










RESEARCH METHODOLOGY: DISCUSSION
PAPER-METHODOLOGY

The co-design of an online support programme with and for informal carers of people with heart failure: A methodological paper

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Abstract

Aim: To describe the co-designing process of an online support programme with and for informal carers of people with heart failure.

Design: A co-design process built on core concepts and ideas embedded in co-design methodology.

Data sources: Our co-design process included three phases involving 32 informal caregivers and 25 content creators; (1) Identification of topics and content through literature searches, focus group interviews and user group sessions; (2) Development of the online support programme and; (3) Refinement and finalization which included testing a paper prototype followed by testing the online version and testing and approval of the final version of the support programme.

Outcomes: The co-design process resulted in a support programme consisting of 15 different modules relevant to informal carers, delivered on a National Health Portal.

Conclusion: Co-design is an explorative process where researchers need to balance a range of potentially conflicting factors and to ensure that the end users are genuinely included in the process.

Relevance to clinical practice: Emphasizing equal involvement of end users (e.g. carers or patients) in the design and development of healthcare interventions aligns with contemporary ideas of person-centred care and provides a valuable learning opportunity for those involved. Furthermore, a co-designed online support programme has the capacity to be both accessible and meet end users' information and support needs, thereby optimizing their self-care abilities. Additionally, an online support programme

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provides the opportunity to address current challenges regarding scarce resources and the lack of healthcare personnel.

Reporting methods: Consolidated criteria for reporting qualitative research (COREQ).

Patient or public contribution: Both informal carers and content creators were involved in developing the support programme.

KEYWORDS

heart diseases, informal caregiving, information and communication technology, participatory design, web-based support

1 | INTRODUCTION

Heart failure is a syndrome that does not only impact those diagnosed, but also partners, children, other relatives and close friends. When family members or friends provide support, help or care to their relative/significant other with heart failure they are often referred to as informal carers (Eurocarers, 2022a). The person living with heart failure will frequently engage in self-care activities such as medication adherence, symptom monitoring, diet changes and exercise (Jaarsma et al., 2021). However, the responsibility and support for self-care can also fall on informal carers who increasingly fill an important role in the support, help and/or care of the person affected (Kitko et al., 2020). As the symptoms of advanced heart failure are usually profound and unpredictable, people living with more severe heart failure may also experience serious consequences in their daily lives (McDonagh et al., 2021). Throughout the disease trajectory, informal carers' lives are also affected in many ways (Nicholas Dionne-Odom et al., 2017). When caring responsibilities become increasingly intensive, carers' psychological and physical health, and in general their quality of life is negatively affected by their caring situation (Kitko et al., 2020).

Carers of people with heart failure, especially those at an early phase of their caring activities and/or those without any prior experience of caring, may not always possess the basic knowledge related to for example disease and medication administration. Informal carers also often report ambiguity and stress in their caregiving tasks (Grant & Graven, 2018), as well as a lack of support from professional carers (Gusdal et al., 2016; Liljeroos et al., 2014). According to the Social Services Act in Sweden, the 290 municipalities are obliged to offer support to carers (European Commission, 2021). By contrast, the healthcare sector does not have the same clearly stated responsibility in the healthcare act. Healthcare services have been slower to recognize the vital role played by informal carers, and as a result there is a relative dearth of supports provided by the healthcare sector. Nevertheless, voices are being raised for healthcare to also provide support to carers (European Commission, 2022; EuroCarers, 2022b). Consequently, research on intervention development to enhance heart failure carer education and support is highly warranted (Kitko et al., 2020). Such support could be provided via information and communication technology (ICT) that has increasingly been emphasized to be relevant (Guay et al., 2017; Kitko et al., 2020) and potentially acceptable to carers of people with heart failure

What does this paper contribute to the wider global clinical community?

- This paper contributes with a more in-depth understanding of the need to weigh the input from end users with those of professionals, to co-design a support that is evidence-based and relevant for the end users.
- This paper underlines the significance of actively considering implementation and sustainability issues already during the planning phase of the co-design process, and thereby ensuring that the support being developed aligns with the available resources within the healthcare system, while meeting the needs and preferences of the end users.
- Finally, this paper provides an insight into both the co-existing opportunities and constraints afforded by designing a carer support intervention within a national health portal infrastructure.

(Allemann et al., 2019). There are also incentives to digitalize healthcare to meet future challenges of an ageing population, together with acute shortages and turnover in healthcare staff (WHO, 2016, 2021).

