

Online support for informal carers of persons with heart failure:

Focus on perceptions,
development and experiences

Hanna Allemann

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Errata

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The concept of support, pp. 17.

First sentence should read: Support could be considered *holding* (not as 'either') 'functional' or 'structural' *aspects*.

The second sentence should read: *Structures* (not *structural support*) relates to network...

The third sentence should read: *Functions* (not *functional support*) on the other hand relates...

The concept of support, pp. 18.

Second paragraph, first sentence should read: Holt-Lunstad outlined potential mechanisms linking social connections (i.e., structural, functional and quality *components*) (not *of support*).

Second paragraph, sixth sentence should read: Holt-Lunstad proposes that low levels of *social connection components* (not *support*) in relation to.....

Findings, pp. 45

First sentence should read:...I) social support from friends, family and significant others is an important factor for the (not *their*) health and well-being *of the person with HF*

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Online support for informal carers of persons with heart failure:

Focus on perceptions, development, and experiences

Hanna Allemann



Department of Health, Medicine and Caring Sciences
Linköping University, Sweden
Linköping 2023



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To my father, who would have been the proudest of me for
doing this work.

"Hope there's someone
who'll set my heart free, nice to hold, when I'm tired..."

Anthony and the Johnsons

CONTENTS

ABSTRACT	1
SVENSK SAMMANFATTNING	3
LIST OF PAPERS	5
ABBREVIATIONS.....	7
PREFACE	9
INTRODUCTION.....	11
BACKGROUND.....	13
Living with heart failure.....	13
Informal care	13
<i>Zooming out: viewing caregiving from a societal perspective</i>	<i>14</i>
<i>Zooming in: viewing caregiving from the carers' perspective</i>	<i>15</i>
The concept of support.....	17
<i>Online support</i>	<i>19</i>
Involving end-users in research and development	20
RATIONALE FOR THE THESIS.....	23
AIMS.....	25
METHOD	27
Design and settings	27
Participants.....	28
<i>Procedures for inclusion of participants.....</i>	<i>28</i>
Data collection.....	29
<i>Study I.....</i>	<i>29</i>
<i>Study II.....</i>	<i>31</i>
<i>Study IV</i>	<i>33</i>
Data analysis.....	35
<i>Study I.....</i>	<i>35</i>
<i>Study II and IV.....</i>	<i>36</i>
Co-designing of an online support programme	37
<i>Group discussions for testing of a paper prototype</i>	<i>39</i>
<i>Individual sessions for testing an online version</i>	<i>41</i>

<i>A final testing</i>	41
<i>An iterative process</i>	41
<i>Published but not publicly available</i>	42
Philosophical assumptions in relation to this thesis.....	43
Ethical considerations	43
FINDINGS.....	45
Study I.....	45
<i>Demographic background data</i>	45
<i>Perceived social support</i>	46
<i>Variables independently associated with social support</i>	46
Study II	48
<i>Demographic background data</i>	48
<i>Participants use of internet</i>	48
<i>Categories and subcategories</i>	49
Study III.....	53
<i>The online support programme</i>	53
Study IV	56
<i>Demographic background data</i>	56
<i>Utilisation of the support programme</i>	56
<i>Categories and subcategories</i>	57
A synthesis of the findings	61
DISCUSSION	63
The online format.....	63
<i>The platform</i>	63
<i>Timely support</i>	64
<i>More for the future – or is it?</i>	65
A focus on the content.....	66
<i>Balancing broad relevance and being usable and useful</i>	66
<i>Straightforward information</i>	67
<i>Minding literacy</i>	67
<i>Not answering to all carers' needs and preferences</i>	68
<i>The potential for tailoring</i>	69

Carers have the person with heart failure in mind.....	69
Considering a broader implementation	71
A final note	72
Methodological considerations.....	73
<i>Credibility</i>	73
<i>Transferability</i>	74
<i>Dependability</i>	75
<i>Confirmability</i>	76
<i>Reflexivity</i>	76
Clinical implications.....	78
Future research	78
CONCLUSIONS	79
ACKNOWLEDGEMENTS	81
REFERENCES	85

ABSTRACT

Background: Heart failure (HF) is a common condition, and its prevalence is expected to increase. The illness trajectory is unpredictable, and its effects will include a potential impact on informal carers, i.e., family, friends, and significant others. Sometimes these persons are affected by the help and care they provide in such a way that they might themselves need support. However, they may be unrecognised in their endeavours, and might also experience a lack of support, especially from healthcare. Online solutions are considered to have the potential to provide accessible support to carers that is also anticipated to be cost-effective.

Aim: This thesis focuses on support to informal carers to persons living with HF, but also take the viewpoint of the person with HF by exploring social supports associations with their health and well-being. The overall aim was to explore perceptions, development, and experiences of online support for informal carers.

Method: This thesis comprises four studies. Study I had a cross-sectional design using self-reported data and data from the Swedish Pacemaker and ICD Registry. Data from 1,550 persons with HF who were living with an ICD and who had complete data on the outcome variable were utilised for both descriptive analysis and logistic regression. The outcome variable, perceived social support, was measured using the questionnaire Multidimensional Scale of Perceived Social Support (MSPSS), which includes measuring support from significant others, family, and friends. The logistic regression was conducted to compare those dichotomised as having low/medium perceived social support to those having high levels of support. Study II had a qualitative design, and data were collected through 8 focus groups with 23 informal carers of persons with HF to explore their perceptions of how online solutions could be of value for support. Data were analysed using qualitative content analysis. Study III had a descriptive design. It describes the co-design process of an online support programme for carers through three phases. In phase I, topics and content that reflected carers needs and preferences were identified. In phase II, the content for the support programme was developed and through phase III the content was refined and finalised. Informal carers participated in every phase, and the co-design process also involved professionals with expertise in, for example, HF and caregiving, for the development of content. It was an iterative process, moving back and forth between phases, and the research group acted as coordinators and ensured that carers' voices were kept central to the process. Study IV had a qualitative design, and data were

collected through individual semi-structured interviews with 15 carers. Interviews were analysed using qualitative content analysis. The study focused on informal carers' experiences of online, co-designed support programme while being participants in a randomised controlled trial (RCT) that has the aim of studying the effects of engaging with the programme.

Results: The findings show that one in five diagnosed with HF and living with an ICD reported low/medium levels of social support and that these persons had higher odds of negative psychosocial outcomes. This underscores the value and importance of support from informal carers for the well-being of those with HF. The thesis focused on perceptions, development, and experiences of online support for informal carers. The findings suggest that a co-designed support programme has the potential to be usable and useful for carers considering the online format and its content. It may provide insights, preparedness, and validation in relation to being a carer of a person with HF. However, carers may have an 'ambiguous stance' towards the online format and going online for support may not be the preferred form of support for all carers.

Conclusion: A co-designed online support programme, when built on a trusted platform within a healthcare context, may be considered both usable and useful for carers. The online format and content also provide the potential to offer timely and adaptable support. The content, developed in a collaboration between carers and professionals, offers evidence-based, relevant information, thereby possibly avoiding seeming impersonal, which can also be beneficial. The programme acknowledges the intertwined lives of carers and those with HF, and its content reflects this, potentially also enhancing its perception as usable and useful for carers. Still, the potential of the support programme depends on carers being aware of its existence, or being made aware, and can further recognise its value. The support programme is considered to have the capacity to be relevant for a broad group of carers, and therefore efforts may be of importance to ensure it is accessed and utilised. However, it is also important to take into account that not everyone may be willing or able to go online for support, or may wish to stay in a caring role. Healthcare also needs to recognise this when offering support to carers and the online support may be regarded an option among several.

Keywords: Informal carers, heart failure, online support, co-design, cross-sectional design, qualitative design, descriptive design.

SVENSK SAMMANFATTNING

Bakgrund: Hjärtsvikt är vanligt och det förväntas också öka i förekomst. Sjukdomsförloppet är oförutsägbart och konsekvenserna av hjärtsvikt kan påverka även anhöriga, det vill säga exempelvis familj, vänner och andra nära personer. Ibland påverkas dessa personer av den hjälp och vård de ger på ett sådant sätt att de själva kan behöva stöd. Det är inte alltid de uppmärksammas för de insatser de gör och de kan uppleva att de saknar stöd, särskilt från hälso- och sjukvården. Stöd till anhöriga via onlinetjänster kan uppfattas som tillgängligt och det förväntas också vara kostnadseffektivt.

Syfte: Denna avhandling fokuserar på stöd till anhöriga till personer med hjärtsvikt, men har också visst fokus på den som lever med hjärtsvikt genom att ha utforskat socialt stöds betydelse för deras hälsa och välmående. Det övergripande syftet med avhandlingen var att utforska uppfattningar, utveckling och erfarenheter av stöd online för anhöriga.

Metod: Denna avhandling innefattar fyra studier. Studie I hade en tvärsnittsdesign. Data från 1 550 personer med hjärtsvikt som har en implanterbar defibrillator och också fullständiga data på utfallsvariabeln användes för både beskrivande analys och logistisk regression. Utfallsvariabeln, upplevt socialt stöd, mättes med hjälp av frågeformuläret Multidimensional Scale of Perceived Social Support. I formuläret ställdes frågor om stöd från familj, vänner och andra nära personer. I den logistiska regressionen jämfördes de med lägre nivåer av upplevt socialt stöd med dem som hade högre nivåer av stöd. Studie II hade en kvalitativ design. Data samlades in genom 8 fokusgrupper med 23 anhöriga till personer med hjärtsvikt för att utforska deras uppfattningar om att använda onlinetjänster för stöd. Fokusgrupperna analyserades med hjälp av kvalitativ innehållsanalys. Studie III hade en beskrivande design och beskriver en co-designprocess där ett online-stöd för anhöriga utvecklades tillsammans med anhöriga. Denna process beskrevs genom tre faser. I fas I identifierades teman och innehåll som reflekterade anhörigas behov. I fas II utvecklades innehållet till stödprogrammet för att i fas III sedan förfinas och slutföras. Anhöriga deltog som experter i alla tre faser. Även professionella deltog och de hade expertis inom exempelvis hjärtviktsvård och anhörigomsorg och bidrog genom att skapa innehåll till stödprogrammet. Utvecklingen skedde i en process och gick fram och tillbaka mellan de olika faserna. Forskargruppen hade en samordnande roll och såg till att anhörigas röster var centrala genom hela processen. Studie IV hade en kvalitativ design och data samlades in genom individuella semi-strukturerade intervjuer med 15

anhöriga. Intervjuerna analyserades med hjälp av kvalitativ innehållsanalys. Studien fokuserade på anhörigas erfarenheter och upplevelser av det samskapade online-stödet medan de deltog i en randomiserad kontrollerad studie, som har som syfte att ta reda på vilka effekter det kan ge att använda stödprogrammet.

Resultat: Resultatet i avhandlingen visade att en av fem personer som lever hjärtsvikt och har en implanterbar defibrillator upplevde lägre nivåer av socialt stöd. Dessa personer hade högre odds att må sämre och ha fler symptom på depression och ångest. De upplevde också oftare att de saknade kontroll i relation till sin hjärtsjukdom jämfört med dem som upplevde att de hade mer stöd. Det här understryker att stöd från anhöriga är värdefullt för personen med hjärtsvikts välmående. Avhandlingen fokuserade på uppfattningar, utveckling och erfarenheter av online-stöd för anhöriga. Resultaten från dessa studier pekade på att ett stödprogram som utvecklats tillsammans med anhöriga och andra experter kan vara användbart och till nytta för anhöriga, både för att det ligger online och med tanke på programmets innehåll. Att ta del av stödprogrammet kan också ge insikter, bekräftelse eller en känsla av att vara mer förberedd i relation till att vara anhörig till en person med hjärtsvikt. Resultaten visar dock också att anhöriga kan ha en tvetydig inställning till att gå online för stöd. Att söka stöd online kanske inte passar alla.

Slutsats: Ett stödprogram som utvecklats genom en co-designprocess, har potential att vara användbart och till nytta för anhöriga till personer med hjärtsvikt när det byggs på en känd och betrodd plattform i en hälso- och sjukvårdskontext (1177.se). Programmet kan också erbjuda stöd som kan anpassas efter anhörigas behov, oavsett om de nyligen hamnat i en anhörigroll eller har varit anhöriga ett längre tag. Att innehållet utvecklas i samarbete mellan anhöriga och professionella, ger anhöriga evidensbaserad och relevant information som möjligen också undviker att uppfattas som opersonlig. Stödprogrammet tar hänsyn till att anhörigas och personen med hjärtsvikts liv kan ses som 'sammanflätade' och innehållet speglar också detta, vilket kan göra programmet ytterligare användbart. För att stödprogrammet ska kunna komma till användning så måste anhöriga vara, eller bli medvetna om att det finns. De behöver också kunna se värdet i att ta del av det. Eftersom stödprogrammet kan vara relevant för en bred grupp av anhöriga, så kan det därför vara viktigt med åtgärder som stöttar användandet. Det är dock viktigt att tänka på att alla inte vill, eller kan, söka stöd online och att det också finns personer som inte kan eller önskar ge stöd, hjälp eller vård till en närstående. Hälso- och sjukvården behöver därför också ha detta i åtanke när de erbjuder anhöriga stöd. Stödprogrammet kan kanske därför ses som ett alternativ bland flera.

Nyckelord: Anhöriga, hjärtsvikt, online-stöd, co-design, tvärsnittsdesign, kvalitativ design, deskriptiv design.

LIST OF PAPERS

- I. Allemann, H., Strömberg, A. and Thylén, I. (2018) 'Perceived Social Support in Persons With Heart Failure Living With an Implantable Cardioverter Defibrillator: A Cross-sectional Explorative Study'. *Journal of Cardiovascular Nursing*, 33(6), pp. E1–E8. doi: 10.1097/JCN.0000000000000523. © 2018 Wolters Kluwer Health, Inc. All rights reserved. [Permission granted to publish]
- II. Allemann, H., Thylén, I., Ågren, S., Liljeroos, M. and Strömberg, A. (2019) 'Perceptions of Information and Communication Technology as support for family members of persons with heart failure: Qualitative Study', *Journal of Medical Internet Research*, 21(7), pp. e13521, 1-12. doi: 10.2196/13521. ©2019. The Authors. Originally published in the Journal of Medical Internet Research [Published under Creative Commons Attribution License].
- III. Allemann, H*, Andréasson, F*, Hanson, E., Magnusson, L., Jaarsma, T. & Strömberg, A. (2023). The co-design of an online support programme with and for informal carers of people with heart failure: a methodological paper. *Journal of Clinical Nursing*, 32, pp. 7589-7604. <https://doi.org/10.1111/jocn.16856>. © 2023. The Authors. Originally published in the Journal of Clinical Nursing published by John Wiley & Sons Ltd. [Published under Creative Commons Attribution License].
- IV. Allemann, H., Thylén, I., Andréasson, F. & Strömberg, A. Exploring informal carers experiences of an online support intervention when participating in a randomised controlled trial: a qualitative analysis [Manuscript].

*Shared first authorship

ABBREVIATIONS

AI	Artificial Intelligence
CAS	Control Attitude Scale (4-item)
CRT-D	Cardiac resynchronisation therapy defibrillator
CVD	Cardiovascular disease
HADS	Hospital and Anxiety and Depression Scale
HF	Heart failure
IACO	The International Alliance of Carer Organizations
ICD	Implantable cardioverter defibrillator
LLM	Large Language Model
MSPSS	Multidimensional Scale of Perceived Social Support
Nka	National Family Care Competence centre

PREFACE

As long as I can remember I have been around professional caring. When I was a child, I used to join my mother - who for a period in my childhood together with colleagues ran a day programme for persons with dementia. For this day programme, they were situated in a beautiful old wooden house with a big garden where they also held hens. They did regular household duties together with the older people that came from their private homes, or from a nursing home. I remember braiding old ladies' hairs, baking and playing board games (and scanning the cupboards for caramels). Specially, what stands out in my memory is the warmth and the genuine dedication my mother and her co-workers had in relation to those coming there. Even though I could not reflect on that then, it is evident to me now, that they were truly there for the older people's well-being and that they had a person-centred approach to what they did.

