First steps to integrate general palliative care into a cardiac hospital setting – using dialogue-based workshops

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All authors discussed the study objective and design. S.G. Roikjær conceived, designed and executed the study, collected data, analysed and interpreted the data as well as drafted and revised the manuscript. H. Timm contributed to designing, analysing and revising the intellectual content of the manuscript. C. Simoný contributed substantially to designing, analysing and revising the intellectual content of the manuscript. All authors read and approved the final version of the manuscript.

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Last but not least we are grateful to PhD student Vicky Joshi for her editing skills.

Keywords: Cardiology, Lived Experience, Palliative Care, Practice Development

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First steps to integrate general palliative care into a cardiac hospital setting – using dialogue-based workshops.

Abstract

Background: Heart failure is a chronic, life-threatening illness with multiple acute events. Palliative care alongside standard treatment is recommended for these patients. There is a lack of knowledge and research literature on how to integrate palliative care interventions for heart failure patients in a general hospital setting.

Aim: The aim of this study was to produce new insight for developing and integrating general palliative care into heart failure treatment.

Methods: Guided by action research, we conducted an interdisciplinary workshop inspired by Tsoukas dialogue theory, where tension between perspectives is used as a facilitator of dialogue and the generation of new insights. Perspectives were incorporated through selected patient narratives and professionals’ experiences. Data from the workshop were analysed using a thematic analysis. The findings are interpreted with Kleinman’s theory on illness and disease and discussed using Tsoukas theory and additional research.

Results: General palliative care must be initiated from the patient’s perspective and wishes. Doing so requires understanding and uniting the different perspectives and objectives of heart failure treatment and...
palliative care. One way of doing this is through a narrative approach with interdisciplinary teams. However, this requires organizational efforts and adaptation to the specific cardiac setting.

Conclusion: Integrating palliative care principles into cardiology is a complex issue. Developing palliative care for heart failure patients requires more than simply designing a set of guidelines. Rather, a wider outlook involving perspectives, competences and organization is necessary. Acknowledging such considerations, we designed an intervention centred on three elements: standard heart failure treatment, integrated sessions applying a narrative approach and monthly interdisciplinary conferences.

Relevance: This article adds to the current research literature on changing palliative care practice for heart failure patients and the value of integrating different perspectives.

Keywords: Cardiology, Lived Experience, Palliative Care, Practice Development.

Word count: 4906

Background

Heart failure and standardized treatment

Heart failure (HF) is an end-stage cardiac illness caused by impaired cardiovascular function or a structural cardiac abnormality that leads to a decrease in the heart’s ability to be filled with or eject blood (1–3). HF increases the risk of premature death and affects over 26 million people across the world (4). The clinical symptoms of HF are breathlessness, oedema, fatigue and weakness. In addition, studies have found that patients have a difficult time understanding HF (5–7) and experience uncertainty, anxiety, depression, loss of social roles, and loss of functional abilities (6–10).

The European Society of Cardiology states that ‘The goals of treatment in patients with HF are to improve their clinical status, functional capacity and quality of life, prevent hospital admission and reduce mortality.’ (1 pg 2147)

With a standardized plan for HF treatment in 2013 (11), the Danish Health Authority aimed to improve quality of life and prognosis for HF patients based on equal access. The standardized plan describes the HF treatment, the information for the patient and the organization of HF from the first encounter with the health system to the rehabilitation phase. The plan does not mention palliative care (PC).
Palliative care

PC is defined as a holistic approach that aims to improve quality of life of patients living with life-threatening illness by relieving physical, psychosocial or existential suffering (12). This different objective from that of standard HF treatment can play an important role in alleviating unmet existential problems.

PC can be organized into general and specialized care. General palliative care is delivered by health professionals in a setting that does not have PC as the main task. Specialized palliative care is delivered by health professionals in a specialized setting where PC is the main task (13).

Ideally, PC is offered regardless of diagnosis and setting and is internationally recommended alongside standard HF treatment (14,15). A report (16) from the Danish Cardiac Society addressing PC in HF has articulated recommendations from the early to the late phases of HF (see Table 1).

However, PC is still lacking in the general hospital setting (17,18). Studies have argued that some barriers could be the historical context of hospitals and the culture of medicine as a curative discipline (19,20). This highlights the need for additional research on how to overcome such barriers and integrate PC into HF treatment and care.

Aim

The aim of this study was to produce new insight for developing and integrating general palliative care in heart failure treatment.

Methodology

This paper reports on phase two of a PhD based on four phases with the chronological aims to: 1) understand life with HF and identify unmet needs, 2) develop an intervention and facilitate change, 3) to integrate the intervention and 4) to evaluate the intervention through qualitative methods.