Interventions generated through research are sometimes developed without involving the so-called end users (e.g. informal carers) in the process. When end users are not involved, there is an inherent risk that the intervention will not meet their actual needs and preferences which might result in the intervention not being deemed relevant or acceptable to them. Participatory designs have been addressed as a possible solution to overcome problems with usability in ICT interventions (Hassan, 2020) which could be of importance since some carers of people with heart failure have expressed scepticism in relation to using ICT for accessing support (Allemann et al., 2019). It is worth noting that the use of definitions, terminology and activities relating to research that engages end users and other stakeholders are sometimes unclear and contradictory (Slattery et al., 2020). For this paper we conform to the definition specified by Vargas et al (Vargas et al., 2022) which states that: 'Co-design describes active collaboration between stakeholders in designing solutions to a prespecified problem', (pp.2). We have therefore adopted a co-design approach in the development of an online support

programme with and for informal carers who support, help or care for a person with heart failure.

2 | AIM

The aim of this article was to describe the co-designing process which resulted in an online support programme with and for informal carers of people with heart failure.

3 | DATA SOURCES

A co-design process was conducted and included core concepts and ideas embedded in co-design methodology (Donetto et al., 2014, 2015; Sanders & Stappers, 2008; Steen, 2011). This section therefore describes the three phases included in this iterative development process of co-designing an online support programme. The co-design process and involvement of informal carers (potential end users) started with the user groups in the Spring of 2017 and the support programme was completed by December 2020. Carers were involved in different phases and steps of the process of developing the support programme, with some individuals being involved in several phases or steps of a phase.

Phase I aimed to assess carers' needs and preferences and identify topics and content to be included in the online support programme; Phase II focused on the building of the programme; and finally phase III consisted of the testing of a prototype, refinements of the support programme and the editing of a final version.

The research group ($n=7$) coordinated the process of co-designing the support programme. Two members of the research group formed a content manager team, responsible for the practicalities concerning building the online programme. The content of the support programme was developed by engaging informal carers ($n=32$) and by involving content creators ($n=25$).

The content creators contributed with material for the support programme and consisted of researchers from the field of heart failure and informal care, and practitioners, such as a physician within palliative care, a carer advocate (a dedicated role within the municipality that provides support to informal carers) and nurses. In addition, a professional communicator and an ICT pedagogue were engaged to provide media content adding to the development of the programme.

Throughout the whole development process the research group had regular meetings with the IT administration within the health-care region, Region Östergötland, which hosts the project. They are responsible for the maintenance of the online health portal called 1177 used in the project. Meeting the IT administration helped in understanding the full potential of the platform as well as the protocols and legal aspects of using the platform. The publicly funded company (Inera), responsible for the infrastructure of the health portal, were also consulted to better understand the portal's potential, usability and technical limitations.

3.1 | Phase I: The identification of topics and content

To help ensure that the support programme would be deemed relevant for end users, informal carers of people with heart failure were invited to explore and assess carers' needs and preferences with regards to education, information and support delivered via ICT. This was done by highlighting the main themes arising from a literature search; through secondary analysis of qualitative data from focus group interviews with family members of heart failure (Allemann et al., 2019) and through user group sessions with carers (Andréasson et al., 2019).

3.1.1 | Literature searches

To achieve an initial overview of the needs and preferences of carers of people with heart failure, the findings of earlier performed literature searches in 2017 using the databases PubMed, Scopus, CINAHL and PsychINFO were studied. The literature searches were based on the search terms 'caregiver(s)'/ 'informal carers'/ 'family', 'heart failure', 'social support' and 'Information and communication Technology' which resulted in a total of 124 articles that fitted the aim to describe informal carers' needs for education, information and support with a focus on Internet technology.

3.1.2 | Focus group interviews

In addition to the literature search, a secondary qualitative analysis was conducted, using data from eight focus group interviews with 23 family members (28–85 years old, 18 women, five men) of people with heart failure performed between March 2015 and January 2017. The analysis added further insights into family members' situations, needs and preferences, including their reflections about ICT-based solutions for support in relation to their respective needs (Allemann et al., 2019).

When compiling the literature search findings and focus group interview data, the focus was on (1) what information and/or educational needs were requested and (2) which ICT-based solutions could support carers in their daily life. An overall summary of both sources of data then acted as the basis for open-ended discussions during the user group sessions.

3.1.3 | User group sessions

The user group sessions involved informal carers in the co-design of the support programme. Seven female carers aged 35–70 being daughters or spouses, one researcher from the field of Health Science and one researcher from the field of Informatics were involved. Carers were invited via a Cardiology Unit at a Regional County Hospital, Health Care Centres and Municipal Home Care in the South of

Sweden as well as from patient and carer organizations. This broad approach both facilitated recruitment and gave a more blended group of carers with different types of experiences.

