SDU

Department of Clinical Research
University of Southern Denmark

Stine Gundtoft Roikjær

Integrating General Palliative Care in a Heart Failure Clinic – Based on Patients' Narratives

February 2021

PhD Thesis

Stine Gundtoft Roikjær
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2021

Supervisors

Professor Helle Timm, REHPA, The Danish Knowledge Centre for Rehabilitation and Palliative Care. Department of Clinical Research, University of Southern Denmark (Main supervisor)

Senior Researcher Charlotte Paaske Simonÿ, Næstved Slagelse and Ringsted Hospital. Department of Regional Health Research, University of Southern Denmark

Specialist Physician in Cardiology Henrik Ryde, Department of cardiology, Næstved, Slagelse and Ringsted Hospitals

Assessment Committee

Associate Professor Lisbeth Rosenbek Minet, Department of Clinical Research, University of Southern Denmark (Chairwoman)

Professor Birgit Rasmussen, Department of Health Sciences, Lund University

Associate Professor Mette Spliid Ludvigsen, Department of Clinical Medicine, Randers Regional Hospital

The narrative link between part and whole, between intention, action and result, between event and affect unite what is separated by time, and in that way becomes an essential way of creating meaning in the human existence.

- quote from Horsdal 1999 pg. 20 (my own translation)

Foreword

I am not a romantic. I have a tendency to forget important events that others hold dear. My siblings are eminent in sharing stories from our childhood and I love it, but I often don’t recall them. Nevertheless, I love how stories provide a social room, and anyone who knows me knows that I am a very sociable person. I remember my first real job. It was in the primary care sector as an unlicensed nursing assistant. I loved it. I loved how I was welcomed, a young girl of 19, into the homes of the elderly. They shared stories from their life and I listened. The funniest thing is that I remember every one of these persons. Their stories resonated in me and stayed. I am not a romantic, but I believe that we live in a social world formed by the stories we share and the interactions we have. Moreover, I believe that these stories shape us.

The story of this PhD started with an informal talk at a cardiac ward at a local Danish hospital. I was standing in the medicine room preparing medicine for a patient when a nurse came in. She was frustrated. Once again, she had sent home a patient with a sense that more could be done: *‘If you are truly to take on a research study then I suggest that you focus your effort on the heart failure patient. It cannot be true that this is all we can do to help them’.* She felt that needs of this patient group were often neglected, as they did not fit the ‘sexy dream’ of acute cardiology. Heart failure patients were repeatedly readmitted due to exacerbation with treatment focusing on the acute event followed up by life-prolonging medical action. She suspected that no one addressed the fact that these people were actually going to die from their illness or helped them understand the seriousness of their illness. I pondered about this for a bit ‘*what can be done to better help these patients’.* Then I decided to do an initial search on the subject. What I found was that although the nurse expressed her statement in frustration and affect - she had a point. The heart failure patient is challenged by a life-threatening chronic illness for which there is no hope for cure hence, palliative care is recommended. Still, their access to palliative care appeared restricted. That clinical frustration led to this PhD project and a determination to develop a palliative care approach for integration in the heart failure clinic. However, as this thesis will show introducing and integrating palliative care in a cardiac hospital setting is no easy task.

Sorø, February 2021

Stine G.

Acknowledgements

This thesis is a write up of a comprehensive PhD study and I would like to begin by thanking the people and organizations who have contributed. My profound gratitude goes to:

- My principle supervisor Professor of Palliative Care Helle Timm for guiding me throughout every little curve of this PhD and for your eminent sense for when to push and when to praise. Your expertise on palliative care, qualitative methods and use of theory have been a pillar for me to lean on.
- My co-supervisor Head of Research at NSR hospitals Charlotte Paaske Simonÿ for your continuous support, clinical research experience and managements skills. Your provision helped me manoeuvring the difficult field within research and clinical practice.
- My co-supervisor Specialist physician of Cardiology Henrik Ryde for your clinical expertise in the field of cardiology and your willingness to always speak the patients' case.
- The team of very dedicated clinicians, who put in a lot of work in developing this palliative care plan. Thank you for joining the dialogue and your willingness to make this happen. Especially a great *thank you* to the cardiac nurses who took on the task of intervention nurses. Your contribution has been essential to the project.
- The patients who accepted to participate in this project. I am forever grateful for this. Without you this PhD could not have been done.
- Annette Lindholm formerly employed as Head nurse at Medicine 2, cardiology at Slagelse Hospital for her support and belief in both the project and in me. I am grateful for it all.
- The Næstved, Slagelse and Ringsted Hospital Research Fund as well as the Health Research Foundation in Region Zealand for finding value in the research project and providing funding.
- The Research Unit PROgrez, Department of Physiotherapy and Occupational Therapy, Næstved-Slagelse-Ringsted Hospitals, Region Zealand, as well as the research unit of palliative care at REHPA, The Danish Knowledge Centre for Rehabilitation and Palliative Care. I am thankful to call you colleagues and friends.
- To friends and family both home and abroad for their love and understanding. A well-served G&T, a long walk and talk, or an empty house has been provided whenever needed.
- Finally yet equally important, I have to acknowledge my husband Thomas for his unshakeable love and belief in me. And to my boys Malthe and Linus for putting things in perspective. You keep my feet on the ground as meals must be prepared and laundry must be washed. I love you completely.

List of Papers

This thesis is based on the following original papers:

Paper I

Roikjær SG, Missel M, Bergenholtz HM, Schønau MN, Timm HU. The use of personal narratives in hospital-based palliative care interventions: An integrative literature review. Palliat Med. 2019 Dec;33(10):1255-1271. doi: 10.1177/0269216319866651. Epub 2019 Aug 1. PMID: 31368845.

Paper II

Roikjær SG. Når hjertet svigter – patientperspektiver og basal palliativ indsats på hospitalet. Omsorg, Nordisk tidsskrift for palliative medisin 2020 sep;3:40-45

Paper III

Roikjær SG, Timm HU and Simonÿ CP: First steps to integrate general palliative care into a cardiac hospital setting – using dialogue-based workshops. Scand J Caring Sci. 2021 Mar 3. doi: 10.1111/scs.12978. Epub ahead of print. PMID: 33656179.

Paper IV

Roikjær SG, Simonÿ CP, Timm HU. Qualitative study to explore what patients with heart failure find significant during integrated palliative care sessions in a Danish clinic. BMJ Open. 2020 Dec 31;10(12):e043955. doi: 10.1136/bmjopen-2020-043955. PMID: 33384400; PMCID: PMC7780519.

Other relevant publication

Hansen VB, Aagaard S, Hygum A, Johansen JB, Pedersen SS, Nielsen VL, Neergaard MA, Salomonsen GR, Guldin MB, Gustafsson I, Eiskjær H, Gustafsson F, Roikjær SG, Nørager B, Larsen H, Zwisler AD. The First Steps Taken to Implement Palliative Care in Advanced Heart Disease: A Position Statement from Denmark. J Palliat Med. 2020 Sep;23(9):1159-1166. doi: 10.1089/jpm.2019.0566. Epub 2020 May 6. PMID: 32380928.