These parts build on different epistemological styles: the first and last on hermeneutic concepts of interpretation and meaning and the others on interaction to co-create knowledge and effect change (21).

To realize change in health care, it is arguably necessary to take the clinical setting into account. We were inspired by action research (22,23), which can be envisioned as a continuous cycle of construction – planning action – taking action – evaluating action (24).
Findings on needs and narrative approaches in phase one

In phase one, we 1) explored needs through an interview study and 2) current knowledge on the use of narrative approaches through an integrative review. Findings from these studies (25,26) have been reported elsewhere but are only briefly mentioned here.

Interview study

In this study (25), we completed six semi-structured interviews with local HF patients followed by a thematic inductive analysis. Like earlier studies (27,28), this study found that patients have a difficult time understanding their condition in medical terms and feel they are unaided with their existential problems. We concluded that HF patients would benefit from an intervention with a focus on integrating the embodied patient perspective in standard treatment to relieve existential suffering. One way of doing this could be through personal narratives.

Literature review study

In the integrative literature review (26) from 2019, we found that personal narratives in hospital-based PC can be realized in a hospital setting to relieve existential suffering. However, the interventions were very time consuming and required adaptability to the practices of the setting and the needs of the patient (26).

By speaking with experts and clinicians in the field, we came across a more pragmatic PC intervention also using personal narratives: the S’ approach (29,30).

The S’ approach focuses on operationalizing the WHO definition of PC. It is based on the idea that symptom control, self-image, self-determination, social relationships, strategy for the future and sense of coherence are all criteria for a good death. Importantly, it is based on the notion that to consider needs and resources in any of these criteria, we need to know more about the patient from his/her perspective (29,30).

The S’ approach is primarily used in specialised PC, so considerations about transferability into a general hospital setting are required. According to prior research on barriers (19,20) to PC in hospitals, an important consideration was the difference in objective, approach and culture between PC and cardiology.

Appendix A shows how we used findings from phase one in this current study.

Theoretical framework

The theoretical framework for the present study draws from action research and PC literature.
**Theory on dialogue**

Dialogue and narratives are central concepts of health research and planning and are well established in the tradition of action research and qualitative methodologies (31–34). Tsoukas argues that although the aim is to reach agreement, it is the tension within a productive dialogue that holds possibilities for new insight (31). The tension between different perspectives becomes the facilitator for a productive dialogue, which again leads to creating new insight.

Inspired by Tsoukas, Labonte and colleagues developed a story/dialogue method (35) for developing health promotion knowledge (35). Labonte et al argue that for health promotion to be transformative it has to be able to incorporate both individual and collective experience and perspective through sharing, skill building and capacity development (see Appendix A).

**Theory on illness and disease**

To interpret the difference in perspectives found in the analysis, we use Kleinman’s definition of illness and disease (36). Illness is the ‘principal difficulties that symptoms and disability create in our life’ (37pg4) It is the embodied patient perspective. Disease is the ‘problem from the practitioner’s perspective’ (37pg5): a professional biomedical perspective originating from a natural paradigm (36).

**Participants**

Based on recommendations in PC and HF (37,38), a group of ten professionals were invited to participate in a workshop. The strategy was purposeful sampling (39), reflecting cardiology as the main setting (see Table 2).

The inclusion criteria were that the professional was 1) currently involved in standard treatment and care of the HF patient or 2) was in a discipline recommended by international guidelines on HF and PC as a necessary profession, 3) was employed at the local hospital or a partner hospital, and 4) was willing to participate and give their time. The individuals were selected in cooperation with the head of their department but were approached directly by the first author by email and in person. Seven professionals accepted, all with over eight years of clinical practice in their medical field. A dietitian, an occupational therapist, a cardiac head nurse and a social worker were invited but declined due to organizational priorities.

**Setting**

Based on the standardized plan, Region Sjaelland has articulated clinical guidelines in the standard care of HF patients. The visits at the HF clinic primarily involve rehabilitative sessions with a cardiac nurse and
clinical control with a cardiac physician. The nurse is in charge of assessing, treating and documenting clinical symptoms. She is also responsible for guiding and teaching the patient about risk factors, lifestyle changes and possible psychological reactions. Sessions last 15 to 20 minutes. The number of sessions is not mentioned, but the treatment is concluded when the pharmaceuticals are adjusted to a satisfactory level. Within this setting, a general PC intervention was developed and integrated.

**Workshop**

The workshop method was inspired by Labonte (35) using narratives to prompt a dialogue (see Appendix A).