To discuss and reach consensus on the foundations for the support programme, five user group sessions were conducted focusing on different topics. These topics included expectations about participating in the project, ideas and reflections about online support and discussions about the summary of the literature search and focus group findings. These discussions aimed at identifying topics of particular interest to informal carers (Andréasson et al., 2019).

The combined literature search, focus group and user group session findings resulted in suggestions on different topics and content of interest to carers of people with heart failure. These included; issues concerning sleep: information about heart failure: the effect of caring and illness on the relationship with the person with heart failure, and questions concerning what formal (publicly funded) help and support is available and could be relevant. With regards to technology and tools, phase I showed that carers have an interest in different kinds of technology to receive support, information and education and to enable interaction with healthcare professionals and other carers.

The research group added topics or content identified from the literature and their professional knowledge and experiences concerning information about living with an ill person at the end of life, and about how to make a care plan for oneself. The final choice of topics and content was the result of a back and forth discussion between informal carers, the research group and content creators in an iterative process spanning phases II and III.

3.2 | Phase II: Development of the online support programme

Based on the results of phase I, content creators were engaged in co-designing material about the different topics. In addition to coordinating the development process, the research group also created content. The support programme was developed to be included in a Swedish national online health portal called '1177' (1177, n.d.). In this portal, citizens can access regionally based information about different conditions, illnesses and support services available. It also provides the opportunity to get an overview of appointments with healthcare personnel, to book and rebook appointments and receive medical test results, for example. The support programme aimed at informal carers of people with heart failure was later published in a section of the portal, called 'Support and treatment' which requires the registered user to log on using an e-identification. 'Support and treatment' can offer support, treatments and education to Swedish residents. Placing the support programme on the national online health portal 1177 meant that the content needed to follow guidelines to ensure it was valid, accessible and easy to read. Based on this, the research group outlined instructions regarding structure, length and concepts to use for the content creators. These instructions also

pointed out that the material being produced should consider that carers have different kinds of relationship to the person living with heart failure, for example, being a friend, a spouse or a sibling. The content creators were also asked to consider that carers might have been providing care for different lengths of time. In addition, they were instructed to use a language that was neutral to, for example, age and sexuality. The research group adjusted the material whenever necessary to ensure it followed the guidelines and instructions.

The content creators contributed on a non-profit basis, and the guidelines and support from the research group were adapted to suit individual creators. For example, depending on the topic and experiences of the content creators, they were asked to contribute with different forms of content, such as text about their topic of expertise, taking part in a video recorded interview, recording a lecture or providing interesting web links where carers could learn more about the topic.

A graphic profile comprising colours, fonts, document templates and a logotype was compiled and used for all graphic material in relation to the support programme. To support the written content, professional photographers were engaged for photographs and films. The production of photographs and films were organized and directed by the research group and for photographs a diversity was striven for, considering factors such as, age and gender to avoid stereotypes and to make pictures relatable.

Developing material for the support programme was conducted in an iterative process that moved between the research group, content creators and informal carers. Reviews, amendments and validation of topics and content were made continuously during the development process. With a few exceptions, each content creator was responsible for the content of a particular module, and the research group was responsible for making the support programme a logical whole. In parallel with the development of the content, the research group commenced the building of the online version of the support programme.

3.3 | Phase III: Refinement and finalization of the support programme

In this phase, the different main activities relating to refinement and finalization of the co-designed support programme are described. Namely, prototype content testing, testing an online version of the support programme, a final testing, and the approval of the final version of the support programme. Carers participated in each step in this third phase and the prototype testing included nine carers (seven women and two men), the online testing included four carers (three women and one man) and in the final testing one female carer was involved. Carers invited for the testing sessions were participants from earlier studies (Allemann et al., 2019; Andréasson et al., 2019) and additional participants were invited through snowball sampling. Phase II and phase III were repeated several times to finalize the content.

3.3.1 | Prototype content testing

During the development process, informal carers were invited to group discussions to review the content of the support programme and to provide formative feedback. Before meeting, carers were provided with information about the support programme 'so far' and a prototype—which entailed some of the content in paper form. They were also provided with questions relating to their experiences when going through the material and were encouraged to write notes. The questions provided to carers concerned the different parts of the programme and are summarized in Table 1.

In total eight carers joined in testing the prototype. Two members of the research team met with seven carers in two separate groups at the university in two regions in the Southeast of Sweden. One researcher moderated the discussion, while the other researcher documented carers' input. In addition, one carer provided feedback in an individual session. During discussions, carers confirmed topics and content in the support programme. They conveyed that the information was appreciated as relatable to them as carers. Carers also gave input on graphic content and films that were viewed during the group discussion, as well as providing suggestions and reasoning as to what could be developed further, excluded or changed.