Roikjær SG. Når hjertet svigter – palliation til hjertepatienten, https://www.rehpa.dk//wp-content/uploads/2019/10/Notat-17.-Når-hjertet-svigter.-Palliation-til-hjertepatienter.pdf (2019)

Papers at a glance

P.	Questions	Method	Conclusion
I	1) What characterizes personal narrative interventions in hospital-based palliative care? 2) What is the purpose and significance of personal narrative interventions for the patients? 3) How does general palliative care provide for using personal narratives?	Systematic integrative review with qualitative analysis and narrative synthesis in accordance with PRISMA where applicable (PROSPERO#:CRD42018089202).	Various types of systematic palliative care interventions use personal narratives. Common to these is a shared psychotherapeutic theoretical understanding and aim. Clinical application in a hospital setting is both feasible and acceptable but requires flexibility regarding the practices of the setting and the needs of the patient. Although the evidence from this review is from a hospital setting, the scope is limited beyond a specialized palliative care setting.
II	What does it mean to live with heart failure and what needs of support do the patients express?	Semi-structured qualitative interviews with six heart failure patients. Thematic analysis using theory from Arthur Kleinman and Arthur W. Frank focused on meaning.	Patients experience heart failure through their everyday life and not as a medical diagnosis. This is in contrast with the biomedical disease perspective in the hospital. With a singular disease perspective, the patient is left without support in integrating treatment and lifeworld. There is a need to integrate the patient's illness perspective in the biomedical disease perspective at the hospital.
III	How to generate new insight and develop a person-centred palliative care approach for a heart failure hospital setting?	Through an interdisciplinary workshop, we used the tension between perspectives on illness and disease as a facilitator for dialogue and new insight. Data from the workshop was analysed through thematic analysis.	Integrating palliative care principles into cardiology is a complex issue. Palliative care must be initiated from the patient's perspective and wishes. One way of doing this is through the S' approach. However, this requires organizational efforts and adaptation to the specific cardiac setting.
IV	What does the patients find significant in integrated palliative care and heart failure sessions using a narrative approach.	Through semi-structured qualitative interviews with 12 heart failure patients, we explored the significance of integrated palliative care and heart failure sessions based on the S' approach; a person-centred palliative care model using narratives.	The method using the S' approach in integrated palliative care and heart failure sessions showed able to bring comfort to lived physical, psychosocial and existential issues. It made patients able to combine their embodied understanding of heart failure with a medical perspective hereby, finding meaning and a sense of coherence.

Abbreviations

ACCF/AHA: American College of Cardiology Foundation/American Heart Association
AR: Action research
CASP: Critical Appraisal Skills Program
DSC: Danish Society of Cardiology
DSPam: Danish Society of Palliative Medicine.
EAPC: European Association of Palliative Care
EF: Ejection fraction
HF: Heart failure
ICN: International Council of Nurses
ICNE: International Centre for Nursing Ethics
GP: General practitioner
NYHA: New York Heart Association
PC: Palliative care
PROM: Patient reported outcome measure
WHO: World Health Organization

List of Figures

List of Tables

Content

Paper I: The use of personal narratives in hospital-based palliative care interventions: An integrative literature review

Paper II: Når hjertet svigter – patientperspektiver og basal palliativ indsats på hospitalet

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

Paper IV: Qualitative study to explore what patients with heart failure find significant during integrated palliative care sessions in a Danish clinic

Appendix A: Information to Patient Participants
Appendix B: Informed Consent Form
Appendix C: Obtained Approval
Appendix D: Semi-structured Interview Guide Phase I
Appendix E: Program for the Seminar
Appendix F: EORTC QLQ-C15-PAL
Appendix G: Inspirational S' question Guide
Appendix H: Letter to Patients
Appendix I: Evaluation Program for the Pilot
Appendix J: Semi-structured Interview Guide Phase IV

Aim & Background

Aim

The aim of this PhD study was to develop, integrate and evaluate the significance of a general palliative care approach in a heart failure clinic based on patients' narratives.

Background

Heart Failure

Heart failure (HF) is an end-stage cardiovascular syndrome affecting cardiac function.[1–5] HF is estimated to affect as many as 37.7 million people around the world,[6] making it a global pandemic.[7,8] In the Rotterdam study presented in 2004[9] Bleumink and colleagues found that at age 55, the lifetime risk of developing HF was 29% for women and 33% for men. As treatments of acute cardiovascular events are improving and the aging global population is growing, the incidence of HF increases.[6] Unfortunately the trends in survival after being diagnosed with HF lags behind.[10] The consequences include considerate health expenditures for the society and for the individual with HF, a poor quality of life.[6]

Although there are treatments available to slow down the progression of HF, it remains a chronic life-threatening illness with no hope of cure. When the hearts ability to pump blood through the body is weakened, it is no longer able to meet the needs of the body. This can have fatal outcomes, and patients with HF have up to a 40% risk of dying within the first year of hospitalization[8,11] which makes HF more lethal than nearly all cancer forms.[8,12] Still, palliative care (PC) aimed at relieving symptoms and suffering associated with a life-threatening illness have been absent in the HF trajectory. In Denmark, it is estimated that nine out of ten patients referred to PC are cancer patients.[13,14]

HF is diagnosed based on physical symptoms like oedema, shortness of breath, pain and fatigue followed by an echocardiogram providing visual pictures of the hearts function, measured in an ejection fraction (EF), although some HF diagnoses have a preserved EF.[12,15] "*Ejection fraction is a measurement, expressed as a percentage, of how much blood the left ventricle pumps out with each contraction. A normal heart's ejection fraction may be between 50 and 70 percent.*"[16]

There are two classifications for HF, the American College of Cardiology Foundation/American Heart Association (ACCF/AHA)[4] stages of HF and the New York Heart Association (NYHA)[1] functional classification (see Table 1). Both these classifications are used to determine presence and severity of HF. The ACCF/AHA show the progressive stages of HF and are often used to describe individuals or a population, whereas the NYHA focus on functionality and symptomatic status of the disease. The NYHA classification is widely used in clinical settings.[4]

Table 1: Classification of Heart Failure

	Symptomatic status (NYHA)[1]		**ACCF/AHA Stages[4]**
		A	Patients at risk for heart failure who have not yet developed structural heart changes (i.e. those with diabetes, those with coronary disease without prior infarct).
I	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, shortness of breath.	**B**	Patients with structural heart disease (i.e. reduced ejection fraction, left ventricular hypertrophy, chamber enlargement) who have not yet developed symptoms of heart failure.
II	Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, shortness of breath.	**C**	Patients who have developed clinical heart failure.
III	Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or shortness of breath.		
IV	Unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases.	**D**	Patients with refractory heart failure requiring advanced intervention (i.e. biventricular pacemakers, left ventricular assist device, transplantation).

The literature on HF seems to agree that the trajectory of illness is unpredictable and HF is typically described by periods of stability and episodes of acute exacerbation.[17–19] However, this notion of the unpredictable HF has been challenged. Based on longitudinal data on 744 HF patients, researchers examined patients' characteristics over time and classified patients into different groups based on their comorbidities.[20] They identified five progressions towards death: Constant Moderate Risk and Unexpected death, Rapid Progression, Late Progression, Early Progression and Constant High Risk, arguing that only about 20% truly have an unpredictable trajectory. They do however acknowledge that progression of disease depends on the quality of care. In addition, their data shows that many patients in the high-risk group lives for a long time and many at moderate risk die swiftly.[20] This demonstrates the difficulties predicting mortality in HF.