The first author led the workshops. Her training was primarily theoretical. She has a background as a nurse in cardiology, but in this workshop, her role was that of the researcher and workshop manager. Based on her previous clinical role, the first author knew most professionals participating in the study; likewise, some professionals already knew each other.

The workshop were divided into two parts. Each lasted five hours. The first part of the workshop was initiated and introduced by the workshop manager. Next, the participants presented their situational contexts in the HF patients’ trajectory.

The workshop manager presented preliminary findings from phase one, illustrated by patient narratives. Narratives were selected to exemplify the findings. In all, three short narratives were presented, along with additional quotes for transparency. One of the narratives was this:

_The woman, ‘Claire’, in front of me is crying silently. Claire is in her 50s and living alone - she has raised two children by herself, but, as it should be, they have left home to establish their own lives. Her illness story contains several hospital admissions due to both epilepsy and advanced cardiac disease, and her most recent diagnosis is heart failure. She is telling me that she is afraid like never before and feels completely alone. Tears are streaming down her face. I ask her if she could bring this up in her next visit to the heart failure clinic. She shakes her head slightly: ‘No, what for?’ When she goes to the clinic, the focus is on the disease and blood samples, and it doesn’t feel like a place to tell her story._ (p2)

Narratives were followed by a semi-structured dialogue around *What happened? Why did it happen? And what can we learn from this?* The participants were invited to discuss using examples from their clinical experience.
The second part of the workshop began with the workshop manager presenting a synthesis of the newly generated insights from day one and invited the participants to discuss *What can we do about it?* The purpose was to continue the dialogue and voice principles and wishes regarding a PC intervention in a cardiac hospital setting.

**Data collection and analysis**

Data for the analysis consisted of fieldnotes derived from the workshop. They included a combination of observations and extracts of dialogue, some rephrased and some direct quotes. The data were gathered as notes during the two parts of the workshop and transcribed into fieldnotes. A thematic analysis focused on meaning was then undertaken involving the following elements: familiarization with the data, coding and generation of themes (40). The analysis was inductive and hence not a linear progression but rather a process of going back and forth from parts to whole until general themes were formed. The first author conducted the coding and initial analysis but discussed themes with the co-authors. The data showed a challenging incongruence between how HF patients experience illness as an embodied perspective and how professionals focus on disease in biomedical terms. Kleinman’s theory on illness and disease was used to understand and illustrate the different perspectives (36). In the Discussion, we apply Tsoukas’s theory on dialogue and relevant research (31).

As the data were originally written in Danish, the translation of quotes focused on meaning rather than on literal translation. The last author helped with this meaningful translation.

To disseminate meaning derived from the analysis we present findings under general themes using a narrative form true to the participants’ dialogue.

**Findings**

Three interconnected general themes emerged from the data: recognition of differing perspectives, building bridges between perspectives and planning action for general palliative care in heart failure treatment. Table 3 shows an example of the analytical process.

**Recognition of differing perspectives**

This general theme revealed a need to recognize and include the patient perspective in future general PC for HF. The analysis shows a disease perspective as the professional outset for assessing problems and planning treatment. This is made evident when nurse 2 shares that a main task is getting the medical treatment optimized and physical symptoms under control, or when nurse 1 conveys how they put emphasis on ‘educating patients to take care of their disease.’
Nonetheless, in the nurses’ experience, patients often wait too long to act on their clinical symptoms or risk factors. It is like ‘the alarm doesn’t ring’ (nurse 1), and the patients do not interpret their symptoms as an exacerbation of their HF. The physiotherapist recognizes this frustration. She shares an experience of difficulty motivating the HF patient to exercise. Further, she conveys a feeling that patients only attend to please her.

Kleinman argues that when the biomedical disease perspective is dominant, it is easier to treat symptoms with success (37pg6). However, these examples show that an approach from a disease perspective does not always have the outcome the participants had hoped for.

A short narrative shared in the workshop is one describing illness as a restriction on life and an experience of bodily manifestation of symptoms. This is detected and discussed by the professionals. Nurse 1 expresses that in general, the physical symptoms seem to control the HF patients’ experience. On the other hand, she also suspects that the patients’ understanding of their diagnosis can lead to neglected or amplified symptoms. This bit shows how participants recognize that there is a subjective element to how (if) the patients understand and manage their clinical symptoms.

The chaplain declares: ‘You are first and foremost a person with an illness - you are not the disease’, putting emphasis on the person and the patient perspective. The participants support this acknowledgement of a patient perspective by nodding their heads. The chaplain then continues the dialogue, putting a focus on ‘Claire’s’ experience of feeling alone. This is discussed by the group and recognized as a problem for the patient, although not necessarily a clinical problem.