The feedback that carers provided was forwarded to the content creators for due consideration and possible changes. The research

group also discussed and considered all carers' input. Sometimes input from different carers was contradictory and suggestions were not always feasible due to technical limitations in the 'content management system' (CMS) used for building the 1177 health portal. In these cases, the research group made the decision on how best to proceed with the intent of testing the processed content in further testing with carers. A concrete example of how the research group balanced different perspectives to adhere to the expertise of carers, content creators and the expertise within the research group concerns the 'the end of life' module. This module consisted of information about how to 'plan ahead' when living with someone who is seriously ill and at the end of life. One carer commented that she/he did not want information about 'the end of life' in the programme. Since other carers had identified the information as being important, and since the responsible content creators and the research group also assessed this as a valuable part of the programme based on previous research and clinical experience, the research group decided it should be included in the programme. The solution came from another carer who suggested splitting the information about 'the end of life' and 'about planning ahead when living with someone that is seriously ill' into two separate modules, making it possible for carers to choose not to read about the end of life if they deemed it to be a sensitive topic. Yet another carer had suggested using 'trigger warnings' in relation to information that could be interpreted as sensitive. Therefore a 'warning' that prompted carers to avoid the information, if they were not comfortable about reading about the end of life, was added to the relevant section of the programme.

Content development was also influenced by other various factors, including constraints in the content manager system (CMS) as well as considerations regarding implementation and the idea of making a sustainable intervention. An example is when carers expressed being positive to having a knowledge test concerning heart failure in the support programme. In relation to this they raised that it would be important to be given the correct answers after having filled in the questionnaire, as the confirmation of answers could be a way to check one's own factual knowledge and/or to consolidate knowledge or to learn something new. However, this was not feasible to carry out within the technical infrastructure in a user-friendly and sustainable way, and the research group and content creator responsible decided to exclude the questionnaire.

During the group discussions one carer provided extensive feedback and clearly expressed a willingness to stay in the process and support the development further. The research group acted on this opportunity and made this carer central in the final testing (described below).

3.3.2 | Testing the online version of the support programme

When the revised content had been added to the online health portal 1177, six carers were invited for the online testing of the support programme, and five accepted. Of these, four in total participated in

TABLE 1 Main questions asked to carers during the prototype and online testing of the support programme.

Prototype testing
Main questions
Do you think that what's covered in the content is relevant to carers of people with heart failure?
Is there something that you found extra valuable or interesting?
Is there something that you find difficult to understand?
In your view, is anything missing (in relation to the topic)?
Online testing
Main questions in relation to the support programme as a whole
What impression did you get from the programme as a whole?
Do you find the topics relevant?
Do you miss any themes or subjects?
Is there something that you disagree with or that does not conform to your own experiences? If so, can you describe the discrepancy/ies?
What do you think about the instructions for logging in and on how to navigate the programme?
Main questions in relation to modules in the support programme
Tell us about your overall impressions of the module.
Do you think that what's covered in the content is relevant to carers of people with heart failure?
Is there something that you found particularly valuable or interesting?
Is there something that you found difficult to understand?
In your view, is anything missing (in relation to the topic)?
Is there a balance or not between the amount of text and other elements (e.g. films and photographs)?

individual sessions. In addition to testing the content for relevancy and accessibility, carers were asked to provide feedback on the information material drafted by the research group regarding how to log onto and navigate the programme.

Carers were able to review the whole programme online from home, but they also received guidelines concerning what to focus on during the testing session. To avoid burdening carers, different carers were asked to focus on different topics and content. All carers were asked to review three modules each. Due to late dropout, two modules were not reviewed in this testing session and a further two modules received sparse feedback. To compensate, these modules were reviewed by content creators.

After reviewing the provided modules at home, the carers were invited to take part in an online interview with two members of the research group and encouraged to provide their honest opinions about the reviewed modules. They were provided with the main questions (Table 1) in advance and were informed that there could be additional questions asked during the interview. Carers were also encouraged to write down their feedback.

Carers' feedback were documented and suggestions were sent to content creators for possible further refinements. In cases where the review was mainly editorial in nature, relating to wording, the research group agreed on which refinements to be made.

3.3.3 | Final testing

The research group carried out a final review of the support programme. In this summative assessment, an informal carer with professional expertise in communication also read the entire programme. The purpose was to review for consistency in the use of language and commenting on any readability issues. Minor language revisions were made following these reviews.