Before coming to Linköping University to study to become a nurse, I also had experience from working as a care assistant, being a professional personal caregiver and a residential support worker working with people in their homes, who needed assistance in taking care of themselves and in managing a household. I quite immediately found studying and the subject of nursing appealing. In equal, I was never very sure about the practicalities concerning for example, the technical parts in relation to nursing though. I really felt at home when it came to communication and in reflecting in and on meetings with patients and their families. One situation that stood out for me during my studies was the time when I initiated a conversation with a woman married to a person who had just received difficult news. When asking the woman how this had been for her, she just burst into tears. I cannot remember what we talked about, but I remember her thanking me later, thanking me for having asked her how *she* was. This is the first meeting with a family member I can remember, and I did not understand this at the time, but when reflecting on it now, I can see that it was not self-evident that she was seen a natural part of the team surrounding the person that was afflicted, in this case of incurable cancer.

The feeling of not truly belonging in clinical practice as a nurse stuck with me during my short but very rewarding clinical experience in forensic care and at a medical acute care clinic. I was young, and at the time unknowledgeable of all the options for nurses, so I decided to leave healthcare for a while. I studied *visible communication and graphic design*, and even though enjoying this, this did not find me at piece either. When I then become pregnant and giving birth to my oldest daughter and this ended up in a dramatic event where we almost lost her, I again found myself face to face

with healthcare. And this was in many ways healthcare at its best. The experiences during these weeks of worry and in great need of healthcare myself led me back to studying and I got a master's degree in nursing – with courses including implementation, communication, pedagogy, and health economics. From here I got a junior lectureship at the nursing programme. At this point a couple of things seemed clear to me. There is a red thread through the experiences from my childhood and my studies and my clinical experience and in my own personal experiences as a patient and informal carer - and that is the interest in communication and understanding of the importance of support. Both when being the one offering support and in understanding the value of being able to embrace support offered to you.

Finally, two remarks that I find important to point out already here. I have chosen to write parts of this thesis from a *first-person perspective*. I have done so to mark an 'active approach' with the intent to highlight that I take ownership of the reasoning and choices made in this thesis (1). Secondly, I will refer to participants included in this thesis as persons if not informal carers or carers when concerning those that support a person with HF. When doing so I recognise that carers living with someone that has HF in the early stages or for other reasons, may not always identify themselves as carers. I will further describe the person that is provided support, help or care as the 'care recipient' rather than patient. When doing so I recognise that this term goes beyond biological bonds and include for example, extended family, friends, or significant others. In addition to doing so for clarity, this also marks a standpoint that I as a nurse, believe that a person is not a disease or an illness (2), and is not well or unwell, but rather - health and well-being reside within continuums that allow a person with severe HF or their informal carer to feel well and a person with mild HF and his or her carer to consider having poor health.

INTRODUCTION

HF is common and can have a profound impact on people throughout the course of the illness. Although advancements in treatment have improved the prognosis, the illness trajectory remains unpredictable (3), and HF is expected to increasingly affect both individuals and society through a rise in prevalence (4). Persons with HF often rely on family members, friends or significant others for support, help, and care. Given the broader implications of HF, these persons, who can be referred to as informal carers, are also impacted (5, 6) and informal carers are sometimes affected in ways that compromise their own health and well-being (6, 7), necessitating support for themselves (8, 9). However, they may feel that they are lacking in such support (8), particularly from healthcare (6, 10). This thesis comprises four studies, each addressing aspects of support but with the focus on carers. The first study focuses on the person with HF and the importance of social support from family, friends, and significant others, in relation to their health and well-being. The subsequent three studies centre on informal carers and their perception of how online solutions could be a support; on the co-design process to develop a support programme with and for them; and finally, on exploring carers' experiences while being in an RCT which included the co-designed online support programme.

BACKGROUND

Living with heart failure

HF is a common and serious syndrome most often caused by ischemic heart disease or hypertension. HF commonly causes fatigue, breathlessness, and a decreased ability to be physically active. The weight of symptoms correlates with the severity of HF and it extends beyond the physical, and encompass for example, symptoms of depression, and generally a lower health-related quality of life and thus impacts many aspects of everyday life (3). Persons with HF are prescribed a complex medical treatment regimen to decrease symptoms and improve cardiac function. They are also often treated with devices such as Implantable Cardioverter Defibrillator (ICD) to prevent severe arrhythmias and cardiac arrest and/or a Cardiac Resynchronisation Therapy (CRT) to treat dyssynchrony - a state where the right and left heart ventricles do not contract at the same time. Improving synchrony between the heart ventricles improves the heart's pumping function and cardiac output. The CRT and ICD devices are often combined into a so-called CRT-D (3, 11). Self-care is a crucial part of a person's management of HF and includes adherence to medical treatment, lifestyle changes such as physical activity and exercise, as well as symptom monitoring (12). Self-care has been found to improve both survival and well-being (13). Informal carers can support patients in doing self-care (5).

Informal care

Informal care has been described being the *backbone* of all long-term care in Europe (14) and it has been highlighted that carers play an important role in society (15). Many citizens will experience being a carer to a spouse, a child, a parent, a friend, or a neighbour at some point during their lives (16). An informal carer can be defined as:

“a person who provides – usually – unpaid care to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal framework” (17).

A person either providing or receiving support may be: “...in the family, household, or social network...” (7), pp. 5. Informal carers usually do not have professional knowledge or training in their caring role (18).

Zooming out: viewing caregiving from a societal perspective

The importance of informal care has been established in relation to alterations in population structures, evident in both the increasingly ageing population and increased prevalence of people living with long-term illnesses (7, 19), and a future shortage of healthcare professionals. It is expected there will be a gap between peoples' need for care and resources available which has expanded the interest in informal care (20). It is possible that informal care "... will become the most critical part of the global health care landscape in this century" (7), pp. 14. Caregiving is a global issue and The International Alliance of Carer Organizations (IACO), which encompasses 18 countries across 4 continents acknowledges the importance of the recognition of carers, for example, through policy-making and financial support from governments. Furthermore, they highlight the significance of targeting carers' health and well-being and working conditions and they point out the importance of ensuring carers are strengthened through relevant education and information and by the provision of evidence-based support (21).

In Sweden, informal care is formalised, i.e., there are policies and legislation focusing on a carer perspective (14). This entails legislation (22) that since 2009 mandates that municipalities shall offer support to carers (15). In the Swedish Healthcare Act (23) the responsibility towards carers is not specified, but since healthcare has a general mission to prevent poor health, this also includes carers who risk ill health due to their caregiving situation (15). Carers in Sweden may further have access to financial support and training (14). Moreover, there is also a National Family Care Competence centre (24) which receives their mandate from the Swedish government and whose main mission is to serve as expert support to both municipalities and regions as well as directly to carers. Additionally, there are carer organisations such as Carers Sweden (25) who provide direct support to carers and lobby to advance the awareness of, and support for carers among decision makers and politicians. Also, the care for a family member or significant other is voluntary in Sweden (15) and, the responsibility for persons needing healthcare or welfare rests with the public sector.

The prevalence of informal care depends on how it is defined and measured (20). IACO noted a prevalence ranging from 4.5% (Taiwan) to 21.3% (USA) in their included nations. According to a study by the European Commission it is estimated that 14.4% of all adults within the European Union provide informal care and that 80% of all long-term care is provided by informal carers (26). The Swedish National Board of Health and Welfare noted that approximately 20% of Swedish citizens provide support, help or care to someone, and further that even though the prevalence of carers may have decreased in recent years, there are indications that those who provide support to a care recipient offer more extensive help than before (15).

Relating to the prevalence, or maybe rather the scope of caregiving, it has been noted that informal carers provide 725 million hours of care yearly in Sweden (27).

Zooming in: viewing caregiving from the carers' perspective

Carers' experiences of providing support, help or care to a care recipient includes finding it a 'natural part of life' (28), and experiencing it as an obligation or something one must do (29). According to the Informal Care Model, a predisposition to caregiving is that someone needs support or help and when people consider providing care this is based on the answer to the questions; *Do I want to?* *Do I have to?* and *Can I?*. The answers to these questions, according to their model, are influenced by personal beliefs and norms, the quality of the relationship and the appreciated reciprocity between carer and care recipient. Moreover, physical distance, lack of time, other resources for support, competence, and the carer's own health status can also affect the willingness and possibility to provide care (30, 31). It has also been noted that the formalisation of healthcare could influence the willingness to offer support and help to a family member and it could be that carers in societies, like Sweden, relying on government aids are less willing to support (31). However, even with such formalisation, norms and moral convictions can sustain the prevalence of informal care (32).

Furthermore, most carers are women (18, 33) and it has been highlighted within a Swedish population study that women may provide more intensive levels of caring compared to men (34). According to a report from the European Commission women also more often provide care while engaged in paid work (18). Paid work, in combination with caring is also a factor that affects the perceived demand of caring and how the caring situation affects the carer (35). Moreover, informal caring can be reviewed in relation to type of relationship between the carer and care recipient (e.g., being a child or a spouse) (36) and socio-economic status (37), since these offer additional insight into caregiving. Additionally, cultural background may influence the experience of caregiving, especially when viewed through the perspective of belonging to a collectivistic or individualistic cultural background (7). This could affect expectations on support. For example, persons from collectivistic cultures may more self-evidently expect support from family and friends compared to those from individualistic cultures. In a Swedish context, where the culture is generally individualistic, citizens may often expect significant support from the government rather than from informal carers. However, it is important to remember that Sweden is home to people from diverse cultural backgrounds. Also, caregiving may hold universalistic attributes, meaning there might be attributes entailed in caregiving that override the above-mentioned factors (7).

Generally, the experience of caregiving has been linked to the extensiveness of the care provided, where there is an increased risk for burden if the carer spends more time on caring over an extended period (7, 38). Caregiving can sometimes be time consuming which may require carers having to balance between caregiving responsibilities and other life obligations or needs (18). Furthermore, also 'passive caring', which includes worrying or feeling responsibility for the care recipient, can impact and cause experiencing burden. Overall, caregiving can have a broad impact and also include potential negative effects on private economy (15).

Being a carer to a person with heart failure

Carers to persons with HF are more likely an older person compared to other informal carers (39). Their experiences include considering that a caregiver role is taken on over time (40). Carers to persons with HF provide support in a range of ways, by being there emotionally (6, 10) and by providing more tangible and practical support in the care recipient's everyday life (6). Also, carers support the person with HF in self-care activities (5), by, for example, managing medical treatment and keeping track of symptoms (6). Caring for a person with HF can be experienced as burdensome (8) and as entailing making sacrifices or overlooking one's own needs (41). The caring experience is likely shaped by the unpredictable trajectory of HF and its inevitable and gradual worsening over time with the incorporation of acute events. These aspects are often highlighted in research on caregiving within the field of HF (5, 6, 8, 41-43). Carers also apprehend having to adjust in relation to the trajectory of HF by, for example, being available (10, 41). Moreover, they can experience a sense of losing control and needing to balance uncertainties (41, 42). This uncertainty, especially when the person with HF is deteriorating, could provide carers with a sense of isolation since they may choose to, or feel obliged not to engage in social activities outside the home (41).

Despite this, caregiving is also experienced as something beneficial that could deepen the bond with the person who has HF (41, 44). Caregiving can provide a sense of doing something meaningful, for example, when the carers' actions have a positive impact on the care recipient (44). Developing new skills relating to caregiving, such as symptom recognition or strategies for care can provide self-confidence and be considered a positive aspect, that additionally could enhance the carer's ability to take care of themselves (41). Additionally, caregiving can provide a sense of 'personal growth' (40, 41).

Carers' needs for support

It is well-established that carers need support in their own situation (6, 8, 10, 15, 42, 43, 45-47) both in relation to the care they provide and in relation to maintaining health and well-being for themselves. It has been emphasised that carers may not seek out support (45) which may relate to that they do not necessarily consider themselves being carers (28) or not wanting to be considered a burden (41). Also, carers to persons with HF have described lacking support from healthcare (6, 8) and may feel overlooked by healthcare professionals (10). From a nursing perspective, carers could be perceived as valuable, but perhaps sometimes mainly as a resource for providing more efficient and better care to the person with HF (48). It has been highlighted that it is important to focus on finding out what support to carers is relevant and effective during different points in the care recipients illness trajectory (7) and further to find support that is cost-effective to be protective of societies resources. Online support may provide such an opportunity (49).

The concept of support

Support could be considered as either 'functional' or 'structural' (50). Structural support relates to network and refers to, for example, marital or cohabiting status and size of network or lack thereof (i.e., social isolation). Functional support on the other hand relates to the tangible support you receive, or to how you perceive the support derived from your structures. Additionally, the importance of the quality of the relationships and connections within these networks or structures have been pointed out (51, 52). By this, even though having a network and even though receiving support, it is still possible to feel lonely or perceive a lack of support (53). The support from a network could therefore be considered as something that provide both positive and negative experiences.

Within the context of nursing, in a concept analysis the attributes of social support were described to include 'emotional', 'instrumental', 'informational', and 'appraisal' support (54). 'Emotional support' was noted as a central aspect of people's perception of being supported and involves feeling empathised with and the general feeling of being cared for. 'Instrumental support' is the practical and concrete support provided, while 'informational support' could facilitate problem-solving and be offered in times of stress. Lastly, 'appraisal support' was described as an attribute that offers affirmation which could be considered important for evaluation of the self (54). According to the authors, the antecedents of social support, i.e., what is required to distil social support, are having a 'social network', 'the embeddedness' within this network, and, moreover, a positive 'social climate', as further outlined by this quote:

“Without a structure of people (network) with the quality of connectedness (embeddedness) required to generate an atmosphere of helpfulness and protection (social climate), social support behaviours can not occur”, (54), pp. 97.

Social support could also be considered from the viewpoint of it deriving from ‘similar others’ or ‘significant others’. Thoits (55) hypothesised, and later found support for the theory (56), that source of support matters for what type of support that is provided. Furthermore, she suggests that different types of support from various sources will entail different value for the one receiving the support. Relating her theory and findings to persons with HF as well as their informal carers, they may find emotional and informational support especially valuable when coming from someone who have similar experiences, i.e., being either a person with HF or an informal carer. When receiving advice, comfort, information, encouragement, reassurance, and empathy from such a person this can be seen as both credible and relevant. Receiving support from a significant other also involves encouragement and emotional support but is considered generally less specialised and more in the form of having a comforting presence. Additionally, persons with HF and their informal carers may by her theory expect and often receive instrumental support from their significant others.

Holt-Lunstad outlined potential mechanisms linking social connections (i.e., structural, functional and quality of support) to morbidity and mortality and she suggest that there are both direct and indirect pathways. For example, social connections can have an effect on morbidity through behavioural, biological, and psychological factors, and it may be that the sense of being supported or cared for could affect the ability to take care of oneself, for example taking medicines as prescribed. Also, if a person suffers from stress, anxiety, or depression; it may be that this affects the appreciation of support, which then could affect the potential of the network to provide support, and by this decrease the sense of social connectedness. Additionally, the potential to form social connections could relate to early life experiences, personality traits or different ability to form attachments to others, which would then shape how people are able to create or maintain social connections (51). Other factors such as bodily functionality (e.g., hearing impairment) or migration to a new country (53) could further impact on this. Holt-Lunstad proposes that low levels of support in relation to structure, function and quality of social connections will increase risk for morbidity and mortality while higher levels will offer protection (52). Considering the connection to health and well-being, social support and social connectedness could be seen both as a ‘buffer in the company of stressors’ or as directly influencing health and well-being positively (50, 57). The linkage between support, or the lack thereof, and its relation to health and well-being is now considered well-established, and there is evidence

supporting that lacking support, or, both being or feeling lonely, increases the mortality risk significantly (58-60).

Online support

In this thesis I have chosen to use the term ‘online support’ for clarity, but I recognise that there is a diversity of concepts concerning digital technology used within healthcare and welfare. Hassan provides a definition of ‘Information and Communication Technology’ within the context of informal care that aligns well with how I consider online support in this thesis:

“Information and communication technology (ICT) based support solutions for informal caregivers are services provided by any private or public organization that address caregivers and/or care recipients’ needs through technological devices that are integrated or not into a wider intervention program. Technology may provide informal caregivers with remote access to information and training about care and caring-related issues through websites, mobile applications and online training materials” (61), pp.15.

Online solutions can be defined as either static, providing content on a web page, or interactive, allowing carers to engage in chats, surveys, or interactions with healthcare professionals or peers (62, 63). These interactions can be synchronous, such as a video consultation with healthcare personnel or an online chat with other carers, or asynchronous, such as sending and responding to emails (64). Moreover, online interventions aimed at carers often combine static and interactive elements (63).