The chaplain suggests that ‘It is worse, existentially, to be ill in the heart because in our culture the heart is a metaphor for our soul – the essence of who we are rather than just a pump.’ The metaphor of the heart as a pump is not new and is often used in cardiology to describe to patients how the heart functions. In this analytic bit, the chaplain challenges the biomedical perspective of the heart as a pump, and once again, her focus is on who we are. This shows her understanding of the illness experience as the embodied patient perspective as defined by Kleinman (36).

Participants discuss how differing perspectives and understandings could explain why HF patients seem to neglect important symptoms. A strictly biomedical perspective is not sufficient. They agree that future general PC must arise from the patient’s perspective and needs.

Building bridges between perspectives

The analysis revealed a necessity of building a bridge between HF treatment and PC objectives as well as between illness and disease perspectives: ‘Care needs to be re-introduced into the cardiac setting’ (nurse 1).
The fieldnotes show a dialogue going back and forth between the importance of getting the patient to recognize the seriousness of HF and an acknowledgement that this requires a new approach and sessions of a more existential character. The chaplain argues that ‘You have to go through your own recognition, and this happens through your emotions.’

Life-threatening illness is commonly understood by the participants to threaten one’s existence, and they discuss how this is reflected in the narratives from their patients. Participants share a frustration that there is little room to talk about existential troubles in clinical sessions at the hospital, so these omit the patient perspective of living with HF.

The cardiac physician expresses that HF is a very difficult syndrome to grasp. He suggests that cardiac professionals are reluctant to talk about HF as a life-threatening illness with death as a likely outcome. He even argues that this might prevent the patient from understanding the seriousness of HF.

The participants discuss the dilemma of talking about death and dying while maintaining hope in the treatment. Cardiac nurses share experiences in which effective treatment brought patients’ health back to an almost normal state, leading in some cases to many years passing before a new cardiac event. With this outlook of near recovery, at least for a while, why talk about death?

The PC nurse states that in a palliative context, the premise is that everyone with a life-threatening illness has at one time or another ‘experienced a death anxiety’. Therefore, consideration of this anxiety and what follows is needed.

Nurse 2 voices the dilemma of inviting the patients to share yet possibly not being able to help them when they do. She shows her medical professionalization as having been taught to isolate a problem and resolve it. The PC nurse responds with a different thought: ‘We cannot solve everyone’s problems.’ She maintains that it is the approach that needs to shift and emphasizes that this implies a genuine curiosity about the patient and an invitation to the patient to share about their life, wishes and concerns: ‘People die as they have lived. We cannot remove death, but we might be able to contribute to the best possible death’ (PC nurse). This statement leaves the room quiet for a minute but is followed by a sigh of relief and nodding.

To summarize, the analysis shows a necessity to bridge perspectives and objectives from HF treatment and PC in general PC for HF patients. A breakthrough in the workshop came with the recognition that including the patient’s illness perspective does not necessarily mean clinically diagnosing and solving every problem but rather acknowledges them. This new insight became the foundation for a dialogue focused on planning action to change practice.
Planning action for general palliative care in heart failure treatment

This theme entails the perceived challenge of applying principles from a PC approach in a cardiac setting, arguing that competences and organization must be considered.

The dialogue involves the S’ approach as a method to include the patient perspective and bridge objectives from PC and HF treatment. The group likes the structure of the S’ approach as an inspiration, but some concerns are expressed.

One concern is the dominant focus on death and dying at the beginning of treatment. The cardiac nurses suspect that they risk taking hope from patients if they talk of death and dying at this early stage of treatment. This concern is acknowledged by other participants: ‘There must be a call to a life that is still worth living’ (chaplain). The chaplain suggests that she can look over the questions from the S’ approach and adapt them to this particular setting.

Another concern is resources, initiating a dialogue on competences. Cardiac nurses in particular wish for additional training in applying a narrative approach and starting a conversation from the patient’s perspective. A dialogue on what is desirable ends in agreement on the need for 1) a workshop on open and inviting communication with a narrative approach and 2) supervision during the first months of a new GPC intervention.

This advances to a talk about organization. The experience is that time with the patients is limited, and standard treatment is focused on the indispensable medical objective. Applying a new approach including the patient perspective will take more time. The chaplain supports this argument with a statement that for people to build trust and share from their life, they must be met in a calm and inviting space; hence, time is essential.