3.3.4 | Approval of the final version of the support programme

Written agreements to be signed by the content creators were prepared together with university lawyers. The agreement was made to clarify ownership of the content and how it could be used. After the final testing, content creators were approached to carry out a final check of the content they had provided and thereafter sign the agreement form. This was an important step in ensuring that the content in the programme was wholly accurate and evidence based. The online version of the support programme was published when all agreements had been signed.

3.4 | Ethical considerations

The different steps in the study have ethical approval from the Swedish Ethical Review Authority: Dnr 2015/55–32, Dnr 2016/241–31;

2017/19–32 and Dnr 2019–05310. The content in the support programme does not include pictures, voices or texts of or from actual informal carers themselves. Legal agreements between content creators and the research group were outlined and signed to clarify ownership and usage of content. No demographic or health related data were collected in relation to the testing sessions in phase III in the co-design process. The researchers have extensive experience of working in similar studies with carers, and participants had the opportunity to contact the research team during the development process.

The Consolidated criteria for reporting qualitative research checklist (COREQ) (Tong et al., 2007) was used for preparing this manuscript (Appendix S1).

4 | OUTCOME

The outcome section provides an overview of the co-designed support programme. The topics elaborated and agreed on in collaboration with carers, content creators and the research group resulted in 15 modules. Each module consists of 2–9 pages, with a median of six and in total, the support programme consists of 83 separate web pages. Modules have a similar structure, with content such as written information, videos, lectures, pictures, tips or quotes from carers, carers' own stories as enacted by amateur actors, and relevant links to other validated home pages for additional information.

After gaining access to the support programme, the user can log on to the support programme multiple times and is able to look at modules and pages in the order they wish. They are also free to skip modules they do not wish to look at. Carers are encouraged to access those modules of interest to them, but they are asked to especially look at 'About the support programme', 'To be a carer', 'About heart failure' and 'A carer's own action plan'—the latter being the 'end product' of the programme, as these modules are considered to be core elements of the programme. A complete overview of the different modules of the programme is described below, in Figure 1, and the content of one specific module is described in Figure 2.

4.1 | Examples of content in the support programme

To provide carers with a programme that was perceived as being of good quality and professional, and to enhance coherence throughout the programme, effort was put into choosing and adding photographs and images that supported the written content and the main messages of the module. To enhance accessibility and readability, text was blended with photographs, images, videoclips and other graphic elements. Some examples of photographs that were used in the programme can be found in Figure 3, as well as information on what they were intended to illustrate within the programme. Furthermore, examples of 'text in boxes' is shown in Figure 4, and 'a carer's story' in Figure 5.

My content

About the support programme	▼
To be a carer	▼
About heart failure	▼
Contacts with healthcare and welfare	▼
To receive support as a carer	▼
Emotional reactions	▼
Changed relationships	▼
Intimacy and sexuality	▼
To be a carer while engaging in paid work	▼
Sleeping difficulties	▼
Physical activity for you and the person with heart failure	▼
Yoga and relaxation	▼
To plan for the future when seriously ill	▼
About the end of life	▼
A carer's own action plan	▼

FIGURE 1 An overview of modules in the 1177 support programme. [Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/jocn.16856)]



FIGURE 2 An overview of one module; To plan for the future when seriously ill. [Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/jocn.16856)]

The content of the final module 'A carer's own action plan' is based on the earlier participatory research work of Hanson & Magnusson with the Carers Outcome Agreement Tool (COAT) (Hanson et al., 2008) and entails a questionnaire with the intent of enabling the carer to reflect on their life situation by focusing on the following aspects; what is important to make life better for oneself, what would be important to be able to support, help or care for the person with heart failure, and what would make life better for the person with heart failure. Following completion of the statements in the questionnaire, carers are encouraged to use the information to make their own plan. Carers are also encouraged to use insights and knowledge gained from going through the different modules in the support programme. They are also provided with an example of a plan in which they are asked to summarize what they do to feel well and to make the situation of being a carer work, what needs to change (according to them) and what they can do themselves to change the situation and what they might need help with. Finally, they are asked to write down to whom they could possibly turn to, to get help and support if needed. Figure 6 illustrates some of the information provided in the module 'A carer's own action plan', while Figure 7 show an example of how such a plan can be outlined.

The content of the support programme, including the option for carers to make their own action plan provides carers with an opportunity to become aware of their situation and be encouraged to ask for support from health and social care sectors and civil society if needed.

The support programme is not publicly available since its effects are currently being formally evaluated in an ongoing randomized controlled trial (RCT). The support programme was published for testing its efficacy within the RCT study in December 2020.

