. They could not imagine refusing their significant other. This was also seen in other studies of the motivations of ICs (30). The consequence of this phenomenon is that it leads to a higher risk of decreased well-being of ICs, as they can feel obligated to take care of the significant other (31). This study found ICs experienced similar problems during HaH program in comparison to outside the HaH program. However, the HaH program can be of added value when it comes to uncertainty and lack of knowledge of ICs. Also, the HaH program can help ICs to arrange the right support, like increasing home care for the patient to reduce burden of the IC. This means the HaH does not have to increase problems of ICs, but also have the abilities to decrease them.

Strenghts & limitations

Strengths were that this study included a wide variety of ICs, to gain a broad insight in their experiences. Also, the codes and themes during analysis were created using peer feedback to increase rigor. A limitation could be that one interview was done by telephone on request of the IC and one interview was done by telephone due to the corona crisis. However, other research showed no limitations in telephone interviews in this type of research(32). Another limitation was that one interview the patient was also present. This may have affected the information the IC provided. Finally, selection for participants was done by nurses of the HaH program. Despite being instructed to provide a wide variety of ICs, their own experiences may have influenced selection.

Implications for clinical practice and future research

This study examined the experiences of ICs during the HaH program and gave insight in their thoughts. In order to improve the HaH program, it is recommended to investigate how to improve communication and educate patients and ICs about the HaH program. Health professionals involved in the HaH program need to be aware of the home situation and arrange extra home care when necessary. As ICs were very positive about the HaH program, it is recommended to expand the program for more patients with heart failure and the experiences can be used to create HaH programs for other patients.

Conclusions

This study found that ICs lacked information at the start of the HaH program to have full confidence in the safety of the program. Also, the home situation of the IC and patient characteristics influenced the burden of ICs during HaH. However, ICs saw it as their task as significant other to take the role as IC during the HaH program.

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Tabels/ figures

Tabel 1

Baseline characteristics.

	Informal caregiver				**Patient**				**HaH program**	**Interview**
Interview	Age	Gender	Relation to the patiënt	Comorbidities*	Age	Gender	Stage of heart failure	Comorbidities*	Duration (days)	Duration (minutes)
I1	52	Female	Daughter	None	90	Male	First admission	1, 10	7	45
I2	79	Male	Spouse	None	78	Female	Terminal	1, 3	14	60
I3	83	Female	Spouse	5	88	Male	First admission	1, 5, 8,9	6	45
I4	77	Male	Spouse	None	76	Female	Chronic	1, 2	10	20
I5	84	Male	Spouse	4	82	Female	Chronic	1	4	25
I6	70	Female	Spouse	1, 4	76	Male	Chronic	1, 3, 7	7	45
I7	53	Female	Daughter	None	81	Female	Chronic	6	10	23
I8	66	Female	Daughter	None	87	Female	First admission	1, 2	21	50
I9	38	Female	Daughter	None	72	Male	Chronic	1, 2, 5	4	25
I10	55	Female	Daughter	None	91	Female	Terminal	1, 4	7	28

**Comorbidities: 1: Cardiovascular diseases, 2: Lung Diseases, 3: Renal diseases, 4: Diabetes Mellitus, 5: Bone System Disorders, 6: Hormonal disorders, 7: Carrier of Resistent Bacteria, 8: Dementia, 9: Urinary system diseases, 10: Neurological diseases*