Providing information and education are common purposes of online support for carers (62-64). In one recent systematic review, it was found that about 40% of included studies had an educational component (63), and in other reviews focusing on carer support for older people, education was also highlighted a common feature (62, 64). Educational content could cover the care recipient’s illness or disease, how to cope and handle the situation as a carer, and information about available support for carers (62). In a Swedish context, access to information was considered the most valuable feature of online support amongst working carers (65).

Furthermore, interactions with peers and/or professionals are common features of online interventions (62-64), and they have been identified as valuable (62). These interactions can serve to provide carers with emotional support (65-67), recognition, advice, comfort, a sense of belonging (68) and social inclusion (66, 68). Additionally, online solutions could also facilitate the potential for carers to participate in meetings with healthcare personnel (67), for example, if living far from the care recipient.

The potential impact on carers utilising online solutions for support includes decreasing stress, depression, anxiety, and burden from caregiving. Moreover, it has been noted that interventions could also increase self-efficacy and sense of control, caregiver competence, compassion, social support, and well-being (63). Focusing on the effects of online interventions that specifically target information and education, without involving interaction with peers or healthcare personnel, Ploeg et al (69) and Sherifali et al (70) observed positive effects on factors such as caregiver strain, self-efficacy, depression, stress, and anxiety. Furthermore, online support solutions are expected to be cost-effective (49, 64, 71).

Involving end-users in research and development

In relation to the development and testing of online solutions for support, the involvement of end-users, such as carers, has been highlighted as a way to enhance the chances for such a solution to be relevant, accepted, and usable (63, 67, 72).

Involving end-users in research and development processes has been described through terms such as ‘human-centred design’ (73) and ‘participatory research’, ‘participatory action research’ (74), ‘patient and public involvement’ (75) ‘co-creation’, ‘co-production’, and ‘co-design’ (76). In this thesis, the term co-design will be used. What is common to all is the understanding that actively and meaningfully involving end-users is integral. Additionally, in research involving end-user’s, empowerment, the consideration of marginalised groups, and power structures to avoid exploitation are vital. Participation in research could also be viewed as something included in a citizenship (77) or as something that is ‘a right’ even (74, 75, 78). On a broader level, involving citizens in research could be considered:

“...a mechanism for the democratization of society and democratization of knowledge” and “Co-design contributes to democratization and empowerment because it can facilitate the closing of the gap between people who have the power to shape important aspects of their life, such as health, welfare, or built environment, and those who do not. On this basis, co-design redistributes power to disadvantaged or marginalized groups within society” (79), pp. 23

These aspects add a value that might be considered exceeding individual benefits or the development of efficient or effective healthcare. Latulippe, Hamel & Giroux further conclude that co-design may not always lead to innovative ideas but does:

“...guarantee, if their participation is promoted, that the tool developed will respect their process of help-seeking and their literacy level....” (80), pp. 13.

Being a participant in participatory processes can provide positive experiences. It can be educating, empowering, increase self-esteem, and add to a sense of self-efficacy (81). Adding to these positive effects, Slattery, Saeri & Bragge point out that engagement can provide participants with positive emotions, increased knowledge, and enhanced skills. It seems that the skills and knowledge can possibly pertain to both the research process, and to knowledge participants might find useful in their everyday lives (82). However, engagement can also entail negative experiences. These can include considering it as time-consuming, tiring or an experience of not having been involved in a meaningful way (i.e., tokenistic involvement) (81, 82). The level or quality of engagement of end-users is therefore central in participatory processes and a recognised model when considering level of engagement is ‘Arnstein’s ladder of citizen participation’ (83). In her ladder, participation is described through steps ranging from what she considers non-participation, to tokenistic involvement to a higher order of involvement with ‘citizen control’ being the highest. Therefore, the higher up the ladder, the more control of the process the citizen has. In relation to a healthcare context, Arnstein’s ladder have been criticised for simplifying the concept of involvement and that ‘citizen control’ (over decision-making) is not necessarily the end goal of involving end-users. Tritter & McCallum consider involvement to be complex and requiring flexibility and that it is an ongoing process. Their critique on Arnstein’s ladder could be interpreted to suggest that not all participants may be able, or indeed willing, to engage in a way that entails having control (78). Bammer has also pointed out that this flexibility could include that different stakeholders are engaged in different ways, meaning that some may be consulted for feedback, while others may be more deeply involved in more equal collaborations (84) to for example, co-design an online intervention.

Liabo et al. have highlighted principles that could underline ‘good involvement’ (i.e., meaningful, and positive) in health research. They considered it relating to ‘values’ which then serve as a foundation for actions taken during the research process. Included as values are; transparency, respect for different ideas and opinions and the belief that everyone involved are equally important for the process. When these values are put into ‘practice’ those involved are provided support, skills, and competences that could give the opportunity for being involved in a meaningful way. Furthermore, the authors emphasised the importance of a climate that allow ‘enjoyment’ which could further serve to support ‘good involvement’. Being pragmatical in relation to depth of involvement, and participants engagement in different phases were also highlighted (85). In her thesis, Malm (86) concluded

that involving carers in research hold the potential to provide a meaningful outcome, and that the potential to provide valuable results will increase if there are meaningful relationships between carers and researcher.

RATIONALE FOR THE THESIS

We have an ageing population and projections indicate it is likely that the number of persons above 60 years of age will almost double worldwide by 2050 (87). In tandem with this, the prevalence of long-term illnesses such as HF will rise. This is due to both the increasing life expectancy, and the improved prognosis of HF stemming from advances in treatment with more people surviving longer after a cardiac event. HF is a common condition affecting around 2% of the population in Sweden. Its prevalence is linked to age, with incidence increasing exponentially (3). Those with HF who live with an ICD may constitute a particularly vulnerable group in need of even more comprehensive support since they might be more severely ill, have more symptoms from their HF, and have a poorer prognosis. The consequences of HF could be impacted by the support they receive, and support can influence for example, the capacity and confidence in performing self-care. Hence informal carers, i.e., family, friends, and significant others, play a pivotal part in the care of persons with HF. Informal carers who provide support and help to an ill person can experience this as an inherent aspect of life, but they could also find it a burden. Therefore, support for carers is of high importance. The rising prevalence of HF will increase the need for a more extended care and support, both to those with HF and their carers. There is moreover a concern that there will be an insufficient number of health and social care professionals to take care of those who need care and support (88). It is therefore not unreasonable to think that informal carers will have an increasingly important role in filling the gap between what the person with HF needs from healthcare, and what healthcare is able to provide. Simultaneously, societies are being digitalised, and Sweden has an outspoken vision of being the 'best in the world' at using digitalisation to serve its citizens (89), and even though not necessarily undisputed, digitalisation has been highlighted as an important aspect in meeting the above challenges to promote public resources to stretch even further (90). To respond to the needs, preferences and goals of carers as well as considering public resources, this thesis focuses on online support for carers who take on caring for a family member, friend or significant other. To develop an online support that meets the carers' needs and preferences, a co-design approach was conducted. Furthermore, the online support was developed and administered within a healthcare setting, an area which is recognised as needing to develop more carer friendly practices.

AIMS

This thesis focuses on support to informal carers to persons living with HF, but also take the viewpoint of the person with HF by exploring social supports associations with their health and well-being. The overall aim was to explore perceptions, development, and experiences of online support for informal carers.

Specific aims:

- I. To explore factors related to perceived social support in a large cohort of individuals with HF living with an implantable cardioverter defibrillator (ICD) or cardiac resynchronization therapy defibrillator (CRT-D).
- II. To explore the perceptions of information and communication technology solutions as supportive aids among family members of persons with heart failure.
- III. To describe the co-designing process of an online support programme with and for informal carers of people with heart failure.
- IV. To explore experiences of informal carers of persons with heart failure participating in a complex interventional study evaluating an online support programme.

METHOD

Design and settings

This thesis is based on four studies with different approaches to research and includes both quantitative (I), qualitative (II, IV) and descriptive design (III) to explore aspects of support. Study I included data from the Swedish Pacemaker and ICD Registry (91), studies II and IV collected data from one site in the Southeast of Sweden and study III included participants from two different sites in the same region (Table 1).

Table 1. An overview of participants, settings, designs, and methods.

<i>Study</i>	<i>I</i>	<i>II</i>	<i>III</i>	<i>IV</i>
Participants and Settings	Persons with HF living with an ICD or CRT-D (N=1550) from the National Swedish Pacemaker and ICD registry.	Informal carers to persons with HF (N=23) from one healthcare region in the Southeast of Sweden.	Informal carers (N=32) from two healthcare regions in the Southeast of Sweden, and content creators (N=25).	Informal carers to persons with HF (N=15) from one healthcare region in the Southeast of Sweden.
Design and Methods	Cross-sectional design. Analysis was based on self-reported survey data and data from the Swedish Pacemaker and ICD Registry collected in 2012 and analysed with IBM SPSS Statistics version 24 for descriptive and correlational statistics exploring associations.	Qualitative design. Data were collected between March 2015 and January 2017 through 8 focus groups and analysed using qualitative content analysis as described by Elo & Kyngäs.	Descriptive design. The co-design process of an online support programme was described in a methodological study. The development process spanned from Spring 2017 to December 2020.	Qualitative design. Data were collected between August and October 2022 through individual semi-structured interviews and analysed using qualitative content analysis as described by Graneheim & Lundman. This study is part of a process evaluation nested within an RCT.

Participants

Participants in this thesis included persons with HF living with an ICD or CRT-D (I) and informal carers to persons with HF (II, IV). The methodological study (III) also included informal carers to persons with HF (i.e., end-users) as well as professionals (i.e., content creators) and the research group in a co-design process. No background data were collected on the participants in this study. Table 2 therefore provides an overview of participants in study I, II and IV. Study III will further be described separately due to its format of being a methodological paper.

Table 2. Overview of participants from study I, II and IV.

	Study I n=1550	Study II n=23	Study IV n=15
Age (mean or range)	67.3	26-85	52-80
Gender (women %)	19.5	78	87
Educational level (post secondary %)	25.9	35*	73
Working status (student/paid work %)	22	43	40
Country of birth (Sweden %)	91**	100	87
Relational status to person with HF (Partner %)	–	96	73
Cohabiting (%)	79	100	100

* The option "other" existed, which could mean that there are additional persons with higher education.

** 5% were born outside the Nordic countries, of which 1.4% reported being born outside of Europe.

Procedures for inclusion of participants

Study I included persons from the Swedish Pacemaker and ICD Registry who had an ICD or CRT-D for more than 6 months. This was a subgroup analysis extracting data of persons with HF from a project focusing on the life experiences of persons living with ICD (92-94). The main study invited all available adults from the registry (N=5535), of whom 3067 accepted participation. There were no further inclusion criteria except being able to fill in a questionnaire in Swedish. Participants indicated their willingness to participate by returning a signed informed consent.

Study II included informal carers to persons with HF. A purposeful sampling method was applied to find participants. The goal was to identify carers who demonstrated diverse experiences in the caregiving situation, in the relationship with the person with HF, in gender, as well as by ethnic

background. Carers were invited through the person with HF who was approached during a visit to the nurse-led HF clinic at a university hospital, or by a research nurse who screened for possible participants. Persons with HF that showed an interest had to be willing to name a person that they considered a support, and to provide contact details to this informal carer. The informal carers received an information letter and were later contacted by telephone. If the informal carer agreed, an invitation letter, including a consent form was sent by postal mail. Participants in the study were offered reimbursements for travelling costs.

Study IV included informal carers enrolled in the intervention group in an ongoing RCT (ClinicalTrials.gov Identifier NCT04885465) commenced to study the effects of using the online support programme. The support programme is described in study III. The RCT's enrolment process involves inviting carers through the person with HF and the inclusion criteria for carers are being at least 18 years old, having access to a computer, tablet or smartphone and having an email address. Carers can be excluded if there are expected difficulties in the ability to utilise an online intervention or probable challenges in answering an online questionnaire. For inclusion of carers to study IV a consecutive sampling strategy was employed. However, the first 9 informal carers in the RCT were excluded as they had already been interviewed for a similar purpose. Subsequently, a total of 19 potential participants were approached for participation. They were contacted via telephone, within a timeframe ranging from 20 to 115 days (median 30 days) after access to the online support programme. If they expressed willingness to partake in an interview, they were emailed information that clarified the purpose of the interview and were then contacted via telephone to answer questions, and if possible, to book a time and a place for the interview. Three participants that initially showed an interest, did not respond to further contacts and 1 additional carer chose to drop out of the RCT due to a change in the life situation and therefore did not want to be in an interview. Participants in the study were offered reimbursements for travelling costs.

Data collection

Study I

Study I included data from 1550 persons who, in addition to having HF, also had complete data on the outcome variable concerning perceived social support. These data were extracted from the main study, in which persons were sent a questionnaire in a prepaid envelope (95). The questionnaires were distributed between September and October of 2012. If the participant did not return the survey, a reminder was sent after approximately

3-4 weeks. The self-reported data included information on background characteristics, whether they had experienced a shock from the ICD, their appreciation of their HF status, comorbidities, perceived control, symptoms of depression and anxiety and health related quality of life. Some data, i.e., time since implantation, whether the participants had CRT-D, and primary or secondary indication for HF were collected from the Swedish Pacemaker and ICD Registry. The selection of variables for the analyses in this study was grounded in theoretical considerations, incorporating the clinical experience and expertise of the research group members. The choice of variables for this study was also constrained by the selections made in the main study.

Outcome variable

Perceived social support was measured by Multidimensional Scale of Perceived Social Support (MSPSS) (96). The instrument consists of 12 questions concerning perceived support from family, significant others, or friends (subscales). The questions concern different aspects of support and are focused on the subjective meaning of having support when needing it, on the perception of having someone to share life's experiences with, and having someone who can comfort and provide support – both practically, in decision-making and emotionally. The instrument uses a 7-point Likert-type scale where a higher score indicates perceiving a higher level of perceived support.

Independent variables

Independent variables entailed data on demographics which included gender, age, and cohabiting status in this study. Clinical variables included the perceived discomfort of having HF, and furthermore ICD related data concerning if the person had received a shock from the ICD or not, which indication there was for the ICD (primary or secondary prevention), time since the ICD implantation and type of device (either ICD or CRT-D). Health related variables were measured by the self-report of co-existing health problems - both cardiac and non-cardiac. This also encompassed data concerning health related quality of life through the Visual Analogue Scale in the Swedish version of EuroQoL-5D (97). Symptoms of depression and anxiety by Hospital Anxiety and Depression Scale (HADS) (98), and perceived control and helplessness in relation to having heart disease through the 4-item Control Attitude Scale (CAS) (99), was measured as signs of 'psychosocial distress'.

Study II

Twenty-three informal carers were interviewed in 8 focus group sessions, using an interview guide. Data were gathered in face-to-face meetings at a university, or at a university hospital. Six of the 8 groups consisted of 2 participants, 1 group had 3 participants, and 1 group consisted of 8 participants. The focus groups were conducted between March of 2015 and January of 2017 and had an average duration of 91 minutes (range 55-121). The structure for the focus groups and the interviews were inspired by Kreuger & Casey (100). In total 4 researchers were involved in data collection. Two researchers participated in each group discussion, one with the task of moderating, for instance, ensuring that everyone got a chance to speak and to ensure a safe climate for the collective discussion. The other researcher had the role of observer with the task of taking notes on interactions within the group and making a summary of discussions in the end of sessions. Participants were also asked to fill in a questionnaire developed for the purpose of providing context and concerned personal characteristics and their use of the internet.

Before the discussion started, participants were reminded about the aim of the study and how their data would be processed and treated. They were also encouraged to respond in the capacity of being a carer to a person with HF. Additionally, they were reminded of taking turns in speaking and ensuring everyone had the opportunity to contribute. The discussion started with an 'opening question' in which carers were asked to state their name and relation to the person with HF. This question had several purposes, and one main reason was to let each participant speak early in the discussion, which could help those who are not accustomed to speaking in a group or who are unfamiliar with taking up space. This question was followed by an 'introductory question' about their everyday life as carers. The next 'transitional question' concerned their general thoughts about what supporting someone could entail, and then progressed further towards the 'key questions'. The emphasis in most key questions was their thoughts and experiences of providing social support – by discussing practical, emotional, informational, and affirmational support to the person with HF. Follow-up questions included getting carers' thoughts on what could have enabled them to provide support. These questions led to a discussion concerning, if and how, online solutions could support them in being an informal carer of someone with HF. Transitional and key questions as well as examples of follow-up questions can be reviewed in Table 3.