Regardless of the discussion on unpredictability, the progressive trajectory of HF necessitates regular contact with the health care system and influence the overall quality of life. Likewise, high hospitalization rates due to readmissions are a rudimentary concern for both the society, the hospital and the individual.[6,8]

Living with Heart Failure

Knowledge on the experiences of living with HF has been gathered from different age groups[21,22], from both men[23] and women[24], from different symptomatic stages of HF[25,26] and from different points in the illness trajectory.[21,27]

One study explored peoples' experiences of being diagnosed.[21] Authors found that the process of getting the diagnosis caused distress and confusion. The diagnostic process was a period of transition from receiving the diagnosis, coming to terms with the diagnosis and ultimately adjusting to a life with a chronic life-threatening illness. Many participants did not recognize their symptoms as related to the heart. Hence, they did not seek medical advice and when they did, they often experienced that the staff had difficulties identifying the problem. Even after being diagnosed, a number of participants did not recognize HF as a serious illness. Some were surprised by the diagnosis. They saw themselves as healthy and active. Others experienced the diagnosis as a wakeup call to face the facts and acknowledge the serious nature of the illness.[21]

Another interview study on HF patients' diagnostic journey support these findings.[28] It demonstrated that participants initially tried to normalize symptoms, and they did not seek medical advice before symptoms affected their daily activity. Furthermore, participants had a hard time understanding the term heart failure causing fear and anxiety. Some participants recalled that the term 'heart failure' had not even been used.[28]

Yet another team of researchers asked HF patients about their quality of life.[29] They found that patients defined their quality of life depending on their ability to 1) perform desired physical and social activities, 2) maintain happiness and 3) engage in fulfilling relationship with others. Furthermore, factors of the physical, psychological, economical, social, spiritual and behavioural character affected patients quality of life in both positive and negative ways.[29]

The difficulties of coming to terms with the new situation seems to be a reoccurring issue throughout the illness trajectory and studies have consistently shown that HF affects patients' physical, social and psychological well-being.[24,30–33] A review from 2015[30] convey that the reduction of physical wellbeing due to fatigue, breathlessness, dizziness, oedema, chest pain and sleeping difficulties have a great influence on the social and psychological wellbeing of the HF patient.[30] Patients feel limited and less able to participate in social life. Hence, they become increasingly isolated and lose confidence in their ability to adhere to the demands of for example their job and other roles in life. This is a great psychological stressor and often leads to depression, anxiety and a fear of death.[30] A possible consequence of these existential and psychosocial problems is a progression of HF, which again forces the patient to come to terms with yet a new situation. Ultimately, this leads to a disastrous downward spiral.

A systematic review from 2017[34] looked at psychosocial needs and interventions for HF patients and their families. They found that although the psychosocial needs of HF patients are very similar to those of cancer patients, the access to psychosocial support differs. The authors mention that communication about prognosis and care options are lacking in HF treatment. In addition, the illness trajectories differs greatly and psychosocial needs manifest in different ways and at different stages compared to cancer.[34] In short, the psychosocial and existential needs of the person with HF are the same as with malignant disease but might present at a different time.

Palliative Care

In Denmark, we use the concept of PC as defined by the World Health Organization (WHO). PC is a holistic approach that aims to improve the quality of life for people living with life-threatening illness as well as their families, by alleviating the suffering of a physical, psychosocial or existential character.[35] WHO asserts that PC *"Is a crucial part of integrated, people-centred health services"* and argue that nothing can be more people-centred than aiming to relieve their suffering.[35]

Historically, PC is born out of the hospice philosophy with Dame Cecily Saunders as a main character.[36] Cecily Saunders was both a nurse and a physician and she firmly believed that every person is unique and that recognizing this will help the patients in finding meaning and quality in life. Saunders use 'the journey' as a metaphor for the process of finding acceptance and meaning in life and death[36]. PC can be understood as a way of helping the person make this journey. In addition, Cecily Saunders introduced the concept of 'Total pain' including "*physical symptoms, mental distress, social problems and emotional problems"*[37]. These symptoms may change or develop during an illness trajectory making it important for health care professionals to be aware of PC symptoms and needs. In PC, the response to total pain should be total care, which the definition from the European Association of Palliative Care (EAPC) clearly reflects: "*Palliative care is the active, total care of the patient whose disease is not responsive to curative treatment"*[38].

Traditionally, cancer patients and pain management at the end of life have been the primary focus for palliative efforts but, in 2002 the WHO changed its definition of PC to declare all people with a life-threatening illness as beneficiaries for PC at all levels of care.[35]

Like many countries, Denmark organizes PC in a general and a specialized setting.[39–41] General PC is part of standard clinical practice and delivered by health care professionals who do not have PC as their primary task. For example by nurses at a cardiac hospital-ward. Complementary, health care professionals with the main purpose of providing PC perform specialized PC. In Denmark, this level is available in hospices, PC units and through specialized PC teams. Throughout this PhD, the emphasis is on general PC as the study setting is a HF clinic.

Palliative care (PC) with its embedded holistic approach and emphasis on the person can play an important role in alleviating the HF patient's problems, and is recommended internationally for HF as an integrated part of treatment.[11,39,42,43] However, based on the evidence from a systematic review[34] it is necessary to modify and adapt PC interventions to fit the HF patient specifically.

Patient-Centred or Person-Centred Approach

The emphasis on the person in need of care is not exclusive to PC. Patient-centred care has been advocated for decades, arguing that the biopsychosocial perspective is not sufficient to understand the patients' problems with illness.[44,45] Although the concept is widely used in health care literature it seems that the meaning of the concept is less applied.

More recently another concept has been promoted: the person-centred care.[46] Person-centred care was developed from the earlier concept of patient-centred care, but with a strong emphasis on personhood.[46] The concept applies a philosophical understanding of personalism which "*emphasizes the significance, uniqueness and inviolability of the person, as well as the person's essentially relational or communitarian dimension*"[47]. Like PC was initially a concept from a cancer setting, person-centred care were traditionally used in elder care and dementia care.[48]

In a review of reviews from 2018[49], researchers explored similarities and differences between patient-centred and person-centred care. The authors found nine consisting themes: 1) empathy, 2) respect, 3) engagement, 4) relationship, 5) communication, 6) shared decision-making, 7) holistic focus and 9) coordinated care. However, they claim that the two concepts have different goals. The goal of a patient-centred approach is a functional life, whereas the goal of person-centred care is a meaningful life.[49]

In a Danish book on specialized palliative care edited by PC nurse educators Helle Nordestgaard Matthiesenn and Lotte Brøndum,[50] PC is defined as a patient-centred approach. However, as this PhD study includes general palliative care closer to the lifeworld of the patients I argue that a person-centred approach is a more accurate definition. Throughout this thesis, I will use the understanding of PC as built on a person-centred care philosophy.

Standardized Heart Failure Treatment

In 2009 the Danish Government along with the Danish Regions agreed on a Standardized plan for treating HF.[51] The aim was to improve prognosis and quality of life for HF patients based on equal access. The standardised treatment plan describes treatment, information for the patient and organisation of HF covering different health care sectors and departments. Based on the Standardized plan an individual treatment strategy should be offered the patient considering the patients overall situation such as the cardiac illness and co-morbidities. The plan emphasise the involvement of the patient through consistent and coordinated communication and information. Further, the plan initiates when the patient first presents to the health system and continues through the phases of diagnosis, treatment and rehabilitation.[51] The aim of treatment and rehabilitation is to obtain and preserve functionality hence, increase the patient's quality of life, independence and autonomy.[51]

Although the plan is not very explicit about its patient-centred approach, it uses a language indication a holistic understanding of treatment. This thesis applies the understanding that standard HF treatment and care builds on a patient-centred approach with functional life as a main goal.

Palliative Care in Heart Failure Treatment Trajectory

Despite international recommendations, integrated PC for HF patients in a general hospital setting is not accessible and still in the early development phase.[40,52,53] This is also evident in Denmark as PC is not mentioned in the standardized plan for HF, although it was revised in 2013.

A mutual consequence and reason for the slow development of PC in cardiology can be attributed to a number of factors. These include; the lack of palliative skills and capacity in cardiology as well as the lack of evidence on how palliative needs of people with HF should be assessed, met and delivered.[12,54] The different professional cultures and perspectives on illness and health in cardiology and PC have also been mentioned as a factor.[55] The cardiac context is one where the goal is to cure and procure functionality, while in PC the goal is to relieve suffering and improve quality of a meaningful life.