The participants also discuss that they need each other’s competences to assess and address patients’ needs. In agreement with guidelines on PC, they decide on a multidisciplinary conference where possible PC needs can be discussed. However, some participants seem unsure of the organization’s willingness to prioritize general PC and support a patient perspective. This is voiced by nurse 2: ‘Time will tell,’ she says with a doubtful tone. This analytic bit shows that new knowledge and competences are not adequate, and organizational support is crucial.
Discussion

Acknowledging perspectives, building bridges and improving care

The continuous dialogue about perspectives formed an acceptance that general PC must arise from the patient’s perspective and needs. However, changing clinical practice and applying a joint perspective is foreseen as a challenge by the group. Interpreting Kleinman, this challenge occurs as medical students are encouraged to prioritize disease before illness as part of the process of professionalization (37pg254).

Scholars from philosophy (41), sociology (42) and medicine (43) have argued for the inclusion of the patient perspective in health care for decades. An accepted approach is through patient narratives (42). This has been tried by Artioli et al. (44) The authors discuss the Integrated Narrative Nursing Model (INNM) as a method to integrate the clinical symptoms of disease with the subjective perception of illness. INNM relies on both narrative competences and quantitative scales and tests (44). The authors argue, citing Charon (45), that bridging the illness and disease perspectives through narratives will ‘allow the professionals to recognize, absorb, metabolize, interpret and be moved by stories of illness’ and hence improve care (45pg14).

It seems that illness as the embodied patient perspective can be joined with the disease perspective, but it requires a well-thought-out approach. In this light, the decision to use the structured S’ approach as inspiration for integrating general PC in HF treatment seems valid.

The concern of talking about death at the early stage of treatment is also worth discussing. The PC nurse argues in favour of talking of death and dying because this will have crossed the patient’s mind. Other participants fear that it will take hope from the patients. In a qualitative study published in 2020 (46), Bergenholtz and colleagues explored the wishes of patients and their relatives with regards to talking about death and dying in a general hospital setting. They found that the wish to talk about end of life was a very personal matter and hence required conversational tools sensitive enough to incorporate this great diversity (46). In conclusion, both the PC nurse and the other participants are right in their views. When adjusting the S’ approach for general PC in HF treatment, we need to consider if it is mindful of the patient’s wishes.

Our analysis shows a need to form an interdisciplinary team around the patient to better understand, assess and relieve symptoms of a psychosocial and existential nature. This is in line with the specialized PC literature recommendations (30,37,47). These recommendations are likely founded on a need for different specialized medical competences. However, based on our findings, we believe that they will also ensure a bridge between perspectives, which will eventually strengthen the quality of treatment. This argument is
supported by Babiker and colleagues (48). They reason that apart from the increasing complexity of illness, a team is vital because it can bring a wide variety of values and principles (48).

However, a recognition of perspectives and forming a team are not sufficient to provide general PC for HF patients. The group foresees the need for additional competences and organizational support to provide the additional time needed both with the patients and for interdisciplinary conferences.

**Trustworthiness**

The pragmatic nature of action research necessitates pragmatic validity consideration. In this paper, we have increased our understanding of differing perspectives in the field of PC and HF treatment and what is needed to create change. The literature has recommendations on PC for HF patients (15,49). However, in practice there has been little change (50). We are convinced that to make new knowledge meaningful, participants need to be engaged from the beginning.

By listening to and working with the patients’ narratives and the professionals’ experiences in the workshops, the group were able to identify and embrace the tension between differing perspectives.

Methods using dialogue is naturally influenced by the participants, and there is a risk that one individual end up dominating the dialogue and the outcomes. In this study, the chaplain has a leading voice. However, we argue that this enables a tension and that on more than one occasion, it was this tension between perspectives that drove the dialogue forward. One example is when the chaplain challenges the idea that recognition is merely a question of information. With a twist in words, a kind of conceptual reframing occurs, as Tsoukas calls it (31).

The chaplain expands the concept of recognition from merely a cognitive issue to involve emotion. Hence, the dialogue is driven towards a comprehensive understanding of the patient’s experience of being ill and a need to recognize the illness perspective. Such communicative events opened the dialogue and eventually built a bridge between the two differing perspectives, acknowledging the value and necessity of joining them in future general PC interventions. Furthermore, the professionals’ direct involvement led them to arrange for an additional workshop on communication taking a narrative approach, among other things.

The premise of the study was dialogue and the voicing of different perspectives. It could be argued that HF patients should have been present at these workshops. However, given the ethical considerations in terms of power relations, we chose to present the patient perspective through short narratives (51).

The first author found that the patient narratives successfully steered the dialogue through a continuous reflection on ‘what is going on’. Furthermore, it was demonstrated that the chaplain and the PC nurse
functioned as interpreters and bearers of the patient perspective thanks to their understanding of illness, while other participants presented a disease perspective. This indicates that the method is sensitive to the constellation of the group and that purposeful sampling is valid.