Table 3. An overview of transitional and key questions and examples of follow-up questions discussed during focus group sessions

	<i>Main questions and examples of follow-up questions</i>
Transitional question	<p>What do you think the act of providing support could entail?</p> <p>Do you have any concrete examples of this from your daily life?</p> <p>Are there different ways to provide support?</p> <p>In what situations do you offer support?</p>
Key questions	<p>Do you have any experience in providing practical support to your family member?</p> <p>Do you have any experience in providing informational support to your family member?</p> <p>Do you have any experience in affirming or validating your family member in what is said or done?</p> <p>Do you have any experience of providing emotional support?</p> <p>Do you have other examples of what this could entail?</p> <p>Can you provide some specific examples?</p> <p>Can you think of anything that could make it easier for you to offer this support?</p> <p>Has your role as a carer changed over time?</p> <p>Do you have any examples of how?</p> <p>Looking back, did you need any support before your family member received their diagnosis?</p> <p>Can you imagine how it might change going forward?</p> <p>What do you do in your daily life to take care of your own well-being?</p> <p>Do you have any thoughts on what you need to feel okay in your role as a carer?</p> <p>From whom, or what, do you receive support?</p> <p>If you were free to fantasise, what do you think internet technology could assist you with in your daily life as a carer?</p>

The observer summarised discussions and participants were encouraged to add to this summary if they felt it incomplete or if something had been misinterpreted. To facilitate the discussion, a PowerPoint presentation displaying the questions was used, along with some examples of different types of support and how online solutions could be utilised in healthcare. The intention was to present the open-ended question first and then provide examples. A pilot focus-group interview was performed to ensure that the interview guide and set-up worked as intended. Since no substantial changes were made, the pilot was included in analysis.

Study IV

Fifteen informal carers were interviewed individually using a semi-structured interview guide. Participants could choose if they wanted to be interviewed face-to-face, online via a video meeting or via telephone. Nine carers chose to meet face-to-face and 5 via video meeting. One carer was interviewed via telephone. The interview guide was developed in collaboration with co-researchers of study IV. It included questions in relation to informal carers' life situation of being carers to a person with HF; their motivations, and reasons regarding participating in the research study, as well as their experiences and reasons for accessing, or not accessing, the support programme (Table 4). The support programme is further described in study III.

Table 4. An overview of questions and examples of follow-up questions

<i>Main question and examples of follow-up questions or cues for further questions</i>
<p>I would like to hear about your experiences of being an informal carer to a person with heart failure. Would you like to tell me about that?</p> <p>In what ways do you help or support that person?</p> <p>How long would you say that you have been helping and supporting this person?</p>
<p>How come you accepted to participate in the research study?</p> <p>Can you tell me more about it?</p>
<p>If you look back, what expectations did you have for participating in the research project?</p> <p>[If the person expressed personal hopes] You said that you had hoped for...has your participation in the study been able to contribute in such a way that your hopes were fulfilled?</p>

Would you like to tell me about *how* you have used the support programme?*

Follow-up questions focused on practical approaches to, and experience of the design of the programme. Furthermore, participants were asked if any particular section had stood out to them.

We in the research group would like to learn more about your experiences and perceptions of the content in the support programme. What would you say that the support programme has contributed with to you?*

If you think for a moment, is there anything in your life/your caregiving situation that has changed after you accessed the support program online? If so, what has changed?

Could you say anything about what you think has affected you in your usage of the support programme?

Follow-up questions were adapted to whether the participant had logged on to the programme or not. Those who had logged on were asked about what might have influenced how they accessed the programme. Those who had not logged on were asked for the reasons, with questions such as: Would you like to tell me why you haven't used the programme?

What do you think about the support programme being online?

Do you have any thoughts about it being on 1177?

Can you see other ways that could work as support for caregivers?

We would like to know more about how our contacts was apprehended by you. How have you experienced the contacts we have taken with you?

What do you think about the different ways that the research group has contacted you?

Is there anything else you would like to share or add before we conclude?

** Questions asked only to those who had logged in and used the support programme to some extent*

Before the interview started, participants were reminded about the purpose of the interview, and how their data would be processed and treated. All interviews ended with a 'debriefing' on how carers had experienced the interview. I performed all interviews, and they lasted between 12-98 minutes (median 53 minutes). A pilot interview was performed to ensure that the interview guide worked as intended. Since no substantial changes were made, the pilot was included in analysis.

Data analysis

Study I

Data were analysed using IBM SPSS Statistics version 24. The database had undergone random sampling checks to ensure that data had been transferred correctly from the paper questionnaires. The analysis was exploratory, which meant there were no predetermined hypotheses. However, research questions guided the exploration of data. These questions were:

1. How do persons with HF – living with an ICD or CRT-D score their social support?
2. Do background characteristics, self-reported comorbidities, perceived control, health related quality of life, symptoms of depression and anxiety, and ICD related variables such as occurrence of ICD shocks, correlate to the social support scoring?
3. What characterise those reporting low or medium social support compared to those with high support?
4. Which factors are independently associated with perceived social support?

For the analysis, data from MSPSS were dichotomised and values above 5 were interpreted indicating a high level of social support whereas 5 or below was interpreted to indicate low or medium social support. In a personal contact with the instrument's developer professor Gregory Zimet this was confirmed to be a reasonable approach since data on the variable was skewed with few reporting low perceived social support. Other variables were also dichotomised, and persons were categorised as either living alone or living with someone. Furthermore, they were categorised based on having had their ICD for either more or less than 3 years. For measurement of HADS, the cut-off value of ≥ 8 was used to indicate symptoms of depression or anxiety (98).

For bivariate comparisons, we utilised independent 2-tailed Student *t*-tests on continuous variables and χ^2 tests on categorical variables. This was to differentiate between groups categorised as having low/medium or high perceived social support. The variables that showed statistically significant differences ($p \leq 0.05$) in bivariate analysis were imputed into a logistic regression using the Enter method to find factors associated with perceived low/medium social support as compared to high social support. The Enter method meant excluding variables that were not statistically significant in an iterative process until there was a model where all included variables showed statistical significance. As the dimension 'helplessness' in CAS,

showed interactional effects with its other dimension of ‘control’ and furthermore with ‘depression’ in HADS, we chose to perform and present the model where helplessness was excluded.

Study II and IV

The interview data in study II and IV were analysed using qualitative content analysis. The analysis of data from the focus group discussions in Study II was conducted according to descriptions of Elo & Kyngäs (101), while the individual interviews in Study IV were analysed using the description of Graneheim & Lundman (102). Both analytical processes focused on exploration and, broadly, entailed the same steps in analysis. On a more detailed level, however, there were differences regarding the choice of unit of analysis, immersion in the data, coding and categorisation, and finally, in how co-writers were involved in the process (Table 5).

Table 5. An overview of the analytical process in study II and IV.

Steps in the analytical process	Study II	Study IV
Tape-recorded interviews transcribed to text	The transcriptions were carried out by a person who was paid for the assignment. This person received specific guidelines on what to consider during transcription, such as noting pauses, laughter, and sighs. The instruction was to avoid 'cleaning' the text to remain faithful to the participants' verbatim statements.	
Unit of analysis/ Content area	The content that related to when participants talked about online solutions was identified as the unit of analysis.	Data were divided into three separate content areas in relation to topics in the interview guide. The content areas were considered for further steps in the analysis.
An inductive approach	There were no pre-conceived theories or concepts to guide the analysis as both studies employed an inductive approach.	
Analysis on a manifest level	Both studies had a focus on the manifest content which included interpretation and abstraction but meant that codes and categories should reflect what was ‘tangible’ in the text, i.e. minding level of interpretation.	
The immersion with data	The immersion included listening to all interviews and reading all transcripts and unit of analysis several times.	The immersion included listening to parts of each interview and reading transcripts and content areas several times.

Interpretation and abstraction through open coding and categorisation in an iterative process, involving movement between analysing parts and considering the whole	Open codes generated while reading the unit of analysis were transferred to coding sheets. These codes were then sorted and categorised, taking into account that an abstraction would occur. Both internal homogeneity within categories and external heterogeneity between categories were considered.	Meaning units in the content areas were marked, condensed and then coded. These codes were then sorted and categorised, taking into account that an abstraction would occur. Both internal homogeneity within categories and external heterogeneity between categories were considered.
Discussions with co-researchers	Co-researchers were actively involved in analysis, and methodological decisions concerning the analytical process. They suggested changes, verified, and validated the coding scheme and categories. Discussion strived for reaching consensus.	Co-researchers collaborated in discussions concerning the analytical process. They suggested changes, verified, and validated the coding scheme and categories. First author made the final decisions.

Co-designing of an online support programme

Study III describes the co-design process of the developing of the online support programme. Co-design is considered an iterative (73, 103) and creative process (73, 104) that accommodates flexibility (105). Co-design has been highlighted as addressing the design of predetermined problems (76) and has been described as constituting both a method and a mindset or philosophy (103-105). At the core of co-design is collaboration and partnership (74, 79, 104, 105) which includes active participation of potential end-users (104-106) academic researchers and other stakeholders (107) in the design of innovations relevant for end-users (79, 105). Stakeholders are all those involved in the process and have been defined as:

“An individual or group who is responsible for or affected by health- and healthcare-related decisions that can be informed by research evidence”, (108), pp. 986.

This study involved end-users, i.e., informal carers (n32) who were considered ‘experts by experience’ (109) and were thought of as equals to other participants, which has been highlighted a core principle in co-design (76, 110). Carers were involved in the whole process and the research group had the intent to engage them in a meaningful way to avoid what has been termed ‘tokenistic’ involvement. The movement away from tokenism is considered inherent in research with a focus on meaningful engagement of end-users. In relation to research involving, for example, carers, tokenism

has been described relating to 'unequal power' (111). The power imbalance, which could be described as inevitable in a healthcare setting (111, 112), risks to marginalise end-users which could diminish their role in a decision-making process (111). Tokenism could therefore inhibit involvement (81, 113). Conversely, meaningful engagement has been identified as an 'antidote' to tokenistic involvement (114). During the co-design process we were therefore particular about supporting carers involvement, which included being flexible in relation to their possibilities to be involved, by, for example, acting on those opportunities that arose throughout the process. Professionals were also included as participants (n25) in the co-design process, and they were engaged as subject matter experts. They were referred to as 'content creators' and they had professional knowledge in, for example, HF care, social work, and spiritual care and included nurses, physicians, a social worker, a priest, a carer advocate (a person working professionally with carer support within Swedish municipalities) and representatives from Nka. The research group (n7) was also included as participants and coordinated the co-design process as well as contributed with content, i.e., also being content creators. The co-design process included three phases (Figure 1) running over 4 years.

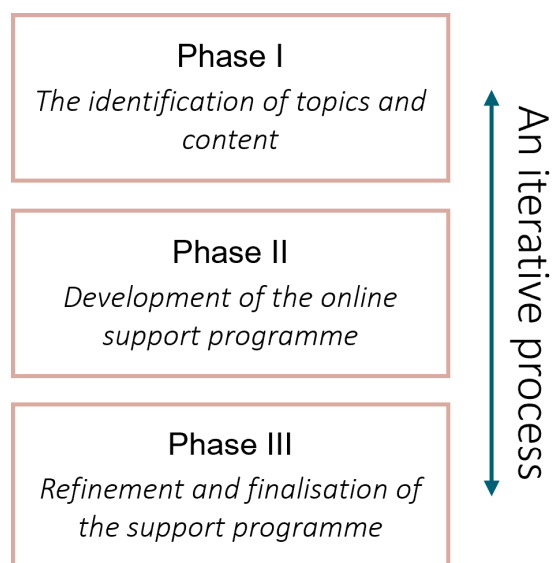


Figure 1. An overview of the co-design process in study III.

Phase I included ‘user group sessions’ coordinated and executed by one of the research group members, Frida Andréasson (115). Through these sessions, suggestions for topics and content for online support were identified. The topics and content from the user group sessions were developed and refined by input from the research group, the content creators as well as other carers. Even though described in different phases, the development of both topics and content was a back-and-forth process that stretched over phase II and III.

During phase II, the emphasis was on creating content, i.e., engaging the content creators. Content creators were provided the topics identified in phase I. They were assigned these topics based on their expertise. Furthermore, we provided them with instructions and offered them practical support if needed. The instructions highlighted that they should be aware that carers could have been in a caring role for different durations of time, and that they could have different kinds of relationships to the person with HF, for example, they could be a spouse or a friend. During this phase content was also added to the Swedish national health portal (116) which was the platform chosen for the support programme. This platform provides Swedish citizens with general information on, for example, diseases and illnesses, and advice on self-care. It offers the possibility to log in using electronic identification to access personal information, such as healthcare appointments or one’s medical record. The platform also includes a section called ‘Support and treatment’, in which the co-design support programme was included.

In phase III carers were recruited for ‘testing sessions’. These sessions encompassed carers from the focus groups in study II who had accepted to be contacted again, and furthermore also carers from the user group sessions (phase I). For the invitation of carers to the testing sessions, we applied a purposeful sampling method. Additionally, two carers were recruited through a snowball sampling strategy. The only stated inclusion criterion for these testing sessions was giving oral consent to partake in group discussions or individual online sessions. No personal data on carer participants were collected. The testing sessions included group discussions to test a prototype of the support programme. We also conducted individual online sessions for further online testing. Details about this and the final testing session will be elaborated on in the coming paragraphs. Participants were offered reimbursements for travelling costs.

Group discussions for testing of a paper prototype

The use of prototypes for testing ideas and for receiving feedback on possible changes to what is being developed is an important tool within co-design (103, 117). The ‘Prototype testing’ in our co-design process included 7 women and 2 men, of which 8 participated in 2 group sessions, at two

different sites. One carer who had been prevented from participating in the group session took part in an individual session later.

We were particular about providing carers with information on the progress of the development of the support programme before meeting them, since co-design processes should incorporate *transparency* in collaborations (79). In addition to keeping carers updated on the progress of the project, the transparency could include being clear about what is expected from participants and what their engagement is expected to result in (74). For these reasons, carers received information on how the project had proceeded before the testing session, together with a paper version of the support programme. Furthermore, carers were also provided instructions on how to prepare before the session (Figure 2).

Things to consider as you review the material

This programme is designed for informal carers like yourself, and we hope you bring this with you as you continue reading. As mentioned before, the material is a draft, which means we may develop both its visual appearance and its written content. You and the experiences you have are essential for the development and completion of the support programme!

We kindly request that you read through the material and also take note of the questions associated with each module/section.

- Feel free to write down your thoughts/reflections; it can help you remember your ideas until we meet and discuss as a group.
- We welcome comments related to both the content and how easy/difficult it is to understand, as well as whether you find it helpful or not.
- As for the language, we will have it reviewed before publication.

The material is considered a '*working document*'. You are welcome to share it with your close ones who have heart failure or other family members or friends who may be affected. However, we kindly request that you refrain from sharing it with others later or keeping a copy for yourself. The reason is that the material is not yet finalised, and we value the contributions of the experts who provided the material as well as ensuring that you receive accurate information.

We aim to collect these 'reference books', so we are grateful if you bring them to the meeting. The potential notes you made in the material can be beneficial in our work to develop the programme further.

Figure 2. Information to participating informal carers prior to prototype testing.

In these instructions we pointed out that, while reviewing the material, we wanted them to think from the perspective of being an informal carer to a person with HF. They received these instructions along with questions concerning the content to discuss at the session. Carers were also encouraged to leave notes in the material if they wanted. At the testing session, videos of interviews with subject matter experts (content creators) and other graphic content from the support programme were shown to participants. The feedback from carers was carefully documented.

Individual sessions for testing an online version

When there was an online version of the support programme at 1177.se, we invited carers for individual video meetings for further testing sessions. Of the 6 invited, 5 accepted and 4 were able to join. The 'online testing' therefore included 3 women and 1 man. Before their session, carers received access to the support programme and were encouraged to review the whole programme if they wanted to, but were asked to focus specifically on certain parts in the programme (Table 9). They were also asked to leave comments on the informational material on how to log in and how to navigate the support programme developed to support users. Carers received the overall questions in advance. The feedback from carers was thoroughly documented. Since one carer that had accepted participation was not able to join the interview as planned, these parts of the programme were assigned to content creators.