Table 2: Characteristics of the stages in progressive heart disease, recommended palliative care and clinical indicators for stage40pg1160

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, 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 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 Heart transplantation and mechanical circulatory support are ruled out
- The patient can no longer tolerate decongestive treatment because of hypotension and/or progressive renal impairment
- Delirium, change in mental status
- Hyponatremia despite normal hydration
- Signs of cardiac cachexia or low albumin
- Repeated implantable cardioverter defibrillator shocks
- Active treatment is reduced, and the aim moves toward 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

In Denmark, the work of integrating PC in cardiology is currently pushed forward through a combined effort from both cardiac and palliative medical societies as well as individuals in either field.[40] The Danish Cardiac Society has published a guideline on PC for the HF patient pending on the severity of HF symptoms (see Table 2). However, the clinical focus is stagnant on advanced HF focused on physical symptoms leaving patients in the early stages of HF without palliative support.[40] Especially a lack of psychosocial support is conveyed in PC literature.[56] In order to recognise these unmet needs we must explore the patients' experiences.

Patient Perspectives and Narratives

A study[57] on wishes and needs of HF patients and their relatives with regards to PC interventions found that patients wanted an approach that supports him or her in relation to limitations (physical or emotional), the future with HF and relief of symptoms. PC should be interdisciplinary, delivered by health care professionals who understands the disease, and family should be involved in the process.[57] This is supported by another study which in addition found that patients wish for PC to begin alongside the treatment of HF and continue throughout the course of illness,[58] just as internationally recommended.[59] However, the challenge is to integrate such an approach into the standard care continuum.[58] Hence, more research seems needed in terms of providing evidence on integrating general PC for the HF patient in a cardiac hospital setting that captures the entire definition of PC, including not only clinical symptoms but also the life situation as a whole.

Maybe as a response to unmet needs and an increased focus on the patient perspective and person-centred care,[45,46,60] there has been a growing interest in narrative interventions in health care.[61] The theoretical origins of narrative theory within health care seems to be inspired mainly from sociology and psychotherapy.[62,63] The "narrative" concept represents various methods to provide meaning to experiences, events or ideas.[64] Narrative interventions have shown promise in addressing existential and psychological domains in PC.[61,65,66] But the paradigm shift that person-centred care represent, will not happen in a cardiac setting overnight. The patient narrative is a first step in establishing a partnership and person-centred care.[46]

Research Questions

The aim of this PhD study was to develop, integrate and evaluate a general PC approach in a HF clinic based on patients' narratives. The following research questions guided the process:

- What characterizes personal narrative interventions in hospital-based palliative care?
- From a local context, what does it mean to live with heart failure and what needs of support do the patients express?
- How to generate new insight and develop a person-centred palliative care approach for a heart failure hospital setting?
- What do the patients find significant in integrated palliative care and heart failure sessions using a narrative approach.

Methodology, Analytical Framework, Design and Methods

Doing any kind of research necessitates a consideration for the intellectual puzzle of ontology, epistemology and methodology.[67] My ontological position is that the social world is relative, meaning that our interpretation of life, phenomenon, culture or ourselves evolve through language and narratives, relations and interactions.

At the core of this PhD is the patient's perspective and his/hers lifeworld experience and narratives on HF and treatment. Furthermore, we also had a key element of developing a PC intervention and facilitating change. These parts build on different epistemological styles. The first on hermeneutic interpretation of how people experience life and can find meaning through their narratives and the other on interaction to co-create knowledge and create change.[67] This chapter will provide an overview on the methodology, theory, design and methods underpinning the PhD.

Hermeneutic

Hermeneutic is a philosophical stance in the human sciences. It is concerned with the two concepts of interpretation and meaning. According to the Danish philosopher Mogens Pahuus, this also entails a hermeneutical argumentation that human sciences and natural sciences differ in significant ways. *"The natural sciences seek explanation to non-meaningful phenomenon; human sciences seek interpretation of meaningful phenomenon".* [68pg225]

The German philosopher and sociologist, Hans-Georg Gadamer is a central figure in the existential hermeneutic. He argued that life must be understood as a continuous interpretation process. How we interpret the world, a story or a phenomenon is defined through our own situational context.[68] This means that, as a qualitative researcher from a hermeneutic position I do not strive for an objective analysis of data. The patient experiences, I hope to uncover during this PhD are interpreted through my presupposition as a nurse from cardiology, qualitative researcher, mother, daughter to parents with heart illness, wife to a middle-aged overworked husband, sister to a beautiful mix of men and women with strong opinions and lots of love, and citizen in a land of plenty. Although this sentence is long, it is far from exhaustive. Gadamer talks of a 'horizon' from where we understand the world.[68] It is important to acknowledge that the findings in this PhD are interpreted through my horizon as well as the theory I apply to the data to open my understanding and continue the process of interpretation.

Likewise, it is important to acknowledge that the participants in this project, be they patients or professionals also interpret the world through their unique horizon. It is therefore important to explore different perspectives.

The Patient Perspective

Many have argued the value of exploring the patient perspective (Kübler Ross,[69] Saunders,[70] Kleinman[44]) and it has become an essential part of explorative PC research. In this PhD thesis, I build on the acknowledgement that these patient perspectives differ from the professional perspective.

MD and Professor in medical anthropology, Arthur Kleinman provides an understanding of these different perspectives and address how listening to the patients' illness stories can make their personal perspective available.[44] As I understand Kleinman, the patient perspective is defined as an embodied Illness experience. He defines 'illness' as the *"principal difficulties that symptoms and disability create in our life"*.[44pg4] Further, he argues that the illness experience is a combination of 1) how patients and society understand and articulate symptoms 2) how the specific disease is viewed in our culture and most importantly 3) the lifeworld of the individual patient.[44]

'Disease' on the other hand is the professional perspective defined as the *"problem from the practitioner's perspective"* [44pg5] Kleinman argues that the medical student learn to focus on the biomedical disease and treatment rather than the embodied experience of illness, and adds that this is problematic as without the patients' perspective something essential about the illness experience is lost.[44] As I understand Kleinman, the lack of 'something essential' can have the unwanted effect that the patient fails to find the treatment meaningful. Hence, a bridge between these perspectives are necessary.

Narrative Theory

Stories are a part of our life. We use stories to share experience and create meaning. We also use stories to present our understanding of an event and maybe persuade others or ourselves to an idea. In a qualitative research understanding, narrative inquiry embraces the idea that stories themselves are raw data.[71]

Although the narrative approach originated from the social and human sciences, it has expanded into many other scientific disciplines like education and health care with different aims and methods.[72] Narrative medicine[73], dignity therapy[74], reminisce practice and therapy[75] are just some of the narrative practices in health sciences.

Defining a 'narrative' is not easy as narratives hold both the idea of a meta-narrative and of the theoretical and analytical concept of narrated stories. Bodil H. Blix and Rita Sørly, two Norwegian nurse researcher have written about narrative theory and method in an interdisciplinary perspective.[76] They do not distinguish between narratives and stories but use them interchangeable. Others have a more strict definition of narrative and story. Like the sociologist Arthur Frank.

Frank defines narratives within a sociological frame arguing that illness narratives can give the patient and body a voice and healing through story telling. When a person turns illness into a story, she transforms fate into experience: *“The disease that sets body apart from others becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability.”* [77pg XIX preface.]

Frank tells the story of Judith Zaruches that experience losing her map and destination of life after becoming ill, and argue that stories are needed to repair this map.[77] A new story linking the narrative between past, present and future, can guide this repair.

The distinction between story and narrative, as I interpret Frank, is the same as between roads and map. The story is how we give our body a voice and try to reflect and understand our situation. The story is also, what we tell our doctor, friend or colleague when they ask *how are you doing?* Frank articulates it beautifully with this sentence: “*A story animates human life”*[64 pg. 3] The narrative is how these stories fit together like roads in a map or chapters in a book.