5 | DISCUSSION

This article has described the co-design process resulting in an online support programme for informal carers of people with heart failure. The development of the support programme included three phases involving carers, content creators, researchers and other consultants (e.g. legal and technical support) contributing with a range of input and content in different phases depending on their specific role and expertise. These three phases resulted in a support programme with 15 modules located on the Swedish national online health portal of 1177. It is to our knowledge, the first co-designed online support programme targeted at carers of people with heart failure that is integrated within a national healthcare portal.

To fully reflect on the co-design process, the discussion will focus on factors that have conditioned and affected the co-design process itself. These factors have been taken into consideration when balancing informal carers' needs and preferences, the professional viewpoints of content creators, and the opportunities and limitations created within the CMS environment. This balancing was important to co-design a programme that is ultimately sustainable via its routine implementation within healthcare.

5.1 | Factors that have conditioned the co-design process

A factor that conditioned the co-design process was the initiative and decision by the research group to develop an online support for carers of people with heart failure. This preceded inviting carers in the co-design process, thus the participating carers did not have a choice in the overall delivery format of the programme itself. Even so, there



FIGURE 3 Photographs from the support programme. The two upper pictures relate to text concerning what support could consist of and the middle picture illustrates text about intimacy and sexuality. The lower photograph to the left illustrates working carers and the pictures to the right illustrate text about physical activity. [Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/jocn.16856)]

Do not hesitate to contact the municipality and ask about carer support if you need help or support in your situation as a carer.

FIGURE 4 These 'text in boxes' are a recurring graphic element throughout the programme. This example is repeated several times in the programme and is a reminder for carers to seek help if they need support themselves. [Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/jocn.16856)]

A carer's story



FIGURE 5 In some of the modules there are sound files telling carers' stories. They were recorded using amateur actors. [Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/jocn.16856)]

is evidence indicating that the provision of support via ICT could be relevant for carers (Allemann et al., 2019; Guay et al., 2017). In addition, the integration of digital healthcare into healthcare systems has become more widely accepted and its importance has been emphasized both on an international (WHO, 2016, 2021) and national level.

Furthermore, the research group had preconceived knowledge in relation to informal care and heart failure. This knowledge was based on both clinical experience and previous research. This likely conditioned some aspects of the co-design process, such as what was focused on in discussions with carers, and what was not. This aspect has also been highlighted by Rapaport et al 2018 (Rapaport et al., 2018) and is discussed in relation to the distribution of power below.

An additional factor that conditioned the process was the choice of what digital platform to use for the support programme. The initial planning included an interactive website on a private domain, but as the planning proceeded, the possibility of using the national online health portal of 1177 occurred. As outlined in the data sources section, the use of the governmental online health portal meant

adhering to certain rules and regulations. Together with constraints in the CMS, this conditioned what was feasible to include in the support programme. For example, it was not possible to provide an interactive tool of any kind where carers could engage in conversations with other carers. The interest of interacting with 'similar others' was clearly expressed during the co-design process and is also known to be an important source of support for carers (Thoits, 1986). Neither was it feasible to respond to carers' interests in interacting with healthcare personnel to specifically receive personalized information even though this has also previously been acknowledged as important for carers (Guay et al., 2017; Hassan, 2020).

5.2 | Factors that have affected the co-design process

Factors that are considered to have affected the result of the co-design process relate to both the factors that conditioned the

FIGURE 6 An extract from the module 'A carer's own action plan'. [Colour figure can be viewed at wileyonlinelibrary.com]

To make your own plan

When you have answered the COAT, you can take your answers and the thoughts you got when you went through the programme as a starting point. What you then see as important for you in your situation and for you to feel well, you can use to formulate your own plan.

One tip is to write it down. Try to be as specific as possible. Feel free to write down both what you want to change and who you think can support you in that change. Then return to your plan regularly, to reflect on whether there has been any change, or if you need support and help to move forward.

In the PDF you will find an example of what a plan can look like.

 What a plan could look like 



Who can help you if you need support

If you need support and help, you can turn to the municipalities' carer support (a carer consultant). Call the municipality's switchboard for help with contact details. Of course, there may also be people close to you who are happy to help you. Consider whether there is anyone you feel comfortable turning to.

process, as well as to factors relating to the participation and engagement of carers themselves. It also includes a reflection on the distribution of power and its impact on decisions made during the co-design process itself.