A final testing

The 'final testing' of the support programme involved the research group reviewing the content to ensure it held the perspective of being a carer for a person with HF and that language was consistent throughout the programme. Additionally, an informal carer, who is also a professional communicator, reviewed the entire support programme for consistency in language and expressions. This carer provided written feedback on each module, highlighting issues such as editorial or grammatical errors. The carer was offered monetary compensation for this task. Ending the co-design process was the approval of contributing content creators who had the opportunity to read the final version. The approval included signing an agreement to make clear ownership and use of content.

An iterative process

As highlighted, the co-design process of developing the online support programme moved back and forth between different phases (Figure 1) and stakeholders to develop content relevant for carers. The feedback and suggestions for changes from carers during the testing sessions were consequently taken into consideration by the research group and conveyed to the

content creators when carers' suggestions concerned more than editorial changes. The content creators were encouraged to make changes according to carers' wishes and preferences, but they were also responsible for the scientific content and had to consider ensuring the accuracy of the information in the programme.

The research group was the core in the co-design process, which entailed having final decision-making authority regarding the content. These decisions were influenced by the fact that informal carers sometimes had differing opinions, that the online national health portal of 1177 had certain limitations, and that the aim was to consider the possibilities for the support programme to be sustainable over time and be perceived as feasible for implementation. Even so, it is important to point out that we were particular about keeping the feedback from carers central in our choices of how to proceed with content when this was not straightforward.

Published but not publicly available

The support programme was published in December of 2020 but is not publicly available (winter 2023) during the inclusion of participants for the RCT (ClinicalTrials.gov Identifier NCT04885465). The RCT focus on the effects of engaging with the support programme on preparedness, health, and well-being. While in the study, carers have access to the support programme for 3 months and during this period they can log on as many times as they wish. In the information provided to the carers when they are given access, there is a description of what the research group recommend them to engage with, but there is also a clear encouragement for them to choose modules based on their own needs or preferences. The support programme needs to be assigned to the carer by using carers' National Insurance Number and the carer then needs to log on using an electronic identification. The assignment of the support programme during the RCT is handled by the research group, but if implemented into routine care, this could be managed by, for example, an administrator or a nurse in a HF clinic.

Philosophical assumptions in relation to this thesis

A researcher's assumptions and worldview will impact their approach to research (118). One might consider that a researcher cannot be completely unbound by contextual factors or utterly separated from what they are studying (119) and as expressed by Thornquist (2021):

“Humans are always situated; researchers are, just like everyone else in society, historical and social beings - shaped by their time and context” (120), pp. 201 [translated from Swedish].

If such a position is considered to show acceptance of subjectivity in research, subjectivity could be considered a strength in that the researcher, with their expertise and experiences, can offer a deeper and more close understanding of the phenomenon under study (121). These aspects are further outlined in the Methodological considerations. I would also like to note that I agree that there could be more than one interpretation of reality and that knowledge is constructed and dependent on context (79, 102, 122).

Ethical considerations

The studies in this thesis conform to the principles of human research outlined in the Declaration of Helsinki (123). All studies have approval from The Swedish Ethical Review Authority (Study I: Dnr. 2011/434-31, Study II/III: Dnr. 2015/55-32, Study III: Dnr. 2016/241-31, 2017/19-32, 2019-05310, Study IV: 2019-05310. Studies that received ethical approval before 2019 were approved by regional committees. Ethical considerations and reflections were included in all steps of the research process, from the planning of the study to writing the results with the goal of protecting participants from harm. This includes a reflection on the potential effects of the research, considering participants safety and well-being during the study and to protect individuals when reporting on the findings.

For Study I, participants signed an informed consent and were made aware that their participation was voluntary. They were provided with written information about the study and had contact information for a research nurse in case they had questions or concerns related to their participation. Additionally, even though it was not expected that answering the questionnaire or being part of the study would have negative consequences, those clinics where the participants were registered were informed about the study. This meant they were prepared if any participants needed support after completing the questionnaire. I did not have access to the raw data or the key, and therefore could not identify any participants.

For Study II and IV, participants signed an informed consent. Before this, carers were provided with both written and oral information about the

study. They were informed that they could withdraw from the study at any point without needing to provide a justification, and without it affecting the provision of healthcare to themselves or their care recipient. Carers were also provided with time to consider their participation. At the group discussions or interviews participants were reminded about confidentiality concerning the storage of tape recordings and transcribed data. Even though not expecting negative consequences of participating in these studies, carers were given information on how they could contact the research group if the focus group discussions evoked feelings or thoughts they wished to discuss further. For study II, the importance of maintaining confidentiality was emphasised; that is, carers were asked not to share personal details discussed in the group with anyone outside the room. While we cannot control for this, addressing it was hoped to further promote a safe environment and make carers aware of this aspect. In study IV, carers could express having a complex life situation and I therefore ended these interviews by offering time for discussing their situation more in detail. This sometimes led to that I offered to provide them information on where to turn with questions or for further support.

Study III included findings from the study by Andreasson, Aidemark, Magnusson, Strömberg & Hanson on the user groups (115) for which ethical considerations is described. For the other phases in the co-design process, we did not collect data from participating carers. However, we were still particular about being protective of carers personal data and considerations on participants safety and well-being. One way to be protective was to be transparent about purpose and set-up of carers involvement in the testing sessions. This transparency, if information is clear and concise at least, could have helped carers to make an informed consent and make a decision about how and what they wanted to share during sessions with other carers or us researchers. This aspect has been highlighted by Löfman, Pelkonen & Pietilä when reasoning about ethics in participatory research. Another important aspect in participatory research is the researcher role and the potential for power structures to affect the research process negatively and this has been noted being an ethical concern (124). We were therefore particular in reminding carers that they could speak freely without any risk of negative consequences for them or the care recipient, and furthermore that we saw their contributions as central in the process.

FINDINGS

Broadly, the findings of the studies included in this thesis suggests that; I) social support from friends, family and significant others is an important factor for their health and well-being since those with lower levels of support more often reported worse outcomes; II) that online solutions constitute a potential resource for support for informal carers to persons with HF, even though carers do not necessarily consider it valuable for everything and everyone; III) that a co-design process including carers and professionals can lead to the designing of relevant content in an online support programme aimed at carers, IV) and that there may be multiple factors affecting carers' usage of the online support programme while being in an RCT, and that the engaging with the programme can provide positive experiences.

Study I

The aim of the study was to explore factors related to perceived social support in a large cohort of persons with HF living with an ICD or CRT-D. The study included 1,550 persons who had complete data on the MSPSS questionnaire, which assesses support from significant others, family, and friends. All subscales had satisfying reliability, with Cronbach's alpha values of 0.81, 0.80, and 0.82 respectively. For the total scale Cronbach's alpha was 0.83.

Demographic background data

Participants in study I were predominantly men (80.5%), and most were cohabiting (78.5%). Almost 15% experienced much discomfort of their HF, while just about half experienced some discomfort from it, and 34.8% experienced no discomfort. Just above 50% had received their implant as secondary prevention, and time since the ICD implant varied between 1-23 years. Across the entire group, on average, each person reported having more than two co-existing health problems in addition to their HF, and 11% had symptoms of depression and 18.6% had symptoms of anxiety. Women more often lived alone compared to men ($p \leq 0.001$). Furthermore, those living alone also reported having more co-existing health problems in comparison to those that were cohabiting with someone ($p \leq 0.05$).

Perceived social support

Participants reported having the most support from family and/or significant others, and least from friends. In total, 82.4% were dichotomised as having a high level of perceived social support which means that almost one in five were dichotomised as having low/medium levels of support. The analysis further indicated that there were differences between these groups. In bivariate analyses, data indicated that participants who had low/medium levels of perceived social support showed statistically significant differences ($P < 0.05$) on several measured variables. These persons were slightly younger and more frequently female (with only the options of identifying as a woman or a man) and lived alone, compared to those with high levels of support. Furthermore, participants with low/medium levels of social support had more frequently experienced a shock from the ICD, reported a slightly higher number of co-existing health problems, and had a worse self-reported health status. They also reported slightly lower values of perceived control and higher values on perceived helplessness. Moreover, they exhibited more symptoms of depression and anxiety compared to those dichotomised to having high levels of perceived social support.

Variables independently associated with social support

The final logistic regression model (enter method) indicated that living alone, having symptoms of depression and anxiety, and experiencing less perceived control in relation to living with heart disease were all independently associated with higher odds ratio (OR) for low/medium levels of perceived social support (Table 6). The variables that were iteratively excluded from the different models, and therefore did not demonstrate an independent association with perceived social support, were age, self-assessed health status, co-existing health problems, whether one had experienced a shock from the ICD, and gender.

Given the finding that those living alone had greater odds of experiencing low/medium levels of social support compared with those who were cohabitating (OR 7.31), we conducted two more logistic regression models, one for those living alone and another for those co-habiting, to explore potential variables that predicted low/medium perceived social support. The logistic regression in relation to living alone showed that low/medium perceived social support was associated with having poorer perceived health status, symptoms of depression, and experiencing less control. For those living with someone, low/medium support was also associated with symptoms of depression and the experiences of less control. Unlike the model for those living alone, it additionally predicted that having symptoms of anxiety and being a woman were independently associated with low/medium support, while health status was not (Table 6).

Table 6. The logistic regressions, performed to determine factors associated with perceived social support. Total model predicts low/medium perceived social support (≤ 5 , $n=1410$).

<i>Total model</i>					
Predictors	<i>B</i>	<i>SE</i>	<i>OR</i>	<i>CI</i>	<i>P</i>
Household status ^a	1.99	0.16	7.31	5.35-9.98	0.000
Symptoms of depression $\geq 8^b$	0.95	0.23	2.58	1.65-4.05	0.000
Symptoms of anxiety $> 8^b$	0.62	0.20	1.85	1.25-2.74	0.002
Perceived control ^c	-0.16	0.03	0.85	0.81-0.90	0.000
<i>Living Alone (n=297)</i>					
Predictors					
Health status ^d	- 0.02	0.01	0.98	0.97-0.99	0.007
Symptoms of depression $\geq 8^b$	0.92	0.37	2.52	1.22-5.18	0.012
Perceived control ^c	- 0.18	0.04	0.84	0.77-0.91	0.000
<i>Cohabiting (n=1129)</i>					
Predictors					
Gender ^e	0.63	0.23	1.88	1.18-2.97	0.007
Symptoms of depression $\geq 8^b$	0.99	0.29	2.70	1.53-4.79	0.001
Symptoms of anxiety $\geq 8^b$	0.67	0.25	1.96	1.19-3.21	0.008
Perceived control ^c	- 0.13	0.03	0.87	0.82-0.93	0.000

^a 0=living alone, 1=living with someone

^b 0 = ≤ 8 , 1 = ≥ 8

^c 2-14, Higher value means higher perceived control

^d 0-100, higher value indicates better health related quality of life

^e 0=man, 1=woman

Variables put in the initial model (total model): gender, age, household status, coexisting health problems, health status (EuroQoL-5D, VAS), symptoms of depression and anxiety separately (Hospital anxiety and depression scale), perceived control (Control Attitude Scale) and received chocks.

Variables put in the initial model (living alone): health status (EuroQoL-5D, VAS), symptoms of depression and anxiety separately (Hospital anxiety and depression scale), perceived control (Control Attitude Scale) and received chocks.

Variables put in the first model (cohabiting): gender, health status (EuroQoL-5D, VAS), symptoms of depression and anxiety separately (Hospital anxiety and depression scale) and perceived control (Control Attitude Scale).

In summary, this study emphasised the (complex) associations between perceived social support and factors relating to health and well-being. Even though this study could not conclude on causal relationships, the results highlight the importance for healthcare personnel to identify support available to the person with HF – especially if the person has symptoms of anxiety and depression, seems to have a sense of lacking control in relation to the HF or if they are living alone. Furthermore, it could be worthwhile to bring special attention to support aspects if the person with HF is a woman, no matter if she lives with someone or not. One conclusion drawn from this study is the importance of including informal carers in the care of - and support to - the person with HF.

Study II

This study included 23 informal carers of persons with HF, who participated in 8 focus group discussions.

Demographic background data

The ages of the participants ranged from 26 to 85, with most being women (n=18). There was diversity in the level of education. Eight reported having completed upper secondary school, and 8 that they had education from university. The remaining participants had either compulsory school (n3) or had reported having another type of education (n4). Employment status varied: approximately half were pensioners (n12), almost half were either employed or a student (n10), and one person reported being on sick leave. Moreover, almost half reported having a health issue (n10), the most common being high blood pressure (n7). Two carers reported having more than one health issue currently. All except one carer were either married or in a partnership with the person with HF; only one carer had a different type of relationship.

Participants use of internet

Except for two participants, everyone had access to the internet at home, and most reported daily use (n17). Common activities included online banking, emailing, and using internet for seeking information. Notably, many had sought illness-related information online (n15). However, only 4 participants had searched for information on informal caregiving. The least prevalent activity was playing online games with others (n3).

Categories and subcategories

The analysis resulted in 4 categories and 9 subcategories, illustrated in Table 7.

Table 7. Overview of categories and subcategories in study II.

Category	Subcategory
<i>Providing possibilities for relevant support</i>	Interaction with healthcare personnel
	Information and confirmation retrieval
	Exchange with peers and external family
<i>Providing access</i>	Unbound by time and place, with endless possibilities
	Arena for family members
<i>Being too impersonal</i>	Apprehensions about usability
	Physical meetings are irreplaceable
<i>Being out of scope</i>	Difficult to visualise
	Something for the future

Providing possibilities for relevant support

This category encompassed the perception that online solutions offer multiple uses, including ‘interaction with healthcare personnel’. Groups discussed this as an opportunity for getting person-centred advice and emphasised the importance of ensuring that those providing them have specific competence in HF. Groups also discussed the wish for direct and transparent information from healthcare. They further highlighted the benefit of receiving personalised answers to one's own questions, as this offered the opportunity to avoid information that one may not wish for. However, groups also discussed the importance of feeling secure going online for information and in contacts with healthcare. They emphasised the potential of online sources for follow-up of the person with HF. This included possibilities like remote monitoring of those living with an ICD or facilitating follow-ups from healthcare visits.

Moreover, the groups discussed that online solutions were useful for ‘information and confirmation retrieval’ which included information on HF. See table 8 for an overview of topics carers suggested. They also saw going online as a resource for receiving specific discharge notes tailored to them as carers.

Table 8. Suggestions from carers on content in online support

Suggestions from carers on what information could be included in an online support aimed at them
Symptoms of HF and its consequences
Warning signs (e.g., of deterioration or an acute event)
Care trajectories
Information on heredity
Cardiac-related anxiety and how to separate this from other type of anxiety
Details for what carers may expect when the person with HF is hospitalised
A wish to read about HF in younger persons
Concrete advice on what to eat when having HF
Suggestions on what to ask during healthcare visits

Carers mentioned that informational needs could differ depending on whether the person with HF was newly diagnosed or not. Online information could potentially also aid in decision-making and provide reassurance and confirmation. It was perceived important to ensure that the information considers readability and avoids the use of 'medical jargon'.

Furthermore, groups discussed that going online could facilitate an ‘exchange with peers and external family members’. These interactions could provide carers with emotional, social, and practical support, and it was perceived as valuable to be able to recognise oneself in others in similar situations. Exchanging experiences with peers could also be beneficial for the person with HF. Interacting with other carers could offer an opportunity to learn from others’ experiences and to share their own insights, i.e., providing an opportunity for reciprocal support. It was noted that online interactions could be complemented by in-person meetings, either by initially meeting in person and then continuing online communication or vice versa. Additionally, carers saw going online as a way to stay in touch with their own family members, and social media could serve as a means of keeping other family members updated on the situation of the person with HF.

Providing access

This category encompassed perceptions regarding the responsiveness of online solutions, as well as the potential for finding answers to 'all one's questions' through online information. Going online was perceived as being 'unbound by time and place, with endless possibilities'. However, groups did not always discuss this in direct relation to its use for informal carers. The ability to go online at their convenience was perceived as a benefit, particularly for carers who are, for example, working or have limited time. Additionally, online solutions could enhance participation in the care of the person with HF and were seen as bringing healthcare closer to those with HF, which was considered to have the potential to make the carer feel safer. Furthermore, maintaining contact online was seen as beneficial for healthcare, as it could enable them to interact with the person with HF and the carer also at their convenience.

Furthermore, carers discussed that online solutions provided an 'arena for family members' (i.e., informal carers) that they might otherwise not have, as they could hesitate to take up space during physical healthcare visits when accompanying the person with HF. Perceptions varied on whether carers should have the option to ask questions without the person with HF present. While some carers believed this was important, others felt that both the carer and the care recipient should have access to the same information. Additionally, online solutions could enhance their potential for participating in the care of the person with HF, even if they cannot always join in during, for instance, a hospital visit.