Frank theorizes that the illness narrative can have properties of restitution, quest or chaos none more ‘proper’ than the other, and that these narratives each hold different capacities. However, from a hospital setting perspective the restitution or quest narrative is preferable, as professionals want patients to recover from illness or at the very least fight it. In the case of chronic illness like HF, the restitution narrative is difficult. The HF patient will not recover from HF. The best they can hope for is a life with manageable problems. The chaos narrative on the other hand is exactly as it sound – chaotic. Leaving both the patient and the health professional with frustration.

In her work on life stories,[78] Professor emeritus Marianne Horsdal also speaks of narratives in a social sense. She argues that our identity is linked to a sense of meaning and coherence, and this experience of coherence is shaped through our narratives. When we tell our story, we not only reflect on our own situation shaping our identity but we share this story and identity with others. Their reaction to our story reflects the culture and norms of the setting, but also influence that same culture.[78]

It appears that whether one uses a strict or a more open definition the sense of meaning enabled by telling your story is a general principle.

I think the divide between story and narrative as Frank presents is helpful in understanding the theory but difficult to keep in clinical research. This dissertation will use a more open definition of story and narrative. Furthermore, a narrative understanding will be applied in different ways: 1) I will use narratives as a qualitative method to explore needs, plan intervention and evaluate the study, 2) The PC intervention itself uses personal narratives as a core dimension to uncover the patient perspective and 3) This thesis holds the wider narrative of my PhD journey.

Action Research

Qualitative research is dynamic and analysis starts at the same time as data collection. It felt natural and important for me to continue this qualitative and hermeneutic mind-set into clinical research and to give patients as well as health care professionals a voice both before, during and after the integration of the PC approach. For this, Action Research (AR) as methodology inspired me.

AR is not a simple unified methodology but can be understood as a relationship between participation, action and research.[79] Three main arguments informed my inspiration of AR. First, this PhD builds on the foundation of holistic health care congruent with a participatory paradigm underpinning AR.[80] Second, I aimed to find an answer to the complex question of '*what can be done to better help these patients'*. Last, I wanted to engage and educate stakeholders and change clinical practice.[81]

In a Danish context, sociologist Gitte Duus define AR as a scientific research approach aimed to create insight and change in a democratic interaction between researchers and the people this change involves.[82] She stresses the notion that AR is situated between insight and change process as well as between theory and practice development.[82]

Professor of Organization behaviour and development, Abraham Shani and Professor emeritus David Coghlan visualise the AR process with a cycle of constructing – planning action – taking action – evaluating action[83] (see Figure 1).

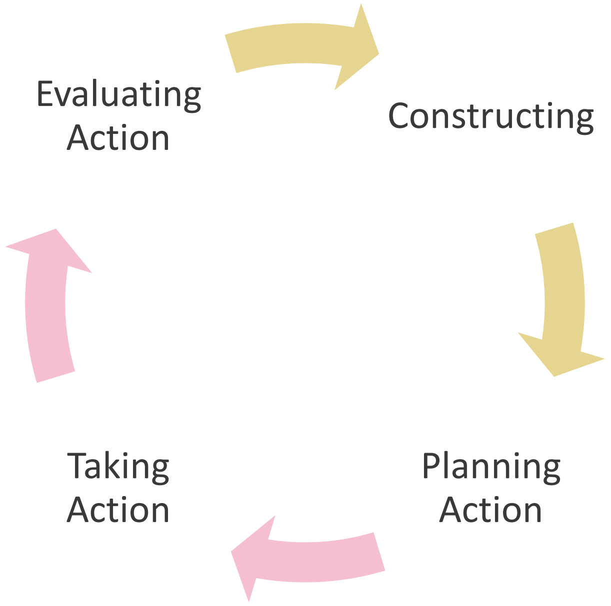


Figure 1: Cycle of action and reflection

‘Constructing’ can be understood as exploring the problem, context and purpose; ‘planning action’ as the response to the problem, ‘taking action’ as integration of the planned action and last, ‘evaluating action’ as appraising different aspects of the change.[83]

Collaboration or participation is essential in AR but can be implemented in different ways throughout the cycle. I have not directly included patients or professionals in every step of the PhD process and plan, but chosen steps in the cycle that would benefit most from collaboration and different perspectives (I elaborate on this in the chapter on ethical considerations). These steps include:

- Interviews with patients in the constructing level as we wanted patients involved in articulating the issues.
- Workshops with professionals to collaborate on the plan for an integrated PC intervention in HF care.
- Interviews with both patients and professionals to evaluate during and after integrating the PC approach.

This whole PhD project can be viewed as one cycle, but within this major cycle are additional cycles of action and evaluation. Through these cycles of planning, action and evaluation, we gained new knowledge and understanding which again informed a new practice combining PC and HF.

Design

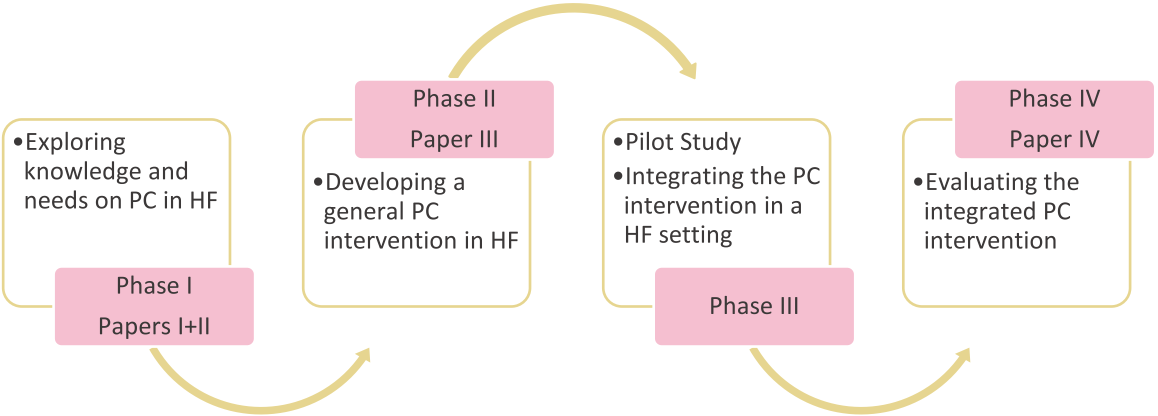


Figure 2: Phases in the PhD project

In accordance with the aim, study questions and framework just described, this study was designed in four phases (see Figure 2). The process occurred in iterative movements so that findings and understandings derived from each phase informed the next as well as reflected the first. Organizational and action researchers, Patricia Gayá Wicks, Peter Reason and Hilary Bradbury use the phrase *“making the road while walking”* as a reference to the way action researchers integrate and make sense of perspectives and influence to their own understanding.[80] In the same way, this project have been ‘making the road while walking’ to ensure that different perspectives and understandings influenced the PC intervention. The concern was an unpredictable process but the gain was an intervention based on involvement from patients and professionals as significant actors.

Integrative Review

The premise of this PhD was narratives and the sense of meaning enabled by telling your story. Therefore, I wanted to start the PhD process with a literature study to assimilate current scientific knowledge on narrative interventions. Furthermore, I wanted a method that would contribute to developing a PC approach feasible in clinical practice. The nurse researchers Robin Whittemore and Kathleen Knafl argue that the integrative review method has potential to build nursing science, inform research, practice and policy initiatives,[84] hence this became our choice of method.