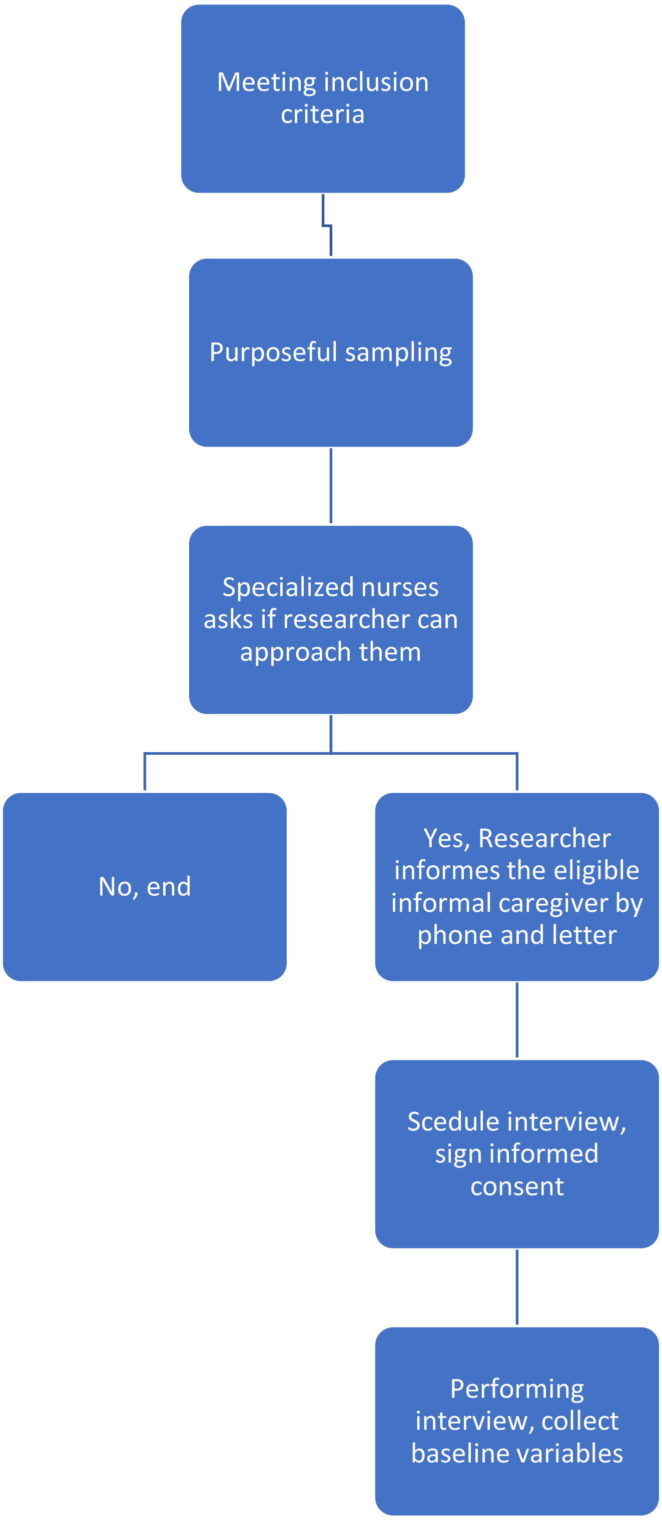

Figure 1. Procedure of inclusion of informal caregivers

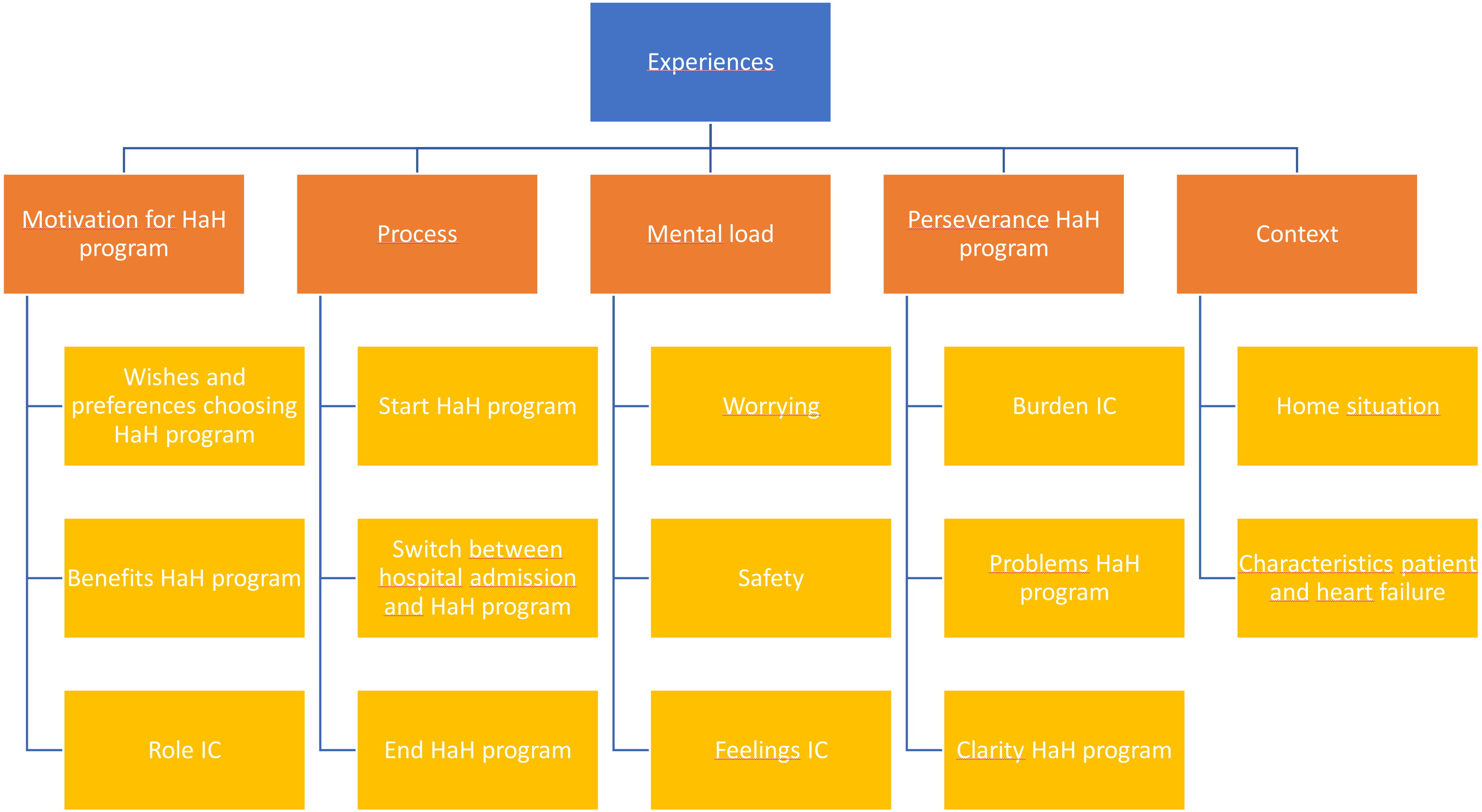

Figure 2. Main themes and categories

Appendix A: Topiclist

Start question	First I want to ask you: how did you experience the HaH program for your partner/father/mother?
General HaH program	What did your day look like during the HaH program?
Pros and cons	What were the benefits of the HaH program?
	What were the cons of the HaH program?
Experiences	How did you experience the safety of your partner/father/mother?
	How did you experience the burden for you as informal caregiver during the HaH program?
	What could you not do what you otherwise could do? And were there things you could do right now, which you couldn't during a hospitalization?
	Can you give examples that made it difficult or not? How was this compared to a previous hospitalization?
Hospital admission	Has your father / mother / partner previously been hospitalized for heart failure? How did you experience safety at the time? How did you experience the tax as a caregiver at the time?
Process	How did the HaH program start? How did you make the choice? How did you get involved in the process? How was the process completed? How do you look back on it? What does it mean to you now? What questions do you still have?

Appendix B: Full codebook

Process	Start HaH program	• Need for more information about healthcare facilities • More capable to take control by experience with home treatment and knowledge of care facilities • The threshold for asking for help with heart failure is lower when the HaH program is known • Threshold to seek help for heart failure symptoms • Enable home treatment by CardioMems data • Long waiting time EHLH • The informal caregiver would have liked to know about home treatment for heart failure • After hospitalization • Unfamiliarity with home treatment and other care facilities • Unfamiliarity with healthcare facilities • Home treatment can be started without a hospital visit
	Switch between hospital admission and HaH program	• Switch between admission and home treatment • Visibility HaH nurses in uniform • Concerns arise between the hospital admission and HaH program
	End HaH program	• End of treatment • End of treatment expected by caregiver • Feeling caregiver about the end of the treatment • Life continues, home treatment comes and goes very quickly • Uncertainty about the course of heart failure • Sudden end of treatment