Being too impersonal

This category encompassed the perceived limits with online solutions for support. Carers discussed 'apprehensions about usability' and how online information might be too general, potentially perceived as lacking the possibility to provide tailored information addressing their specific questions and needs. This, in turn, could diminish the usability of online solutions. The lack of specificity could potentially even provide information that would cause distress and online solutions or information were not necessarily trusted. Although groups had discussed the benefits of connecting with other carers online, they also highlighted the need for external moderation to prevent conversations from going off track in a negative way.

Furthermore, the category entailed perceptions that 'physical meetings are irreplaceable', and that going online could not provide full compensation for other types of support they already felt they had from, for example, physical meetings with healthcare personnel. It was highlighted that information via the internet was not necessarily considered 'real' information.

Being out of scope

The final category encompassed perceptions on how going online was not necessarily an option for support and carers expressed it could be 'difficult to visualise' its use in relation to being a carer. Even so, when groups were presented with examples of online solutions such as web-meetings between informal carers and healthcare personnel, seeking information online and chatting with others, this sometimes sparked the discussion within the groups. Additionally, this category also entailed perceptions about online solutions being 'something for the future'. This discussion focused partly on an age perspective, and even though not everyone agreed, groups discussed it would probably be more self-evident for future generations to go online for support. Furthermore, groups discussed that going online for support also could be evoked if the condition of the person with HF deteriorated.

In summary, these findings indicated that carers could find online solutions useful for obtaining information and confirmation, as well as for communication with others, including other informal carers and healthcare personnel. This communication was considered having the potential to be valuable. There is a risk for online solutions to be apprehended as impersonal or even out of scope and groups reasoned that it may not be for everyone or everything. To make online solutions more useful it could be valuable to adapt information to different carers different needs and to provide carers with information on what it could be used for, to help them decide if it is something they wish to engage in or not.

Study III

The co-design process resulted in the online support programme detailed in this section.

The online support programme

The support programme consists of 15 modules, each reflecting different topics and content (Table 9).

Table 9. An overview of modules and content in the support programme

Modules	Short description of the content in the different modules
<i>About the support programme</i>	Provides information about the purpose of the programme and about what it may entail to be an informal carer for someone with HF.
<i>To be a carer</i>	This module is intended to help carers reflect on their own health and well-being. The hope is that the content will support carers in living their best possible life. They are provided tips and tools within the module.
<i>About heart failure</i>	Provides information about HF and what it is/entails. In the module, informal carers also learn more about common symptoms, treatment, and self-care.
<i>Contacts with health-care and welfare</i>	Provides information about how the care for a person with HF is organised. Additionally, it includes information about where informal carers can turn for their questions.
<i>To receive support as a carer</i>	The module focuses on the support that informal carers can receive through the region, municipality, and voluntary organisations.
<i>Emotional reactions</i>	Provides information about the potentially difficult emotions carers may experience and how they can be recognised. It provides concrete tools which can be used to manage emotional reactions when supporting someone with HF.
<i>Changed relationships</i>	The module addresses how relationships can be impacted when someone is affected by HF/illness. It also provides practical advice on how to communicate with the care recipient and offers guidance on how to navigate the situation if the relationship is strained or considered not working. The carer is given information on how to seek additional support if necessary.

<i>Intimacy and sexuality</i>	The module is aimed at informal carers who have a partner with HF. The module addresses how HF/illness can impact intimacy and sexuality, both for the person who is ill and for the informal carer. It provides concrete tips to those carers who wish to talk about these things, on how to approach the topic with their partner.
<i>To be a carer while engaging in paid work</i>	Provides informal carers with an opportunity to reflect on how their professional life and role as informal carers may influence each other.
<i>Sleeping difficulties</i>	Is about how HF can affect the informal carer's sleep in various ways, whether you live together with the person who is ill or not.
<i>Physical activity for you and for the person with heart failure</i>	Addresses the importance of physical activity for both the person with HF and the informal carer, and also includes concrete tips.
<i>Yoga and relaxation</i>	Provides instructions on yoga/relaxation exercises and how it can be incorporated into the informal carer's daily life.
<i>To plan for the future when seriously ill</i>	This module is intended for those who wish to consider and plan for the possibility of either themselves or the care recipient experiencing deterioration or more severe illness. Informal carers will find concrete tips and tools on how they can prepare for the uncertainties in the future, such as a situation where one becomes too ill to make decisions for oneself. Additionally, it offers tips on how to talk about difficult subjects.
<i>About the end of life</i>	This module focuses on situations when the care recipients' health condition deteriorates, and they may require more care and support. They are provided information on how to organize the care during such times. Additionally, end-of-life aspects are addressed, and informal carers are provided information on where they can receive support and assistance if needed.
<i>A carer's own action plan</i>	Provides carers with the opportunity to summarise the impressions from what they have learned or reflected upon in other modules. It also gives an opportunity to answer questions through a questionnaire as a help to overview their own situation. The reflections that informal carers have can be used to create "a personal action plan." In this module, those who wish to do so receive tips and advice on how such a plan can be formulated.

All modules have the same logical structure, and each module comprises 2-9 pages and starts with an explanation of the content in the module. In total there are 83 web pages in the programme. The modules contain texts, photos, video-recorded interviews, and recorded lectures. In some modules there are also 'carer stories'. These stories were developed by the research group, and later validated during the testing sessions. These stories are presented in the support programme as sound recordings using amateur actors. Furthermore, tips or experiences from carers are included. They were collected from carers during the co-design process and then presented in relevant modules (Figure 3). Finally, contact details for seeking support and links for further learning or reading on the topics are provided.

"A carer I have been in contact with chose to move apart despite criticism from those around them. The care recipient then received help from home care services in their daily life. Today, they maintain a wonderful relationship in many ways".

An experience from an informal carer

Figure 3. An experience from a carer, published in the module about Changed relationships.

In summary, the co-design process, described in the Method section, resulted in the online support programme. Carers engaged in various ways and to varying degrees throughout the different phases of this process. The research group maintained an exploratory and flexible approach to ensure that the online support programme stayed close to carers' wishes and preferences. This encompassed balancing carers' needs and preferences with content creators' professional knowledge and experiences, taking into consideration the technological limitations of the 1177 platform, while also aiming to provide an online solution that can be implemented and remains sustainable over time. This meant that the end-product might not reflect all carers' wishes and preferences, such as having interactive features with other carers or healthcare personnel. The programme's content was considered relevant, but its usefulness in carers' daily lives remained uncertain.

Study IV

This study included 15 informal carers of persons with HF, who participated in individual semi-structured interviews while being in an RCT.

Demographic background data

Carers' ages ranged from 52-80 years old, with 13 being women and 2 being men. Eleven carers reported having a post-secondary education, while one person reported having finished compulsory school and 3 that they had a vocational education. Nine were pensioners, while 6 were engaged in paid work. Furthermore, 9 reported having a 'good or very good' health status while 6 reported having 'neither good nor bad'. All participants cohabited with someone, and of these, 11 lived with the person with HF and were also their partner. Among the participants, one was also a sibling, one was a parent, and two were adult children of the person with HF. In relation to how demanding it was perceived to provide care, support, or help to the care recipient, most carers (n13) reported 'not very demanding' or 'not demanding at all' while 2 found the caring situation 'quite demanding'.

Carers also reported on what kind of support, help, or care they provide. All except 1 conveyed they provided emotional and psychosocial support and 10 reported providing household tasks. Around half managed finances (n8), while 5 took on roles related to 'care and treatment' or 'organising and managing care, support, or help'. Also, 4 provided financial support. Only one carer reported supporting the person with HF in their 'personal care' and similarly, only one supporting 'indoor or outdoor mobility'.

Per the RCT's inclusion criteria, all carers were regular users of devices such as computers, smartphones, or tablets. When considering the potential of online platforms to support their health, 4 carers responded they did not believe this was an option, and 6 responded with a maybe. Regarding the belief about the internet's capacity to facilitate in supporting others, 3 carers reported no, while 9 said maybe. Eight believed that the internet could help in their communication with healthcare personnel, while 6 said maybe, and one said no.

Utilisation of the support programme

Regarding the use of the support programme, 6 carers reported not having logged in at all, 4 had logged in 1-4 times, and 5 more than 4 times. Six carers stated they spent no time on the programme, 3 spent 2 hours or less, and 6 spent more than two hours. Five had not looked at any modules, 2 had looked at 1-3 modules, and 8 at between 4 to 15 modules. The latter was not self-reported, but instead collected from the programme at 1177.

Categories and subcategories

The analysis resulted in 3 categories and 8 subcategories, illustrated in Table 10.

Table 10. Overview of categories and subcategories in study IV

Category	Subcategory
<i>Motives for participation ranged from altruism to individualism</i>	For the sake of the good
	For the benefit of others
	For my own interest
<i>Usage was influenced by macrocosm, mesocosm and microcosm</i>	To be online is timely
	The delivery of the intervention matters
	Happenings in life always impact
<i>Engagement could lead to individual benefits and contribute to common good</i>	Content provided insights, preparedness, and validation
	Carers may not be the only beneficiaries

Motives for participation ranged from altruism to individualism

This category reflected carers' motives for choosing to participate in the RCT, including the online support programme. Their motives included having altruistic reasons to participate. Carers could have chosen to accept participation 'for the sake of the good' and consider that participation in research have intrinsic value. It could even be seen as a duty. Carers also expressed a hope that this project could aid healthcare and relief some burden on them. Another reason for accepting was 'for the benefit of others' and hoping that their contribution could provide valuable support to carers in need. Furthermore, carers also pointed out that support for carers could be beneficial for the care recipient which then also was a reason for accepting to participate. Carers' motives also entailed accepting participation for personal reasons, i.e., 'for my own interest'. They expressed hoping that their participation could contribute something to themselves. For example, they could aim to become more knowledgeable, receive an update, or become better prepared to support the person with HF. This was conveyed through their own previous experiences, such as having felt unprepared for

the emotional impact of the caregiving situation or having witnessed the deterioration of the person with HF and feeling that the offer to participate in the study came at the right time. They also expressed finding it rewarding to be in the focus. Carers could also be driven by what seemed like a general curiosity. However, not all carers were able to provide a motive, and one reason for this was not fully having understood the research project. Yet another reason was that when the person with HF asked (as they were the ones approached by the research group), it felt difficult to say no.

Usage was influenced by macrocosm, mesocosm, and microcosm'

This category covered carers' experiences related to the support programme's online format. It also explored what influenced their use of the programme while they had access to it. Carers described their experiences with the online format, and it was conveyed that 'to be online is timely'. The online format was deemed unproblematic and self-evident, aligning with the current trend of many activities being online. This perception extended to those who had not logged on to the support programme. The choice of platform, the National health portal 1177.se (116), was considered 'natural' as it was already familiar. The use of electronic identification for logging in could convey a sense of safety. However, it was noted as potentially unnecessary if no personal information was being exchanged. Carers also expressed concerns that electronic identification could create inequality, especially among an older population who might not be familiar with it and therefore may be unable to use the support programme. Additionally, carers commented on the instructions they received on how to log in and navigate the support programme. Carers had diverse experiences concerning these instructions, with one carer pointing out that they had not used them at all, and others commenting that they found them confusing and yet others that it may be enough to have instructions on how to log in.

Furthermore, carers described how factors related to 'the delivery of the intervention matters' for the usage of the support programme. Carers conveyed that they were influenced by reminders from the research group, which seemed to be motivating to log in and engage with the programme's content. Carers' experiences indicated that the method of delivery of these reminders made a difference. Carers were contacted through telephone calls, emails, and SMS messages during their participation. They noted that these various forms of communication could be valuable for different purposes. SMS and email were appreciated for their convenience since carers could read them when it suited. On the other hand, telephone calls were seen as more personal and could be valuable when the contact had a purpose beyond serving as a reminder. However, not all carers were receptive to reminders, and those who had not logged on to the support programme

could express feeling guilty due to reminders even though not motivated to log in. Additionally, reminders could provide carers with information they had missed in earlier communications, such as the specific timeline for access (3 months). When reminders repeated information that carers were already aware of, they could be perceived as impersonal. The time limit for accessing the support programme also appeared to influence usage, and carers had different perspectives on the timeframe. Some found the 3-month duration sufficient and believed that a time limit could be motivating, pushing them to engage. Others expressed wanting continuous access to revisit information when needed, and the time limit could therefore impact the usefulness of the support programme. Carers also associated their usage of the support programme to their desire to be 'good participants' and mentioned engaging with it for this reason. Additionally, some carers considered the questions in the baseline questionnaire (related to the RCT) as unrelated to their own situation, leading them to think that the support programme might be irrelevant to them.

Carers also conveyed that events in their personal lives could influence their usage, i.e., 'happenings in life always impact'. These factors included work-related issues, which sometimes discouraged them from engaging with an online programme due to feeling that they had already spent enough time with computers and technology during the workday. Carers also stated that they had limited time, which included having more intensive caregiving responsibilities, which was conveyed may have affected the ability to engage with the content. Additionally, carers expressed having experienced that the support programme came at the right time, which seem to encourage usage. Conversely, when the person with HF was not severely ill, it was mentioned that carers might be more motivated to use the support programme if the situation changed. Moreover, carers' own health issues, the loss of a family member, or problems with internet connections were also highlighted as hindrances to usage.

Engagement could lead to individual benefits and contribute to common good

This category included conveying the notion that engaging with the content in the support programme had been a generally positive experience. Carers that had engaged with the support programme had not necessarily looked at everything but had not actively avoided any topic or content in the programme. The broad variation of topics was highlighted, and it was pointed out that it could be useful for both new, as well as more experienced carers. The support programme could be apprehended as emotional, but carers did not express this as negative. Another experience was that the programme was appreciated as entailing 'humanity'.

Engaging with the ‘content provided insights, preparedness, and validation’. This encompassed the feeling of having gained updated knowledge or new knowledge, such as a better understanding of the seriousness of HF. Carers expressed that engaging with the content could provide validation and insight into how other carers had experienced similar situations, which contributed to this feeling. Additionally, carers expressed feeling empowered to take better care of themselves and felt a sense of acknowledgment through the content. Engaging with the support programme also left carers feeling more prepared, including knowing how to act if circumstances in their lives changed, such as the person with HF's condition worsening, which brought a sense of safety. Furthermore, the content sometimes prompted new questions and reflections related to the person with HF. This was experienced as an opportunity to behave differently, by, for example, being able to provide more insightful advice. Another experience was that the programme had given a feeling of being ‘lucky’ and that others seemed to have it worse. Additionally, carers did not necessarily find that they were able to relate to the content in the support programme. However, they could still find the content potentially valuable for the future. These experiences might reflect that some carers, because they were part of the study, chose to engage with all the content in the support programme, rather than selecting what they personally found most relevant. It was also pointed out that, even though considering the content potentially helpful, it may not necessarily replace having personal contacts with, for example, healthcare personnel.

Furthermore, carers also highlighted the potential value of the support programme for other family members and for the person with HF. It was emphasised that if other close family members engaged with the programme, it could be beneficial for carers as it might help relieve some of their responsibilities. For example, if adult children had a better understanding of HF and what caring for someone with HF entails, it could be helpful for the primary carer. Additionally, there could be potential benefits for the person with HF if they also engaged with the content. Carers also conveyed that such support could be of interest and importance for those caring for people with diseases or illnesses other than HF. Moreover, the support programme could possibly alleviate some of the burden on healthcare if carers found answers to (some of) their questions within the programme.

In summary, the findings indicate that carers, regardless of their motive or reason for engaging with the support programme, could have positive experience from doing so. This was interpreted to suggest a broad use for the support programme that may even exceed carers’ initial appreciation of its usefulness to them personally. To support usage reminders to carers may

be valuable. The time-limited access appeared to influence usage, potentially reducing the programme's overall usefulness. Engaging with the support programme could provide positive experiences beyond personal benefits for carers. Even though seeing the online format as unproblematic, carers also conveyed that going online may not be the preferred method when looking for support. Understanding participants' experiences can offer insights into how the support programme interacts with carers and which mechanisms are important for its effectiveness. These insights could be considered when studying the effects of using the support programme in the RCT. Furthermore, this information can also provide valuable information for a potential broader implementation, highlighting, for example, that it may take an effort to help carers to see how engaging with the programme might be helpful to them.