An element of this participatory method is that the group members act as representatives for the larger organization. This puts great responsibility on each member to push change forward, which requires both authority and courage. We had hoped to involve a head nurse from cardiology, but unfortunately, this was not possible.

**Limitations**

Ensuring that every voice and perspective is heard requires a skilled workshop manager and providing a thorough analysis necessitates a competent researcher. Hence, one plausible limitation is the situation of the workshop manager/researcher. Guiding the dialogue in the workshop while at the same time being responsible for gathering, coding and analysing the data is a potential source of bias. However, being a qualitative hermeneutic researcher is never an objective activity, and participatory observational design does have advantages.

To strengthen the internal validity, insights from the workshop were presented to the professionals, who recognized their contributions and their part in the discussion. In addition, the analysis and themes were examined and discussed with other qualitative researchers.

A common feature of the qualitative methods used in action research studies is that the findings are not easily transferable (52). This is also true for the current study. However, the dialogue method can be transferred to another setting, enabling a similar process for change.

**Conclusion**

The aim of this study was to produce new insight for developing and integrating general PC in HF treatment. The study revealed a complex issue where several areas must be considered. First, general PC must be based on the patient’s perspective and needs. However, uniting the different medical fields of cardiology and PC is a challenge, and it is essential to acknowledge the difference in perspectives and objectives between them. The S’ approach can help bridge the perspectives and objectives from HF treatment to PC. To do so requires adjustments to this particular setting, additional training and organizational support.
Acknowledging the above considerations, we designed an intervention centred on three elements: standard HF treatment, integrated sessions with nurses that applied an adjusted S’ approach and monthly interdisciplinary conferences (see Figure 1).

**Ethical considerations**

The ethical considerations in this project are based on the International Council of Nurses ethical guidelines (53). This study is part of a larger PhD project approved by the Committee on Health Research Ethics for Region Zealand, Denmark (REG-108-2017), covering the Næstved, Slagelse and Ringsted Hospitals. No other official approval was needed.

Patients in the interview study provided confirmed consent according to ethical guidelines. The professional participants provided oral consent to participate. All participants were informed about both their individual part of the project and the larger aim of the PhD. Patients’ names have been altered in this paper, and we have tried our best to consider professional anonymity.

**Acknowledgement**

The authors would like to acknowledge Henrik Ryde, MD for his essential contribution in the planning of this PC intervention for HF patients.

Furthermore, we would like to express our appreciation to post-doc Ditte Høgsgaard for her input and feedback on the methodology of AR.

Finally, we are grateful to PhD student Vicky Joshi for her editing skills.

**Conflict of interest**

We declare that we have no competing interests.

**Author contribution**

All authors discussed the study objective and design. PhD student and registered nurse Stine Gundtoft Roikjær conceived, designed and executed the study, collected data, analysed and interpreted the data and drafted and revised the manuscript. Professor of Palliation, Helle Timm contributed to designing, analysing and revising the intellectual content of the manuscript. Post-doc and Head of Research at Næstved, Slagelse, Ringsted Hospitals, Charlotte Simony contributed substantially to designing, analysing and revising the intellectual content of the manuscript. All authors read and approved the final version of the manuscript.

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Table 1: Characteristics of the stages of progressive heart disease, recommended palliative care and clinical indicators for each stage. Translated from (16pg4)