Co-design has been stated to include pragmatism and strategic approaches (Zamenopoulos TaA, 2018). Even though aspiring to invite carers with different caring experiences, this approach was nevertheless necessary when including carers. Since carers could be considered as a vulnerable group in research terms (Gheduzzi et al., 2021; Moll et al., 2020) and who may often have limited opportunities for participating in research (Malm et al., 2021) it was recognized that it could be challenging to attract carers to engage in a co-design process. To be able to involve carers, guiding principles were applied to include all carers who expressed an interest and also to be flexible in, for example, how and to what extent carers that

accepted to take part could actually contribute. This approach might have led to that we did not include those carers deemed to be most vulnerable since it might be that they need more of an 'outreach' approach (Malm et al., 2021; Moll et al., 2020) which could be considered a limitation.

It is well known that co-designing is time-consuming (Donetto et al., 2015; Green et al., 2020) and the inherent unpredictability in co-design, often including revisions and adaptations (Mosleh & Larsen, 2021) could contribute to this extended time factor. The co-design process spanned over approximately 4 years which might be viewed as a limitation since prolonged time between different phases in co-design has been described as a cause for dropout (Green et al., 2020) and it could potentially have made it difficult to keep carers engaged throughout the whole co-design process. Nevertheless, some carers were able to continue to



Heart Failure
INFORMAL CARER SUPPORT

Suggestion for an own plan

This makes me feel well and that my situation as a carer works:

What needs to change in my situation as a carer?

What can I do myself, and with what do I need help from others with?

If I need help and support - where and to whom do I turn?

Date :

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FIGURE 7 Carers are provided with an example of how to summarize their own plan. [Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/jocn.16856)]

participate in several phases. This can be seen as a strength since it allowed the research group to gather more in-depth insights and feedback from carers with multiple years of caring experience, thereby resulting in a more relevant support programme that covers the whole caring trajectory.

To promote and maintain engagement throughout the co-design process feedback to participant could be of importance (Bombard et al., 2018). The research group kept carers and content creators regularly informed about the project and purpose of their involvement. Further, events were organized and staged for joint discussions—creating an infrastructure for engaging in co-design (Mosleh & Larsen, 2021). The research group strived to be flexible and pragmatic in relation to carers' opportunities for joining in different activities as this could enable engagement (Liabo et al., 2020). Being mindful of creating a climate that facilitated carers to share their opinions and emotions has been stressed important in co-design (McNeil et al., 2016) and the research group were attentive to this during the process. The group also 'transferred' and 'translated' (Zamenopoulos TaA, 2018) information between carers and content creators who did not meet physically during the process. These different actions could be important precursors for 'meaningful engagement' (McNeil et al., 2016). One practical method that was employed to also promote engagement and hopefully also adding to carers' sense of having an impact on the support programme was the conscious choice by the research group of providing carers with a paper prototype in the initial testing phase. This was done as prior research highlighted that if the intervention or product under review is seen as nearing an end product, this could inhibit speaking truthfully for fear of hurting the creators' feelings or by thinking that their opinions do not matter at such an advanced stage in the process (Czaja et al., 2019).

An important aspect affecting the co-design process relates to the decision-making concerning the content in the support programme. When reflecting on how the carers' contributions were received by the research group during the co-design process, it is valid to relate this to the distribution of power since this is fundamental issues in co-design (Bombard et al., 2018). Power differences in co-design have been described as a 'wicked problem' (Farrington, 2016). And even though this implies that it is not possible to eradicate the imbalance in power between carers and researchers in the co-design process, it is a core value in co-design to endeavour to try (Éidín Ní & Reema, 2021; Moll et al., 2020) with the hope that this has enabled them to contribute to the process. One way to practically do this was to be scrupulous in how informal carers and content creators were informed and to make sure that everyone involved had sufficient information to act on.

In co-design it is common to have workshops bringing, for example, researchers, professionals and end users together in joint sessions and discussions, see for example Latulippe et al. (2020). Since the project involved a variety of content creators, who did not always reside in the same city, it was not practically feasible to have these kinds of workshops. In the project, carers predominantly met two members of the research team. These two members were

a constant in the co-design process, even though not all carers met both. Not having content creators and carers in joint sessions may be a limitation due to loss of a synergy effect from discussions based on different perspectives. Further, when information between carers and content creators had to be transferred and translated by the researchers it may not be accurately conveyed. Although the iterative process—going back and forth between phases could have worked as a protecting factor of these possible misunderstandings or misses in information of what to include or change in the content. On the contrary, not having joint sessions could have decreased the impact from potential power imbalances between those involved in the co-design process. The two researchers were able to form sustained relationships with carers which could provide a positive atmosphere for carers to share their thoughts and feelings.

5.3 | Co-designing an online support programme requires balancing on different levels

Several factors have required balancing when making decisions concerning the co-design process and development of the support programme. The balancing was important to be able to design a support that is relevant for carers as well as evidence based and feasible to implement and sustain over time, taking current policies and healthcare resources into consideration.