A synthesis of the findings

The findings of this thesis suggest that persons with HF, living with an ICD, most commonly perceive having high levels of social support from family, friends, and significant others. However, when they do not, the odds of experiencing symptoms of depression and anxiety are higher, so are the odds of perceiving having less control in relation to the heart condition (I). This highlights the importance of informal carers for the health and well-being of the person with HF. This thesis focused on online support for carers and when studying perceptions (II) and experiences (IV) as well as when involving carers in the development of online support aimed at them (III), informal carers often kept the person with HF in mind. This was demonstrated when carers considered how an online support could be helpful for supporting the person with HF (II, IV) and furthermore when discussing topics and content during the co-design process (III). Overall, findings indicate that online support can be usable as well as useful for carers when contemplating the online format and its content (II-IV). The findings also suggest that engaging with the co-designed online support programme can provide carers with a positive experience. It has the potential to offer insights, preparedness, and validation in relation to being a carer of a person with HF (IV) even though it does not meet all the wishes and expectations of carers (II, III). Additionally, the findings also suggest that the co-designed online support can be useful, even for those not necessarily considering themselves as informal carers, or in need of support (IV). However, findings are also interpreted to highlight an 'ambiguous stance' towards going online for support, as it, on the one hand, is thought of as 'a given' (II, IV) but on the other hand may be considered as something more for the future (II), that may not necessarily be the preferred form of support for carers (II, IV).

DISCUSSION

The overall aim in this thesis was to explore perceptions, development, and experiences of online support for informal carers. Since the support programme is considered the result of studies II, III, and IV in my thesis, I will focus the discussion on the support programme, specifically on its online format and the programme's content, and through this, its potential to be usable and useful for carers. The content in the support programme also explicitly takes into account the perspective of the person with HF, and as the lives of carers and care recipients can be considered intertwined, the discussion will also highlight this.

The online format

The platform

Carers may experience distrust towards online solutions (72) potentially affecting the willingness to go online for support. When selecting the platform, an important factor was that the National health portal 1177.se was already well-known and an 'entry point' for citizens to access public healthcare. A majority of Swedish citizens further finds it trustworthy (71.6%) (125). Having chosen this well-integrated platform can therefore be considered an enabling factor (72) that can enhance the likelihood that the support programme will be used, thereby making it usable and useful. Moreover, the Covid-19 pandemic has provided Swedish citizens additional reasons to seek health-related information online. The term "shock digitalization" was used to describe how, particularly older people, were more or less compelled to use the internet for many healthcare interactions (126). One study also demonstrated that Swedish citizens primarily used governmental online healthcare services for Covid-19-related information, more often than directly contacting healthcare personnel (127). These factors may have contributed to a perception that the support programme is even more usable now than when we initiated this project.

Furthermore, fear of privacy issues has been identified as a challenge for carers when going online (67, 72) and aspects relating to this were also highlighted by carers in this thesis (II, IV). However, this may not be as evident in the case of using the 1177 platform since it is generally trusted and as we do not interact with or store any details about carers. Given this, when discussing the online format, carers (IV) expressed that using electronic identification to access the support programme may be unnecessary.

At the time of its development, this was the only method for sharing the programme with carers. However, it is now technically possible to publish support programmes accessible to everyone. This could be a practical approach for the future, making it more convenient and usable for carers as well as for ensuring timelier support. Moreover, this could potentially also reduce the administrative burden on healthcare, since they would not have to assign or manage carers within the system.

Timely support

The importance of timely information and support to carers has been noted (47, 128, 129). Support to carers should adhere to both the illness trajectory of the person with HF and the care trajectory as needs may vary based on the different phases of the care recipient's illness (5, 7, 130). The broad set of topics that an online support may provide has been highlighted as potentially helpful for this (64). An online format may therefore be considered to hold the potential to match support in relation to carers' needs and preferences (62, 72), i.e., provide timely support. The online support programme developed in this thesis includes a wide range of topics and content with the intent of being relevant to carers whether the person with HF is newly diagnosed or in later stages of the disease. The potential value of this was pointed out by carers in the focus groups (II). This was further confirmed through the co-design process where carers and content creators added suggestions for topics and later in testing sessions confirmed their relevance (III). Carers in study IV also pointed out the broad set of topics as beneficial. The importance of timely support was additionally emphasised when carers expressed that the programme came at the right time or that it may be of interest when the care recipient might be more affected by the HF (IV). The latter was similarly pointed out in study II. Even so, it was also highlighted that some topics can be more useful for those who are new in the situation of being an informal carer (II, IV) and others for those having been in a caring role for a longer time (IV). According to Cameron & Gignac (2008), in the early stages when the care recipient is recently diagnosed, acquiring knowledge related to the illness or health condition and its treatments might be valuable. Emotional support could also be essential to manage the possible immediate stress and worry. As the care recipient stabilises, carers may feel the need for skills that assist in tasks like self-care. Support in navigating worries about the future and planning for what could happen if there are deteriorations in the care recipient's condition can also be beneficial. Once the situation achieves stability (if it does), carers might be more prone to reflect on how the circumstances have impacted them personally and therefore feel the need for support in relation to this (130). Since the support programme offers, for example, information on HF, on emotional reactions, and support for reflecting on the caring role, it

may be considered to provide a support that can accommodate to carers' varying needs over time, thereby strengthening the potential to be usable and useful. It also suggests that providing access to the support programme over an extended period might be considered as more useful. This was further indicated by carers in study IV who expressed wanting to engage with content when needed and to be able to revisit certain information (IV). In this study, it was highlighted that one of the reasons carers may not have engaged with the support programme as much was that they felt they did not have the time, for example, due to their caregiving situation or due to work commitments. These are known factors that can hinder carers from going online (67, 72), even if they understand its potential usefulness (67). These aspects could further strengthen the argument for providing the support programme without the current 3-month time constraint to provide it more usable and useful for carers that may be more heavily burdened during certain periods.

More for the future – or is it?

Despite presenting arguments on how more people are turning to online solutions for support since the Covid-19 pandemic, and that Swedes might be especially inclined to use governmental, professionally developed solutions (127), carers might still consider it better suited for future generations and potentially less usable and useful for those who are older (II, IV). Furthermore, age still seems to be an important factor that affects which carers go online and which do not. In one study, almost 55% of the Swedish carers (n253) utilised online service for support regularly but higher age was significantly associated with how often it was used (131), i.e., older persons utilised online services less frequently. When studying predictors of carers going online for information relating to the covid-19 pandemic, in a Swedish sample (n198) almost 80% had utilised this opportunity, but still, age predicted usage and those who were older were less likely to search for this kind of information (127). Carers in other studies have also referred to age to describe not being interested in online support (132). However, most people in Sweden regularly use the internet for accessing information and other services (133). Even though many of the elderly go online and further also utilise 1177, age may still be an important factor in determining 'who is in and who is out', since it has been pointed out being an essential contributor to the about 4% of Swedish non-users (134). This indicates that older carers may still be partially out of scope for online solutions, even though it may be a lesser problem in a country like Sweden.

A focus on the content

Balancing broad relevance and being usable and useful

Carers in this thesis expressed that online solutions could be regarded as impersonal or perceived as too general (II). The risk of online information being perceived as impersonal mirrors other findings (72, 132) which could highlight that carers may have a preference for tailored information more closely adapted to their individual situations (47). Moreover, information that feels impersonal might be viewed as 'unwanted' and could also be a source of worry (II), reasons carers have provided for not engaging with online content (135). During the co-design process, we therefore considered it essential to ensure that content was related to HF and the experience of caring for someone with HF, in addition to aligning closely with the expressed needs and preferences of carers. The intention was to find a balance in providing information that could be considered relevant to many, while also sufficiently precise to be considered usable and useful to anyone. General information concerning specific diseases or illnesses has been highlighted as valuable for carers (47). Furthermore, carer-specific information can also be important (64). The support programme addresses both these aspects, which may enhance its usefulness. While the specific focus on HF is seen as a strength, many people with HF and their informal carers live with multiple diseases or conditions, potentially adding to their burden (136). This might motivate a broader perspective in the programme, or the addition of modules on living with multiple illnesses or other diseases with similar trajectories.

Another aspect that may provide carers with content they find sufficiently specific and therefore useful, is that the content incorporates the knowledge and experiences of content creators. These were mainly healthcare professionals well-established in the field of HF or in the field of caregiving. Also, the iterative process, where content moved back and forth between carers and content creators (III) may have paved a path that combined and balanced diverse carer needs and lived experiences with evidence-based information from professionals, which could be considered a valuable contribution from a co-design process (74) that added specificity to the programme. Moreover, having trust in those creating online content could affect carers assessment of the credibility of information (72, 137) and knowing that the information has been reviewed by professionals could increase its trustworthiness (138). This, in turn, could further strengthen the apprehension that the support programme is perceived as usable and useful for support.

Straightforward information

An additional aspect that could enhance the usefulness of the content in the support programme, aligning it with carers' preferences and needs (II, IV) is the inclusion of sensitive topics like 'Intimacy and Sexuality' and 'About the end of life'. For instance, during the co-design process, carers expressed a wish for answers regarding end-of-life situations when living with HF. Even though it wasn't specified in such detail, carers in study II emphasised the importance of having this type of 'straightforward information', without avoiding topics due to fear of causing worry, which has been emphasised also in previous research (41). However, it is possible that if we did not have this input from carers and further concrete suggestions for what to ask, for example, the palliative care physician, we may not have been equally straightforward, since researchers (and clinicians) might avoid certain topics fearing potential harm (139). We further gained more confidence in this content through testing sessions with carers (III), as we received no negative feedback on how this information was delivered. Similarly, no carers in study IV indicated having experienced any 'unwanted' emotions from their engagement with the content. However, topics such as 'About the end of life' may not be relevant to everyone. During the co-design process, it was emphasised that information about the end of life should be provided in a separate module, allowing those who wish to avoid this subject to do so. It is also possible that this kind of information might be more relevant to carers living with someone in the later stages of HF, as carers who have recently taken on this role might not find it beneficial to read about this in relation to where they are in their care trajectory (130).

Minding literacy

As health literacy (and eHealth literacy) is an important aspect that may affect how well carers are able to utilise online information for support of their health and well-being throughout life (140, 141), we have been meticulous about providing content that avoid too advanced language, for example by avoiding medical jargon. The importance of considering language was highlighted by carers in study II. In addition to carers providing feedback about the language (III), we also used guidelines provided by the 1177 (116) and technology, i.e., an online calculator for readability, to make certain that the language were both relatable and understandable. Additionally, an informal carer reviewed the finished support programme with the opportunity to also point out difficulties regarding language. Having minded language using these different measures could be crucial for its potential to be usable and useful.

Not answering to all carers' needs and preferences

The online support programme might not fulfil all carers' preferences as it does not provide them the opportunity to have personal contact with healthcare (II, IV). Nonetheless, the co-designed content that comprises texts, videotaped interviews, and lectures, created with and by nurses, a physician, and a social worker with expertise in HF (III), may potentially provide a 'proxy' for some of these contacts. Carers also highlighted the potential of online support (II) and the co-designed support programme (IV) for avoiding certain contacts with healthcare. However, carers might also view physical meetings or 'non-online' support forms as irreplaceable (II, IV) and potentially more useful than seeking online support, an apprehension that has been emphasised in previous research (65, 132). While the co-designed online support programme offers relevant and credible content within a healthcare context, it is important to bear in mind that carers may not consider it their primary option for support (II, IV). Carers may even fear that it would add burden (135) or worry that this form of support could replace other valuable types or even be perceived as potentially decreasing the overall support or 'dehumanising' care (72). Yet another factor for not wanting to engage online might be a 'saturation' with computers or technology due to professional engagements, a factor highlighted by carers in this thesis (IV). It has been highlighted that working carers might lack the time and energy to go online (67), suggesting that some carers could experience 'technology fatigue' and may hesitate to go online for support. This could therefore inhibit the support programme's usability and its usefulness for some carers.

Moreover, the platform did not allow for carers to interact with other carers, which was pointed out as a potentially valuable feature in online support by carers in this thesis (II, III) and, this has also been highlighted in previous research (66, 68). The absence of this feature could potentially make the support programme appear less useful for carers, as engaging with persons with similar experiences has been underscored as an important aspect of support (55). It is not assumed that the support programme can remove the need to meet other carers in person or online. However, the experience of the co-designed programme as humane and the fact that carers indicated they could recognise themselves in and feel confirmed and empowered by the co-designed content (IV), suggest it could provide support of a similar value to that gained by engaging with other carers (56). Furthermore, it could be that the information in the support programme about where to find support as a carer could give those who wish, the opportunity to expand their network, enhancing their perception of having social support, from for example, other carers. In addition to experiencing this as useful, it could potentially also lead to feeling or being

less lonely (i.e., perceiving support), which may then contribute to better health and well-being (58, 60).

The potential for tailoring

Through the co-design process the content in the support programme is considered relevant for carers and, to an extent, specific or tailored, at least potentially more so than online support that is not co-designed. However, an even more tailored solution could entail that carers can access the information they are looking for more efficiently, which might enhance its perception as usable and useful. This may be especially true for carers who experience time constraints due to their caring situation or from paid work. The use of artificial intelligence (AI) through a large language model (LLM) and an interface such as a chatbot (142, 143) may be helpful for tailoring. Using this type of interface, carers could potentially discuss and interact with the support programme more directly in line with their needs and preferences without having to engage with content they may not consider useful. This might further address the risk of online support being considered too general as discussed earlier. Another potential advantage is that such a solution could cater to varying health literacy levels among carers and might also be adaptable to peoples' preferences for engagement, and for easy translation to different languages. However, the potential of using AI for this requires further study. It may not necessarily be trusted by citizens and there are still practical and ethical issues to resolve (142, 144).

Carers have the person with heart failure in mind

In this thesis, when discussing online support aimed at them, carers consistently, even though not exclusively, held the perspective of the person with HF (II-IV). That carers have and keep the care recipient in mind aligns with findings from previous research (145, 146). In this thesis carers conveyed the perception that online support (II) and, more specifically, the support programme (IV), could have positive implications also for the person with HF. For instance, in study IV, it was pointed out that the information provided in the support programme had assisted in the support of the person with HF. The importance of information as a supportive aid for carers have been emphasised (7) and within the field of HF, this may encompass providing carers with information on HF, symptoms, and treatment (43, 128). This was content that carers in this thesis also suggested as valuable in an online support (II, III, IV). While this thesis cannot establish whether the experiences of carers had an impact on the person with HF, others have pointed out the potential of support from informal carers in how it can impact self-care, health and well-being in the person with HF (5, 147). Findings from study I, which indicate that support from family,

friends, and significant others is associated with better outcomes on symptoms of depression and anxiety as well as perceived control in the persons with HF, also highlight the importance of support from carers. In study IV, it was further emphasised that engagement with the support programme had contributed to carers feeling more prepared and secure, and that this sense of security could extend, in a positive way, to the person with HF. This aligns with earlier research that have highlighted the importance of preparedness (41, 44). Moreover, when carers feel more prepared this could add confidence to support the persons with HF in their self-care (148) and have positive implications for the person with HF (149). These aspects are considered pointing out that carers' and care recipients' lives are intertwined to some extent. However, if informal care is managed by carers who lack knowledge and experience, this could potentially risk diminishing the quality of care provided (18). Therefore, it may be considered useful that the support programme has a focus on providing information about, for example, HF. This could aid carers in both being and feeling more prepared for a caregiving role.

The intertwined lives of carers and care recipients may not always be beneficial though. Carers might, for example, 'push too hard' or become overly protective due to their own emotional responses to the situation (150). Increased knowledge, about HF and emotional reactions related to caregiving, can potentially help carers to adopt a more reflective approach to their caregiving. This may in turn further strengthen the emotional bond between the carer and the person with HF. The presence of an emotional bond has been underscored as having the potential to bolster the quality of care provided by the carer (18). The potential for an emotional bond or feeling social connectedness could be reasoned to depend, at least partly, on the quality of the relationship (51). The quality of the relationship could impact both the person with HF and the informal carers' health and well-being (151) and could influence the self-care of the person with HF (152), as well as the carers' perception of burden from caregiving (152, 153). Another focus in the co-designed support programme, which may therefore be considered useful, is the content on emotional reactions and how the relationship can change when living with someone who is ill. Carers are provided information and practical advice on how to handle their emotional reactions and how to bring up aspects that they find difficult in the relationship. By above reasoning, this could impact the carer and indirectly also the person with HF.