The integrative review design is a systematic approach to search, assess and synthesize different types of research designs on a topic for further use in clinical practice. The design is systematically guided through five stages: problem identification, literature search, data evaluation, data analysis and presentation.[84]

The data evaluations and analysis stages in the integrative review method differs from a traditional systematic review. The reason is that the integrative review allows for diverse primary sources and research designs. In data analysis, we chose to use qualitative researchers Matthew B. Miles, Michael Huberman and Johnny Saldana as our reference frame.[85] They describe a qualitative analytical process consisting of data reduction, data display, data comparison, conclusion drawing and verification.[84,85]

Action Research Inspired Activities

Workshops

Changing clinical practice requires democratic activities that engage the actors involved. As part of the development phase, I used workshops to generate new insight for a PC intervention in a cardiac setting, join different perspectives from patients and professionals from cardiology and PC settings and to enable a relational engagement within the interdisciplinary project group (see Paper III). For this, I was guided by Professor of Organizational studies, Haridimos Tsoukas concept of a *Dialogical Approach to the Creation of New Knowledge,*[86] arguing that tension holds the key to unlock a productive dialogue hence, new insight.

Furthermore, Professor Ronald Labonté inspired the workshop design with his Story/dialogue method.[87] In this method, narratives are used to spark a reflection and dialogue. I adjusted the method to allow the patients’ narratives to support the interdisciplinary professionals in a dialogue on the complex issue of life and HF treatment.

The World Café Methodology

The idea behind the world café is co-creation through dialogue.[88] Organizational researchers, Juanita Brown and David Isaacs formed the idea of a world café. They define the world café as both a vision and a method of dialogue and argue that when people through dialogue gain a common understanding of 'real-life issues', it initiates a power of action.[88]

Seven principles of ideas and practices forms the world café design: 1) set the context, 2) create hospitable space, 3) explore questions that matter, 4) encourage everyone's contribution, 5) connect diverse perspectives, 6) listen together for patterns and insights and 7) share collective discoveries.[89]

We used this as inspiration for evaluating the pilot study by exploring patient experiences, gain new insight and modify the intervention if necessary. In addition, it had the aim of keeping the project group engaged in the process of change by giving them feedback from the patients.

Action Research Inspired Evaluation

Evaluating action in health care is necessary if we are to understand the value of a change. To evaluate the integrated PC intervention we found inspiration in AR theory.[90] John Øvretveit, Professor of Health Innovation Implementation and Evaluation describes evaluation as a judgement of value of something with the purpose of deciding what to do or to contribute to scientific knowledge.[90pg12] He defines six different kinds of evaluation designs on health programme and change:

1. Descriptive
2. Audit
3. Outcome
4. Comparative
5. Randomised controlled trial
6. Intentional change to organisations[91]

Inspired by these designs, I took on a descriptive approach to explore the content of sessions using participant observation. I also draw from his sixth type of evaluating intentional change to organisation. He describes this type as an outcome evaluation with a focus on the impact on professionals and/or patients. To explore this impact on patients I chose interviews. To explore the impact on the professionals I chose feedback meetings. Shared reflections through democratic methods are a key element in AR as this enables a continuation of the AR cycle.

Ethnographic Fieldwork

Different ethnographic methods can be applied under AR, and I have built my choice of methods around the research questions. All methods focus on meaning making and interpretation. Furthermore, the methods chosen allow for the hermeneutic understanding that the researcher as the participants are in a social interaction and will grow and learn through this research. Two books have primarily informed choices of methods: Kvale & Brinkmann 2015[92] and Mason 2018.[93] Table 3 at the end of this chapter shows where the different methods were applied and to what objective. This section will briefly present design and methods used throughout the PhD study, additional information can be found in the published papers or in the following chapters in this dissertation.

Individual Semi-structured Interviews

Individual semi-structured interviews were planned for phase I and IV. According to the Professors of Psychology Steinar Kvale and Svend Brinkman, the qualitative interview enables an understanding of themes from lived life based on the interviewees' own perspectives.[92] This fit our focus of exploring the lived experience of life with HF as well as our focus on the lived experience of the integrated PC intervention.

Furthermore, Kvale & Brinkmann argue that the knowledge derived through interviews can be described as produced, relational, based on conversation, contextual, linguistic, narrative and pragmatic.[92] As I understand this, knowledge is produced in a social room between me the researcher and the participating patient, and the semi-structured design allows for a balance between a systematic approach and a consideration for the specific context, situation, relation and narrative. The researcher is a factor in this hence, the knowledge produced in the interview very much rely on my ability to sense and interpret where an answer leads. An open and inviting interview style with open-ended questions was chosen to allow for spontaneous and descriptive stories creating rich interview data.

Focus Groups

The purpose of a focus group is to get more perspectives on a given topic making it suitable for examining new areas and initiatives.[92] Focus groups require an atmosphere that allows conflicting perspectives to be expressed. It is not a goal to reach an agreement. The interviewer is not controlling, but sets out the overall topics and facilitates the dialogue.[92]

I applied the rationale of the focus groups as part of phase II, III and IV. By doing so, I enabled a discussion among interdisciplinary professionals with focus on the patients' experiences, but also on their own experiences with the PC intervention.

Participant Observation

Participant observation was conducted as part of the descriptive evaluation and was guided by Professor of Anthropology, James P. Spradleys definition.[94] The purpose was to provide a supplementary perspective on the evaluation. In addition, I used participant observations to establish a relation with the participants by engaging in their social situation. Last, the observations provided insight information that I could explore further during the interview study.

Spradley argues that the participant observation method enables a direct experience of activities, as the researcher is present. Furthermore, the method can reveal both explicit and tacit knowledge as observation is collected through both actions and spoken language.[94]

Spradley also describes different types of participation depending on degree of involvement. I place my type of participation in what he calls passive as I only participated as a spectator.[94]

Spradley presents nine major dimensions of every social situation (space, actor, activity, object, act, event, time, goal and feeling).[95] These dimensions may guide the observations. However, in this PhD the data produced with this method was never meant to stand alone or have the same weight as the final interview study, rather it was meant to inform the iterative process and provide situational context for findings.[96] I therefore chose to focus on observations regarding the activities and actors reaction, verbally or through expressions. The actors in focus was the patient. In addition, nurses and family members were also present.

During these observations, I witnessed the practice of the sessions and use of a narrative approach. The interviews did not entail descriptions of these activities; hence, observations added an extra dimension to findings.