<table>
<thead>
<tr>
<th>Stage I: Management of chronic heart failure (NYHA I–III)—early palliative care</th>
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<tbody>
<tr>
<td>• Active treatment with the aim of prolonging life and controlling symptoms</td>
</tr>
<tr>
<td>• The patient and caregivers are educated on the condition, causes, treatment, and prognosis of HF, with the aim of improving the self-management of symptoms</td>
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<tr>
<td>• Treatment is provided in accordance with the national guidelines and local protocols, including rehabilitation and exercise training</td>
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<tr>
<th>Stage II: Supportive and palliative treatment (NYHA III–IV)—late palliative care with a focus on clinical indicators</th>
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<tbody>
<tr>
<td>• The patient's symptoms become increasingly pronounced, with multiple hospitalizations and periods with decompensated heart failure despite optimal treatment in accordance with the guidelines</td>
</tr>
<tr>
<td>• Old age and other comorbidities rule out heart transplantation and mechanical circulatory support</td>
</tr>
<tr>
<td>• The patient cannot longer tolerate decongestive treatment because of hypotension and/or progressive renal impairment</td>
</tr>
<tr>
<td>• Delirium, change in mental status</td>
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<tr>
<td>• Hyponatraemia despite normal hydration</td>
</tr>
<tr>
<td>• Signs of cardiac cachexia or low albumin</td>
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<tr>
<td>• Repeated implantable cardioverter defibrillator shocks</td>
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<tr>
<td>• Active treatment is reduced, and the aim moves towards sustaining optimal symptom control and quality of life</td>
</tr>
<tr>
<td>• Identification of a key health professional is recommended to ensure optimal individualized continuity of care across multiple sectors and disciplines</td>
</tr>
<tr>
<td>• A holistic, multidisciplinary assessment of the patient and his or her needs should be conducted continually in consultation with the patient and relatives, preferably with the same health professional and when the condition is clinically stable</td>
</tr>
<tr>
<td>• Declaration of terminal care and financial support decisions should be considered</td>
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<th>Stage III: Terminal treatment and palliative care</th>
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<tbody>
<tr>
<td>• The patient will die imminently</td>
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<tr>
<td>• Heart failure treatment changes to alleviating symptoms only</td>
</tr>
<tr>
<td>• A do-not-resuscitate order in case of cardiac arrest and waiver of intensive treatment needs should be discussed and documented</td>
</tr>
<tr>
<td>• An integrated care plan should be devised, focusing on the psychosocial support needs of the patient and the family or caregivers</td>
</tr>
<tr>
<td>• The preferred place of final care and death should be discussed</td>
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Table 2: Participant data. ♀= cardiology, ♂= palliative care, †= theology

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Table 3: Example of derived themes
Will it be okay to pick up the phone and give you (the chaplain) a ring? (nurse 2).

“A new approach takes time” (physician).

“The patient who has just received a life-threatening diagnosis is in a state of inner chaos. We need to provide a calm setting” (chaplain).

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Empirical/theoretical base: PC is recommended integrated in the HF trajectory. However, access to PC in cardiology is lacking. A PC intervention should incorporate the whole WHO definition by also addressing existential issues. It should integrate the illness perspective in the current disease-oriented approach by inviting the HF patient to share from his life and experience. Hereby supporting the patient in understanding his illness.

**Goal:** To change the access of PC for HF patients by integrating an adapted version of the S’approach in their current treatment plan and care.

<table>
<thead>
<tr>
<th>Standard treatment content of sessions in the HF clinic</th>
<th>The S’Approach</th>
<th>Interdisciplinary approach</th>
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<tbody>
<tr>
<td>Based on age, sex, medical history, and treatment offered</td>
<td>- This approach is integrated in the standard treatment at the heart failure clinic extending the duration of session without changing the premise of the standard treatment.</td>
<td>- Patients are explained that this approach is intended to support decision-making, and it's thus integrated into the standard treatment used at the heart failure clinic, extending the duration of session without changing the premise of the standard treatment.</td>
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<tr>
<td>- First session from 60 to 120 minutes followed by the following from 30 to 60 minutes</td>
<td>- First session from 60 to 120 minutes followed by the following from 30 to 60 minutes</td>
<td>- Every 4 weeks a conference is held with the purpose of exploring the personal meaning of the patient’s health in order to get a nuanced understanding of the patients’ problems and offer advice on how to acknowledge these problems.</td>
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<tr>
<td>- The nurse use interpersonal questions to invite the patient to talk about his illness and emotions</td>
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Appendix A: Rationale and content of workshop