Mental load	Worrying	• Fear that something will go wrong during HaH program • Fewer concerns with HaH program than with hospital admission • Psychological burden for caregiver • Many care for caregiver during the first night at home • Worry for patient death • Worry about falling
	Safety	• Importance of own environment • By specialized nurses • No continuous monitoring during home treatment • Telephone number easily accessible • less risk of falling at home than in the hospital • Safe feeling through control • Safe feeling caregiver through good network around the house • Safe feeling caregiver because treatment takes place in-house • Feel safe at home, as long as doctors indicate that treatment can still be done at home • Home safety guaranteed by adjustments at home • Prevent hospitalization as much as possible
	Feelings IC	• Coping caregiver to deal with powerlessness • Double feeling of caregiver at home treatment • Keeping your own direction as a caregiver • Frustration about stagnation home treatment • Feeling caregiver at home treatment stagnation

		• Powerlessness of caregiver • Negative caregiver feeling during hospitalization • Conflicting feelings about going home from EHLH
Motivation for HaH program	Role IC	• Attention to caregiver during home treatment • Experience caregiver with heart failure symptoms • No personal care by nurses • Feeling of value as a caregiver • Intense bond between spouses • Life caregiver is all about partner • Informal care is part of the role of a daughter • Caregiver refuses to call in help • Unthinkable to say no to informal care during home treatment • Role as a caregiver from the sidelines • The role of caregiver lies with the person who lives closest to it • Collaboration with the caregiver with other family members • Caregiver tasks • Caregiver duties are part of a role as a spouse • Not a caregiver during previous admission
	Benefits HaH program	• Happy with the result of the HaH program • Lower costs as an advantage for HaH program • Disadvantages of hospital treatment • Privacy

		• Rest for caregiver and patient • HaH program as the norm • HaH program as a plus • HaH program is easy for patients and caregivers • Choosing the future for HaH program • Nurses have more time • Benefits of HaH program
	Wishes and preferences choosing HaH program	• No clear preference for HaH program or hospital admission • Empathy with caregiver in patient's wish to stay at home • Caregiver conforms to patient's wishes • Caregivers opinion is passed by doctor and children • More care for caregiver when patient's wish is not met • Rest for caregiver because the patient's wishes are met • Resistance to hospitalization • Satisfaction of family care through gratitude of the patient • Wish caregiver to have the patient hospitalized • Wish patient known to caregiver • Wish patient more important than burden for caregiver • Desire patient not to be admitted • Desire patient to be treated at home • Wish of both patient and caregiver to be treated by HaH program • Hospitalization only approved for patient when he is seriously ill

Context of home situation	Home situation	- Obstacles to caregiver freedom by living with daughter - Restriction of patient freedom during home treatment - Family does not suffer from home treatment - Caregiver and patient live with daughter
	Characteristics patient and heart failure	- Gaining weight as a symptom of heart failure - Shortness of breath as a symptom of heart failure - Patient involvement in heart failure - Fatigue as a symptom of heart failure - Sobriety patient - Heart failure progression, increase in treatments by HaH program - Symptoms of the dementia patient - Retaining too much moisture - Had delirium during previous hospitalization - Moisture problem not enough reason for hospitalization for patient - Patient's independence - Disease insight patient - Disease course days before HaH program
Persevere HaH program	Burden IC	- Caregiver burden by patient with dementia - Daily patient visit by caregiver - Daily schedule caregiver remains the same during home treatment - Experienced busyness by caregiver during home treatment - No more time for yourself as a caregiver

		Larger network needed as a caregiver Hobbies caregiver High load but can be maintained for a short time Get help from home care Choice of home treatment depends on caregiver condition Caregiver does not experience additional stress during home treatment Caregiver overloaded home treatment takes a lot of time
	Problems HaH program	Dilemma choosing between heart and kidneys Consult a cardiologist during difficult home treatment Home treatment does not work
	Clarity HaH program	Clear agreements by chance @ home Clarity about the duration of home treatment helps to maintain the burden as a caregiver Call earlier that they come by Enjoyable home treatment experience by clarity Different approach by nurses