Data Analysis

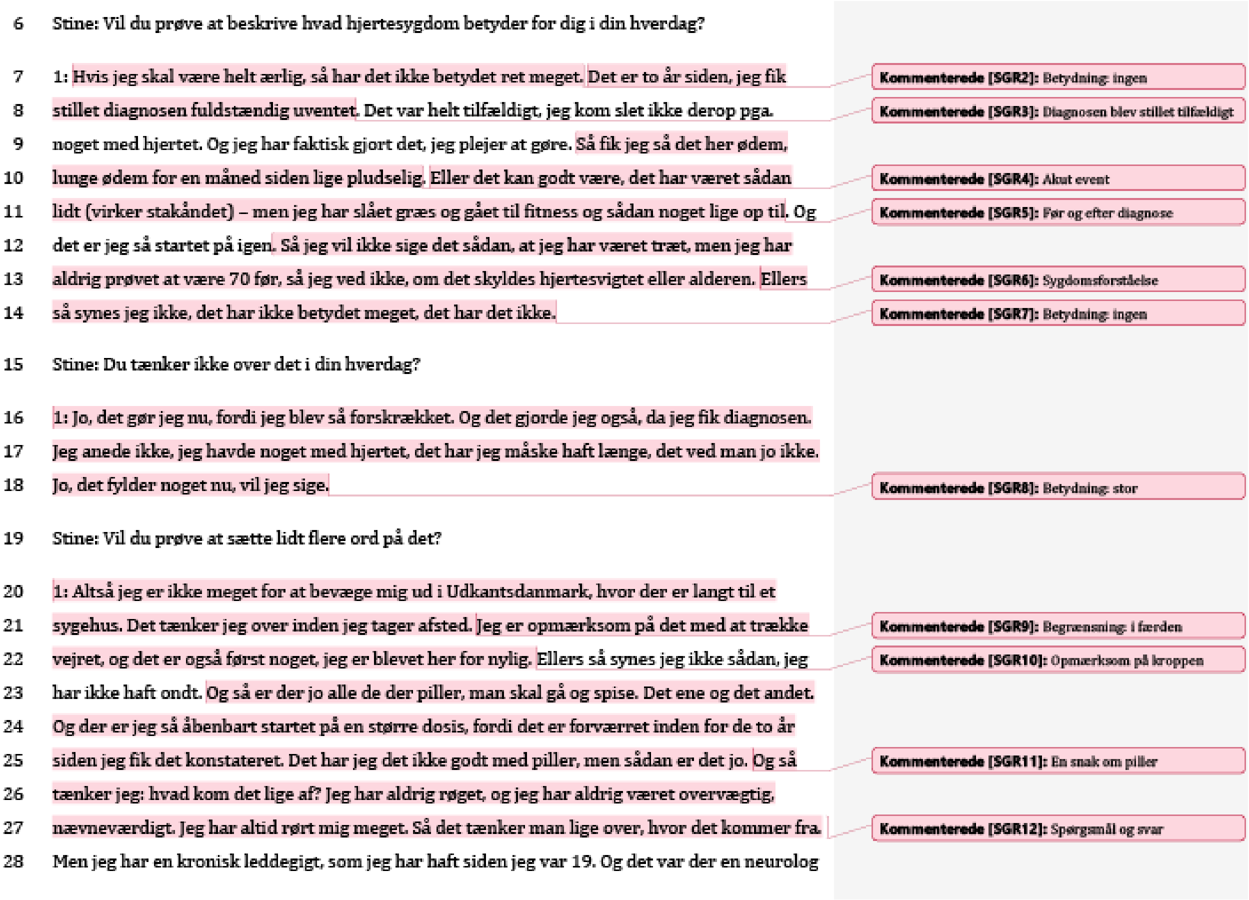
Thematic Analysis

Making sense of qualitative data can seem both overwhelming and exciting. During this PhD, I have realised that my clinical background have had an enormous impact of methodological choices. The seemingly simple thematic approach is an example. I have been introduced to various creative analyses, but I always fall back to the systematic approach presented in this analysis.

The thematic analysis aims to identify themes under which we can organise and describe content of the data. It follows the steps of: 1) organizing the data, 2) familiarizing myself with data by reading and re-reading interview transcripts and notes, 3) writing initial thoughts of ‘what is going on’ in margins of my transcripts, 4) starting a coding scheme and 5) coding additional data.[97] In the following, I will try to guide the reader through the steps of my analytical process from coding to interpretation.

Throughout the analyses, I was the only data coder. In the evaluation phase, I used the software program Nvivo12pro[98] to manage the interview and observational data and construct central and general themes. Up until that phase, I used a more pragmatic approach of cutting out meaning units from transcripts, placing them in a scheme and building themes.

I was responsible for the derivation of themes followed by a discussion with my supervisors arguing how and why the themes were conveyed from data. The construction of themes was an iterative process, but led by my semi-structured guide and research questions. The first time I read a transcript or listened to a recording I tried to be open and immediately after I asked myself ‘what were the three most important or surprising things conveyed in this interview?’ The answers to these questions were jotted down on the front of each transcript.



Stine: Vil du prøve at beskrive hvad hjertesygdom betyder for dig i din hverdag?

1: Hvis jeg skal være helt ærlig, så har det ikke betydet ret meget. Det er to år siden, jeg fik stillet diagnosen fuldstændig uventet. Det var helt tilfældigt, jeg kom slet ikke derop pga. noget med hjertet. Og jeg har faktisk gjort det, jeg plejer at gøre. Så fik jeg så det her ødem, lunge ødem for en måned siden lige pludselig. Eller det kan godt være, det har været sådan lidt (virker stakåndet) – men jeg har slået græs og gået til fitness og sådan noget lige op til. Og det er jeg så startet på igen. Så jeg vil ikke sige det sådan, at jeg har været træt, men jeg har aldrig prøvet at være 70 før, så jeg ved ikke, om det skyldes hjertesvigtet eller alderen. Ellers så synes jeg ikke, det har ikke betydet meget, det har det ikke.

Stine: Du tænker ikke over det i din hverdag?

1: Jo, det gør jeg nu, fordi jeg blev så forskrækket. Og det gjorde jeg også, da jeg fik diagnosen. Jeg anede ikke, jeg havde noget med hjertet, det har jeg måske haft længe, det ved man jo ikke. Jo, det fylder noget nu, vil jeg sige.

Stine: Vil du prøve at sætte lidt flere ord på det?

1: Altså jeg er ikke meget for at bevæge mig ud i Udkantsdanmark, hvor der er langt til et sygehus. Det tænker jeg over inden jeg tager afsted. Jeg er opmærksom på det med at trække vejret, og det er også først noget, jeg er blevet her for nylig. Ellers så synes jeg ikke sådan, jeg har ikke haft ondt. Og så er der jo alle de der piller, man skal gå og spise. Det ene og det andet. Og der er jeg så åbenbart startet på en større dosis, fordi det er forværret inden for de to år siden jeg fik det konstateret. Det har jeg det ikke godt med piller, men sådan er det jo. Og så tænker jeg: hvad kom det lige af? Jeg har aldrig røget, og jeg har aldrig været overvægtig, nævneværdigt. Jeg har altid rørt mig meget. Så det tænker man lige over, hvor det kommer fra. Men jeg har en kronisk leddegigt, som jeg har haft siden jeg var 19. Og det var der en neurolog

Kommenterede [SGR2]: Betydning: ingen
Kommenterede [SGR3]: Diagnosen blev stillet tilfældigt
Kommenterede [SGR4]: Akut event
Kommenterede [SGR5]: Før og efter diagnose
Kommenterede [SGR6]: Sygdomsforståelse
Kommenterede [SGR7]: Betydning: ingen
Kommenterede [SGR8]: Betydning: stor
Kommenterede [SGR9]: Begrænsning: i færden
Kommenterede [SGR10]: Opmærksom på kroppen
Kommenterede [SGR11]: En snak om piller
Kommenterede [SGR12]: Spørgsmål og svar

Figure 3: Extract from coded interview transcript

Then I started to look at the questions I wanted to explore using my initial semi-structured guide. To exemplify, in the first interview study, I asked patients what it meant for them to live with HF. Looking at this question I went through my data again, writing codes like ‘medical treatment’, ‘fear for the future’, limitation’, in the margin and highlight meaning units. An example of coded data is shown in Figure 3.

My coding scheme was never a static model, but changed as I moved through the data and gained a continuously better understanding of what was going on. Once I was happy with the coding, I started copy pasting the coded meaning units into larger data piles under a central theme heading. Last, the central themes were gathered under general theme headings. Examples of this is shown in Table 8 and Table 13. During coding and derivation of themes, I went back to my initial jotted down understandings of every transcript. On occasion, I would simply call up a research colleague and tell her what was going on across data. Sometimes this was a senior researcher other times a fellow Ph.D. student. By articulating this on the spot, I experienced being more open to themes outside my semi-structured guide. This process of going back and forth from parts and whole enabled me to distance myself from the detail and look at the data in a bigger picture.

With the emphasis on meaning and interpretation, my focus was not merely on a literal understanding of the data, neither was I aiming to test an already established thesis. Hence, my approach was explorative and inductive. Kvale & Brinkmann describe a continuum from meaning coding through meaning condensing to meaning interpretation and I used this approach to gain a more interpretive and reflective understanding.[99] The meaning condensing responds to my themes. An example is the general theme of 'A Sisyphean struggle with exhausting cycles of relapse and progress' from study II. This is a condensed meaning of life with HF which is opened again with the interpretation that patients experienced that living with HF was an up-hill struggle. When they finally felt they were about to reach a place with a sense of balance between life and illness something happened and the struggle started all over again. Some even questioned why this had happened to them, as if it was a punishment or simply bad luck. The example of the Sisyphean struggle also show how I let my analysis be influenced by an intuitive feeling of recognition and used metaphors to explain such understanding. As I went through the data on life with HF, I literally pictured a man climbing a mountain but never reaching the top.