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<th>Purpose</th>
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<td>The purpose of this workshop using dialogue method was threefold. 1) to generate new insight for a palliative care intervention in a cardiac setting 2) to join different perspectives from patients and professionals from cardiology and palliative care settings and 3) to enable a relational engagement within the interdisciplinary project group. Changing clinical practice and culture is no easy task and requires methods that engage with the actors involved. For this, we chose Tsoukas concept of a Dialogical Approach to the Creation of New Knowledge. A key aspect of this concept is that tension holds the key for productive dialogue and new insight. Further, our workshop design was inspired by Labontes Story/dialogue method using narratives to prompt a reflection on detected issues. We adjusted the method to support the interdisciplinary professionals in a dialogue on the complex issue of life, treatment and care in regards to heart failure. By presenting patient narratives from a previous study, we incorporated the patient perspective on illness and found it to be completely different from the professional perspective on disease. This created the tension needed to push dialogue and generate new insight.</td>
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<td>Participation was based on predetermined inclusion criteria and recommendations from both cardiac and palliative care literature. The participants included: 1 administrative palliative care nurse, 2 cardiac nurses from a heart failure clinic, 1 cardiac nurse from a cardiac ward, 1 cardiac physician, 1 physiotherapist, 1 chaplain and 1 workshop manager. A social worker, a palliative care nurse and an occupational therapist were also invited but not able to join at this point. A core element of this method is the use of patient narratives and the participants’ willingness to reflect on issues they detect in these narratives while at the same time, share and reflect on their own experience. The workshop manager engage in these reflections supporting the professionals to challenge both narrative and perspectives.</td>
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<td>The structure and time for these workshops were discussed with other researchers in the field. We wanted the structure to allow for the following: 1) time for the initial ‘getting to know each other’ – an important element in ensuring a relational engagement, 2) for unforeseen discussions that could prove valuable in terms of either process or findings, 3) to endorsed personal reflections between sessions and 4) leave time for the workshop manager to write a synthesis of findings from day one based on her field notes. The workshop was scheduled to 2 sessions 2 weeks apart lasting 5 hours. The venue was a conference room at the hospital making it easily accessible for the participant.</td>
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<td>Before the workshops the participants were introduced to the S’ approach - a palliative care model based on the premise that symptom control, self-image, self-determination, social relationships, strategy for the future and sense of coherence are all criteria’s for a good death. To provide a good foundation for the dialogue the professionals had: 1) Attended a seminar with the overall aim of assimilating knowledge and competences in the field of palliative medicine and advanced heart disease, 2) been on a study trip to Hospice Djursland and experienced the S’ approach in a clinical setting and 3)</td>
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been asked to prepare a talk of their role in the treatment and care of HF patients as well as experiences from their everyday practice. To incorporate the patient perspectives the WM had prepared patient narratives based on a n interview study.

**Workshop part I - playbook**

09.00-09.30 The participants meet one another in a friendly environment with coffee and breakfast

09.30-10.30 Participants present themselves and their involvement in treatment and care of heart failure patients.

10:30-11.30 The workshop manager present an outline of the action research project, the overall aim of developing and implementing a palliative care intervention inspired by the S’ approach in a cardiac hospital setting and the purpose of this workshop.

11.30-12.00 Lunch

12.00-12.30 The workshop manager presents the interview study with focus on patient narratives

12.30-14.00 A semi-structured dialogue enable the participants to reflect and discuss the patient narratives providing perspectives from their own clinical experience.

**Workshop part II - playbook**

09.00-09.30 Coffee and breakfast

09.30-10.00 The workshop manager presents a synthesis of the generated insight from day one

10.00-11.30 The participants are invited to comment on the findings followed by a semi-structured dialogue on requirements, ideas and challenges to implement palliative care in a cardiac setting

11.30-12.30 Lunch

12.30-14.00 The semi-structured dialogue on requirements, ideas and challenges to implement palliative care in a cardiac setting is continued and tasks in regards to designing the intervention are delegated
Stage I: Management of chronic heart failure (NYHA I–III)—early palliative care

- Active treatment with the aim of prolonging life and controlling symptoms
- The patient and caregivers are educated on the condition, causes, treatment, and prognosis of HF, with the aim of improving the self-management of symptoms
- Treatment is provided in accordance with the national guidelines and local protocols, including rehabilitation and exercise training

Stage II: Supportive and palliative treatment (NYHA III–IV)—late palliative care with a focus on clinical indicators

- The patient's symptoms become increasingly pronounced, with multiple hospitalizations and periods with decompensated heart failure despite optimal treatment in accordance with the guidelines
- Old age and other comorbidities rule out heart transplantation and mechanical circulatory support
- The patient can no longer tolerate decongestive treatment because of hypotension and/or progressive renal impairment
- Delirium, change in mental status
- Hyponatraemia despite normal hydration
- Signs of cardiac cachexia or low albumin
- Repeated implantable cardioverter defibrillator shocks
- Active treatment is reduced, and the aim moves towards sustaining optimal symptom control and quality of life
- Identification of a key health professional is recommended to ensure optimal individualized continuity of care across multiple sectors and disciplines
- A holistic, multidisciplinary assessment of the patient and his or her needs should be conducted continually in consultation with the patient and relatives, preferably with the same health professional and when the condition is clinically stable
- Declaration of terminal care and financial support decisions should be considered

Stage III: Terminal treatment and palliative care

- The patient will die imminently
- Heart failure treatment changes to alleviating symptoms only
- A do-not-resuscitate order in case of cardiac arrest and waiver of intensive treatment needs should be discussed and documented
- An integrated care plan should be devised, focusing on the psychosocial support needs of the patient and the family or caregivers
- The preferred place of final care and death should be discussed
- The care includes follow-up bereavement support as needed
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