One way of balancing the political drive and policies to digitalize healthcare, while meeting the needs of informal carers as well as protecting healthcare's scarce resources, is to develop digital interventions that demand minimal resources from healthcare. The co-designed support programme offers such an opportunity, even though it can be argued to limit the choice for carers in determining how they would ideally like to receive information and education (see above). The programme is evidence-based and provides carers with information and suggestions on self-care for support and has the potential to enable them to be more prepared to take care of themselves as well as the person living with heart failure. The support programme therefore responds to some of the calls in the position paper by EuroCarers that was written in response to the European Commission's care strategy (EuroCarers, 2022b), for example, that it entails a cooperation with carers and that it provides information and advice that could be used for self-care. Further, considering enabling a wide implementation, a digital support could be a reasonable choice since it offers the possibility for carers to ultimately access the programme regardless of time and place, unlike more traditional sources of 'in real life' support. Using a governmental platform also entails a technical possibility to implement the support programme swiftly and effectively in all regions of Sweden, as well as assuring a credibility and quality stamp concerning the programme itself, thereby optimizing its take up by both healthcare staff and carers.

A further factor which entailed balancing was the choice of platform, previously outlined in the section 'Factors conditioning the co-design process' above. The choice of platform affected the content

and sometimes overrode the personal preferences expressed by carers. A web portal on a private domain could have better supported more interactive elements, but would have also demanded administrative resources, technical competences and high levels of maintenance dependent on research funding which has been pointed out as a threat to sustainability (O'Donnell et al., 2019). Since the Swedish national online health portal has a core infrastructure concerning administration it offers a more extensive degree of sustainability for the support programme. Ensuring a sustainable support programme is also important from an ethical perspective. If carers find the support programme useful and ultimately acceptable, it is arguably unethical to choose a solution difficult to sustain when research funding ends.

In the study, decisions about content were made in the intersection between different experts' views and experiences, also addressed in previous research by Tindall (Tindall et al., 2021) and Latulippe (Latulippe et al., 2020). Even if the intention has been to distribute power and to engage end users in decision making, previous research has shown that final decisions can sometimes fall on the research group (Latulippe et al., 2020; Rapaport et al., 2018). Clearly, the research group held the final decision about content, but was nevertheless mindful in making the suggestions and feedback by carers a central point and continuously discussed how to balance their voices with the voices of content creators and the research group's own knowledge and experiences, including knowledge about limitations in the health portal. Overspecialization has been described as a risk in relation to having few participants in co-design (Latulippe et al., 2020), and making decisions taking all voices into account hopefully lessened the risk of creating content that is overspecialized. The ability of the support programme to support a wide range of carers has not yet been studied but will be evaluated in a process evaluation and in an RCT, further illuminating the co-design process.

6 | CONCLUSIONS

This co-design study resulted in an online support programme for informal carers of people with heart failure. To conduct a co-design process involving carers and other actors involves navigating and managing diverse interests on different levels. It is an explorative process in which we as researchers need to be flexible and sufficiently reflexive to balance different voices and to make sure that the end users, namely carers of people with heart failure, are genuinely included in decision-making during the co-design process of the support programme. The co-design process has led to a relevant support programme, but it remains to be seen if it acts as a useful support in carers' everyday lives.

7 | RELEVANCE TO CLINICAL PRACTICE

Co-designing with and for end users within healthcare offers a flexible approach and an opportunity to design support that is more

relevant to their needs. Moreover, by emphasizing equal involvement of carers, and patients if suitable, in the design and development of healthcare interventions, it aligns with contemporary ideas of person-centred care while providing a valuable learning opportunity for those involved. It is important to consider that co-design processes could be time-consuming and that the inclusion of, at times vulnerable end users in the process, requires careful consideration when planning projects and then designing and evaluating interventions. A co-designed online support programme aimed at informal carers has the capacity to be both accessible and meet their information and support needs and thereby optimizing their self-care abilities. Additionally, an online support programme provides the opportunity to address current challenges regarding scarce resources and the lack of healthcare personnel.

AUTHOR CONTRIBUTIONS

H.A and F.A were involved in conceptualization, formal analysis, investigation, methodology, project administration, visualization, writing—original draft and writing—review and editing. E.H and L.M were involved in validation, writing—review and editing. T.J was involved in conceptualization, methodology, validation, writing—review and editing. I.T was involved in conceptualization, methodology, supervision, validation, writing—review and editing. A.S was involved in conceptualization, data curation, funding acquisition, methodology, project administration, resources, supervision, validation, writing—review and editing.

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CONFLICT OF INTEREST STATEMENT

The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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SUPPORTING INFORMATION

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