Considering a broader implementation

The support programme, based on the above reasoning, can potentially be usable and useful for carers to persons with HF. However, this does not ensure that the support programme will reach all those who could possibly benefit from reading and engaging with the content. There may be several factors, that should be considered if contemplating a broader implementation. Most fundamentally, is that carers must be aware that the programme exists. One potential reason why carers may not seek online support is simply that they are unaware that support aimed directly at them is available (67, 72, 137). This could of course include that carers already have the necessary information and support and therefore are not looking for help (135), but their reluctance could also reflect not being able to visualise what online solutions could provide in terms of support, which could then affect their interest in it (154). Making carers aware of available solutions and their potential benefits might help them better appreciate its usefulness (137) which could then trigger their interest to go online. Nonetheless, as already mentioned, it is also important to consider that not everyone is inclined to, or wish to go online for support (65, 67, 135). Additionally, nurses and other healthcare personnel may also be reluctant (132), which could add complexity to a broader implementation effort.

Moreover, this thesis points out that older age may be a factor that affects the willingness to go online for support. In addition, there might also be other aspects that exert an influence. In his thesis, Hassan (61) concluded that the extent of caregiving in terms of time and effort, gender, the carer's own health status, the relationship between the carer and care recipient, and level of education can influence how carers interact with online solutions. Moreover, having relocated to another country and peoples' income could affect who seeks health-related information online (155). Financial constraints might pose a barrier, as not everyone can afford the necessary technology (67). Lacking the skills for going online would also be a hindering factor (67, 72). Some of these aspects underscore the significance of an 'outreach approach' to promote usage if it is deemed valid to do so. However, when offering carers support options, these should also include 'non-online' alternatives.

A final note

Since this project started there may be additional considerations to be made in relation to informal care and the need for support to informal carers. In 2017, the Swedish government initiated a state-commissioned public inquiry “Good and close care” that had the task:

*“...to co-ordinately develop a modern, equitable, accessible, and efficient healthcare system with a focus on primary care” (156)
[translated by the author].*

By 2023, an agreement was reached between the state, Sweden's municipalities, and regions concerning the proposals of this inquiry (157). This plan involves changes that will shift greater emphasis to primary care and increase the provision of healthcare services in people's homes. It is possible that this could incorporate additional dependency on informal care (21). This can possibly, in turn, increase the need for efforts to prepare carers for their role (5, 71). In 2022, the Swedish government launched a national carer strategy (158) with the aim of strengthening a carer perspective within health and social care services and which places informal carers on the agenda for further governmental initiatives. This strategy highlights the importance of carer focused solutions that are proactive. In Sweden, there is moreover a high-aiming goal of making citizens and society digital to support them in their health and to support more equal care (89). Furthermore, the potential for digital solutions to support carers have been highlighted (158). Additionally, support for informal carers have also been highlighted as potentially cost-effective (27). Relating to above reasoning, the support programme may be considered timely.

However, not every carer is willing or capable of providing, help, care and support (16). Given the strain on healthcare due to changing demographics — with fewer healthcare personnel and an increasing number of people living with long-term conditions such as HF — there might be a perceived necessity to promote online solutions. Still, in Sweden informal carers, in general, do not have the legal responsibility to support care recipients in relation to health and welfare, and therefore, support options should include helping carers' to make a choice – possibly to withdraw from a caring role (158). While the co-designed online support programme is considered a potentially valuable contribution for supporting those carers who wish to remain in their caring role, it still is important that healthcare support those carers who wish otherwise.

Methodological considerations

The overall quality of the research in this thesis will be reflected by discussing trustworthiness. Trustworthiness can be evaluated using the quality criteria of ‘credibility’, ‘transferability’, ‘dependability’, and ‘confirmability’, which will be expanded upon in the sections below. Additionally, ‘reflexivity’, recognised as a vital ‘tool’ in relation to trustworthiness (122), will also be discussed.

Credibility

‘Credibility’ has been described as being about the potential to appraise how believable or plausible it is that findings from research reflect the perceptions or experiences of the included participants (1). In research using quantitative methods credibility is often discussed under the term ‘internal validity’ (1, 122) and this will be addressed partially in a separate section.

The ‘prolonged engagement’ (122) within the fields of ‘caregiving’ and ‘heart failure’ I have attained over the course of working on my thesis may be considered a strength. Studies have consistently included carers of persons with HF (II, III, IV) and persons with HF (I). Prolonged engagement can imply trustworthiness, as the researcher’s claims might be seen as more robust due to deeper insights into what is being studied (121). Furthermore, some participants from study II also participated in the co-design process (III), providing another layer of insight into their situations. When engaging with carers, creating a safe space for interviews or discussions was considered important. This has been highlighted as pivotal (159-161) and may even be crucial, since if participants are not comfortable with the situation this could impact on their willingness to share their thoughts and experiences. If there is a lack of participants willingness to share, research may be considered lacking credibility, or even being invalid, because it would impact on data collection negatively (122). For me, the goal was to ensure ‘thick’ and credible data collection but without compromising participants’ integrity.

The iterative process of co-design, which entailed revisiting phases and steps, could be considered as having integrated so called ‘member checking’ (121, 122). As we continuously ‘tested our data’ (i.e., the content of the support programme) this can be viewed as a strength since it allowed for reflection on how accurately I and we had grasped and interpreted the carers’ perceptions and experiences. Furthermore, during analysis in study II and IV, I have moved back and forth between codes, the raw data, and categories to ensure that they accurately represent carers perceptions and experiences in relation to the aim of the study. This approach could also be viewed as a measure of credibility of the findings (102). Additionally, the use of diverse data collection methods, combined with the involvement of

multiple researchers (I-IV) and content creators (III) who are well-established in fields relevant to the research (for example, nursing, medicine, and sociology) likely strengthened the credibility of the findings through triangulation (162).

In relation to study I, I will reflect on its internal validity, which has been described as whether the findings of a study accurately represent reality (121). Study I was a cross-sectional study using the instrument MSPSS for exploring participants perceived social support. The instrument's validity and reliability has been supported (96, 163, 164). The instrument has also been interpreted and tested for validity and reliability in a Swedish context (165) and in the context of having an ICD (166). The choice of conducting logistic regression models was related to the aim and discussions on that such an approach might give findings that would be more easily interpreted and, therefore, more useful for clinicians. Nonetheless, I recognise the potential drawbacks of this approach, particularly the risk of "losing information" by dichotomising the ordinal variable. This loss could have reduced the potential of identifying nuances on what differentiated those perceiving high support from those perceiving low/medium support (167). Nevertheless, we identified differences between the groups, which was considered meaningful information in relation to the study aim.

Lastly, I was not experienced in conducting research or established in the field of HF or caregiving when starting the work with my thesis. For this reason, discussing with my supervisors and other researchers, by visiting relevant scientific conferences, through discussions in doctoral seminars and by doing a short field study at a HF clinic have been valuable. These interactions may be regarded as so-called 'peer debriefings' (121, 122), which I consider have provided opportunities for testing and refining my research methods and assumptions in the fields of HF and caregiving. This, in turn, could strengthen the credibility of the findings in this thesis.

Transferability

'Transferability' pertains to the potential of research findings being applicable in other contexts. In research that uses quantitative data collection, this is often discussed using the term 'external validity' (1, 122). Lincoln & Guba argue that the decision regarding the 'transferability' of findings rests with those who wish to apply them (122), which implies the importance of transparency and comprehensive descriptions of context. With respect to the transferability of findings in this thesis and its included studies, I have made efforts to provide details that would assist other researchers or readers in determining the applicability of the findings. This has entailed descriptions of the research context and participants, while ensuring their privacy and adherence to the different studies' ethical approvals and journals' author guidelines.

One overarching reflection is that in studies II, III, and IV, most carers were women, spouses to the person with HF and living with someone. Furthermore, all except two carers were born in Sweden and to my knowledge, only one had their fully origin outside Sweden and the Nordic countries (IV). Despite our active efforts to achieve diversity we did not succeed as well as we had hoped. In study I, most participants were born in Sweden, the majority were male, and a majority also cohabited with someone. As most persons with HF are male and most carers are typically their female spouses (33), this perhaps reflects the general population concerning gender and relationship status. Even so, the lack of, for example, diversity considering ethnic background may have caused that certain perspectives, experiences, and perceptions are underrepresented or absent. If certain groups are non-recruited or by their own choice exclude themselves from participation (self-selection) this could introduce systematic biases affecting the interpretation and, subsequently, the transferability and generalisability of research findings (168, 169). Even if this may have different implications depending on study design or approach, more proactive methods and strategies might be needed to recruit those who do not self-evidently accept participation in research (170). Malm has argued that when involving carers in research, it is vital to consider potential power structures that may prevent certain groups from participating (86) and this could possibly also be true for research in general. The Swedish Healthcare Act (23) stipulates that everyone residing in Sweden, or who resides here on a continual basis should receive quality care. Recruiting diverse groups of carers or persons with HF could therefore assist healthcare in this mission by eliminating uncertainties about the population for whom research results are valid. Thus, I see participation in research both as a methodological and an ethical concern. However, concerning the carers in this thesis, as Revenson have suggested, there might be universal experiences overriding differences in informal care, rendering the findings valuable for carers from varied backgrounds (7). This might also hold true for people with HF living with an ICD or CRT-D.

Dependability

By ensuring transparency and thoroughness in the description of methods, one could provide a means for others to assess the research's 'dependability' (1, 122). In research using quantitative methods for data collection, dependability is often discussed by the term 'reliability' (1, 122). In Study I, the dependent variable (perceived social support) achieved Cronbach's alpha values above 0.8 for both subscales and the entire scale, reflecting good internal consistency. This suggests participants' responses were consistent, reinforcing the dependability of the perceived social support measure.

Furthermore, I have been meticulous in understanding and describing my methods for data collection and analysis (I-IV). I have maintained detailed notes, capturing my decision-making process and choices throughout, thereby establishing an 'audit trail' that offers the potential for others to trace what I have done (122). Moreover, I have been thorough about using all data that are relevant in relation to the study purpose and further also account for these in the different studies, which can also be considered as strengthening dependability.

Confirmability

The term 'confirmability' concerns whether interpretations of data are logical or could be a result of for example, researchers' unreflective pre-understandings or positions (bias) (122). In research using quantitative methods, objectivity could be used for discussing 'confirmability' (1, 122). To allow other researchers to determine the confirmability of my findings, I have had the intent to be clear on how I have managed my analysis (I-IV) by using for example, quotes (II, IV) and provide examples from the analytical process. A statistician was involved in guiding the analysis in Study I and I performed analysis in collaboration with my supervisors which could be considered assuring that both methods and results were 'confirmed'.

Reflexivity

Being reflexive in relation to one's research might contribute to the trustworthiness of the findings (122). Clarifying my position in relation to the research in this thesis is a way to show how I have reflected on how my understanding may have impacted the findings. This could be considered a way of dealing with potential 'bias', even though bias in 'qualitative terms' may be considered a strength (121). The position and closeness to the fields under study, might mean that the researcher can provide a deep and insightful description of what is studied. Reflexivity may more often be associated with research using qualitative data collection, but Polit & Beck highlight its importance in any type of study (159).

Throughout my studies, I have striven to be reflexive on my position in relation to both participants and data. In hindsight, I think I may have moved my position from being more of an 'outsider' in study I and II to having more of an 'inside perspective' in study III and IV. By this, I mean that at the beginning of my thesis work, I might have aimed for a more objective approach. However, through reflection and peer debriefing (122), I have come to realise that what I learn and come to know may help me in, for example, asking more insightful questions. It hopefully also helps me delve deeper into interpreting the data.

There are other aspects that I consider have had an impact throughout the work with my thesis. The values, concepts, and theories within the field of nursing will have had an influence. Therefore, myself being schooled to become a nurse, my master studies in nursing, the teaching of nursing students and being tutored by nurses (in a Swedish context) have contributed to the shaping of this thesis (171). I have used peer-debriefings (122) to reflect on my role as a researcher when conducting interviews and group discussions and in the analysis of findings. I regarded this as important for reflecting on whether I maintained the role of the researcher and not primarily that of a nurse (172). My concern was ensuring I kept my focus on the purpose of the interview and the research questions, while also considering the participants, as they might have reasons for participating that differ from simply contributing to research (173). Through peer-debriefings, I found a way to adopt what might be termed a 'dual perspective' (174) where I aimed to ensure a positive and meaningful relationship with the participants by using competencies from my nursing profession, while also ensuring I collected 'thick descriptions' of their experiences or perceptions focused in the study. One tool that aided me in this was to be transparent and open with participants.

Lastly, I have personal experiences of being an informal carer, which undoubtedly has made an impact on my research. By a reflexive stance in relation to this and other aspects mentioned above, my hope is that my prior knowledge and experiences - together with the ones I have developed during my PhD studies - have served this thesis and its participants, and that this thesis will serve the interests of informal carers.

Clinical implications

In 2022, the national carer strategy was launched, with the intent to strengthen a carer perspective within healthcare. The strategy highlights that support for carers would benefit from being proactive and preventive. Furthermore, support should be available and developed in relation to carers' needs. The co-designed online support programme, which is situated at the National health portal 1177, could potentially aid healthcare in the provision of such support to informal carers for persons with HF. If the programme is broadly implemented, it could serve as a 'tool' that healthcare might also find feasible. Perhaps especially if the programme can be assigned without the requirement of logging in, as this would necessitate someone to manage granting and terminating access to the programme. Nonetheless, nurses and other healthcare personnel might have their focus on the person with HF, or they themselves might be hesitant towards online solutions, and may need encouragement to promote the use of online support. Moreover, healthcare personnel and carers may need to be made aware that the support programme exists. These could be important aspects to consider in an implementation strategy to support the use of the support programme in a clinical setting.

Future research

By exploring the effects of using the support programme (ClinicalTrials.gov Identifier: NCT04885465), insights will be gained into its impact on preparedness for caring and on carers' health and well-being. While this is intrinsically valuable, it may also provide a deeper understanding of who the support programme might especially benefit, which could guide additional efforts in a potential implementation.

Furthermore, exploring whether the use of AI and an LLM, via a chatbot could offer more person-centred online support may be valuable. For instance, interacting with a chatbot might help carers find information within the support programme that is tailored to their needs more effectively. Additionally, using AI to navigate the support programme could allow carers to choose the format in which they wish the programme to be delivered and further enable it to be delivered in a language they are comfortable with.

During the work on this thesis, challenges were encountered regarding recruiting carers from diverse backgrounds. Future research projects could explore strategies to encourage a broader range of carers or other research participants to engage in research, as this is of importance for the relevance and applicability of the findings.

CONCLUSIONS

This thesis delved into online solutions for support of carers. In conclusion, it highlights that a co-designed online support programme has the potential to be usable as well as useful for carers of persons with HF, due to the choice of a well-known and trusted platform situated within a healthcare context. Moreover, it offers the potential to provide timely support that is adaptable to the carer trajectory. This might be especially true if carers could log on without using electronic identification and furthermore if the current time limit was excluded. Additionally, the co-designed content which comprises both carers' and professionals' voices has provided carers with evidence-based content that may be appreciated as relevant, without being perceived as overly generic or impersonal. Since carers kept the person with HF in mind when contemplating online support, the focus on HF and on 'dyadic' aspects in the programme, may also add to perceiving the content as usable and useful. Furthermore, engagement with the content may also impact the person with HF as carers and care recipients' lives may be regarded as intertwined.

Nonetheless, the potential of the support programme depends on carers being aware of its existence and having the skills and interest to go online. Given the findings of this thesis, which suggest that the support programme have the capacity to be relevant for a wide range of carers, these factors can underscore the importance of an outreach approach for a broader implementation, ensuring that it will be available to those who wish and need support in their role as carers. However, while online solutions are viewed as increasingly important for future care and support provision – to, for example, stretch healthcare resources, healthcare must also recognise and support those who might not wish to seek online support or maintain a caregiving role. The online support may be considered one option among several.

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Papers

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The background of the cover is a composite image. The lower half features a close-up of a pink, fuzzy flower, possibly a peony, with soft, layered petals. The upper half shows a wicker chair with a curved backrest, set against a blurred background of green foliage and a blue sky. A semi-transparent white box is overlaid on the upper left portion of the image, containing text.

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Department of Health, Medicine and Caring Sciences

Linköping University
SE-581 83 Linköping, Sweden

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