In addition, I have applied theory to my analysis to go from a common sense understanding to a more scientific understanding of themes. For instance, another theme derived in study II was 'Understanding heart failure' describing different perspectives on HF. I took this up with my main supervisor and she recommended that I read Kleinman's theory on illness and disease[44] to open for an additional understanding. With this new understanding, I came to an acknowledgement that standard treatment was framed from a professional perspective but patients understood their illness as the problems in their everyday life.

Every analysis was different as the question I explored differed, and still they were all connected in a hermeneutic process towards new understanding. The understanding I derived from study I and II guided the development of the intervention, and the knowledge produced during the development phase guided the research question and analysis during the evaluation phase. Professor of Sociology, Jennifer Mason describes that even the style of arguments when presenting your findings is a question of conscious choice.[100] To be honest, for me this was not the case. It was a subconscious choice to present my arguments through an interpretively and narrative style. However, the choice came somewhat 'natural' as a continuation of my choice of interpretive analysis focused on meaning.

Table 3: Design for the PhD project

Phases	Research question/objectives	Methods	Data	Analysis	Main results
Phase I. Identifying knowledge and needs of PC in HF	What characterizes personal narrative interventions in hospital-based palliative care?	International literature study following the guidelines for an integrative review	24 Quantitative or qualitative research articles	Systematic qualitative analysis with a narrative synthesis	Narrative interventions show clinical value in relieving psychosocial and existential suffering. However the included interventions cannot easily be integrated in a HF clinic.
	From a local context, what does it mean to live with HF and what needs of support do the patients express?	Local interview study through semi-structured individual interviews	6 interviews	Thematic analysis guided by narrative theory	Life with HF can be described as a Sisyphean struggle. Psychosocial and existential needs in everyday life with HF goes unacknowledged in standard HF treatment with a dominating professional perspective.
Phase II. Developing a general PC intervention in HF	Increase palliative care skills and knowledge in cardiology	Seminar focusing on palliative care to the heart failure patient Study trip to hospice			Enhanced an understanding of PC and the ability to identify PC needs. Formed a collaboration between PC and cardiology
	Generate new insight to develop a palliative care intervention in a cardiac hospital setting	Interdisciplinary workshop based on dialogue	Field notes gathered from workshop sessions	Thematic analysis guided by dialogical theory	PC must be initiated from the patient's perspective and wishes. One way of doing this is through the S' approach. However, this requires organizational efforts and adaptation to the specific cardiac setting.
Phase III. Integrating the PC intervention	Piloting an integrated PC intervention in HF	Interview sessions inspired by the World café method	1 patient interview + 1 group dialogue with the interdisciplinary project group	Qualitative inspired analysis guided by Kvale and content summary	The PC intervention showed meaningful to the patient and brought a sense of safety in an uncertain life with HF. The PC intervention provided a setting where professionals could support the HF patient with not only clinical symptoms but also existential issues.
Phase IV. Evaluating the PC intervention	To explore the content of the sessions	Observational design	Approximately 37 hours of participatory observations	Thematic analysis guided by theory on the S' approach	Sessions showed capable of joining patient and professional perspectives. Session integrated the different S' dimensions although the nurses did not necessarily follow the structure of the S' question guide.
	What does the HF patient find significant in integrated PC sessions using a narrative approach?	Local interview study through semi-structured individual interviews	12 interviews	Thematic analysis guided by narrative theory	The person-centred S' approach integrated in HF sessions made patients feel a calm and safe atmosphere, showed an ability to bring comfort to lived physical, psychosocial and existential issues and integrated treatment in patients everyday life.
	Evaluation from the interdisciplinary group	Feedback group meeting	Group dialogue	Qualitative content summary	PC with a narrative approach is acceptable but feasibility is still an issue.

Ethical Considerations

ICNE, The International Centre for Nursing Ethics have articulated ethical considerations in international nursing research.[101] They argue for five guiding principles: 1) respect for persons, 2) beneficence, 3) justice, 4) respect for community, and 5) contextual caring. The first three are central in western bioethics as explicit in The Declaration of Helsinki[102] and The Code of ethics for nurses from the ICN, International Council of Nurses.[103] These involves the effort to assure that research is conducted with respect to personhood, recognizing human dignity and autonomy while aiming to do good without jeopardizing the person's health in any way. Furthermore, justice is about treating participants fairly and distribute benefits and burdens fair at individual and community level.[101]

It has been argued that special ethical consideration should be taken in AR research.[104] Respect for the person is often addressed through informed consent as it was in this PhD. However, in AR this consideration expands to include the conviction that every person have the capacity to contribute to the process of knowledge. Power plays an essential role in this and knowing the power relationships within a group can be beneficial.[104] A way to understand roles and power in AR is through the work of action researchers John Kretzman and John McKnight, who developed a theory of assets-based community development.[105] They argue that a primary building block for change is located within the community and under the control of the community. Another building block is located outside the community and outside the control of the community.[105]

The last two goes beyond the standard of western bioethics by including research settings that requires considerations for a larger community context. ICNE argues that the forth principle is a reaction to the historical focus on the individual rights in western research ethics. A predominant focus on the individual can lead to an overemphasis on rights and a neglect of relationships and responsibilities, whereas always prioritizing the common good over the good of the individual can lead to oppression.[101] The AR researcher needs to be very careful when balancing this act between individual and collective action.[104]

The last principle is about contextual caring and a concern for coercion. In AR as in qualitative research, the gold standard of being objective is rejected, and research is conducted in the context of relationships.[104] Contextual caring entails a personal caring concern for participants and is closely bound to an individual's emotional reactions and founded in the researcher's personal values.[101]

Patients receiving PC is considered vulnerable in PC research literature.[106] Furthermore, 'palliative care' in health care is often associated with death and dying and can be challenging to talk about. Literature on ethical challenges of research collaborating with patients point to the fact that patients can experience overburden by their responsibilities,[107] or engagement can cause patients harm as participation might include sensitive topics or cause 'a resurfacing of bad memories'.[108] A recent scoping review[108] recommend that researchers should only select patients in stable health conditions and ensure a meaningful implication and involvement of patients.

We have used both the Declaration of Helsinki[102] and the ICN code of ethics[103] to discuss ethical concerns throughout the study. In addition, we have turned to ethical considerations specific for AR.[104]

Reflections on Ethical Issues in This Project

As mentioned, a way to ensure respect for the persons participating is through informed consent. The patients participating in this study all received information about the study in writing and were encouraged to talk it over with family, professionals, others or myself before deciding on participating (see Appendix A). Before the first session, patients signed an informed consent form (see Appendix B).

In addition, I chose to ask for consent ongoing. Before a session in the HF clinic, I would ask for permission to sit in the corner and observe. As patients often had relatives with them, I ensured that they also gave their oral consent. Before interviews, I would call the patients and ensure that they still agreed to participate.

The professional participants were invited to join the project in collaboration with leading health personal. The professionals were informed of both project aim, studies and what it would entail for them to participate. Their consent was not written.

In this AR inspired study both patients and professionals have valuable expertise and the capacity to produce knowledge,[104] making it evident that both groups should be involved. However, it has been argued that the increased demand of patient engagement must not be the sole rational for involving patients in research as this might lead to a merely symbolic engagement.[108,109] In addition, I had to consider the logistic restrictions of this project. I did not have a large AR research group available, nor did I have unlimited resources. Therefore it was necessary to discuss how much patients and professionals should be involved and at what level.

The rational to involve patients in our study was based on their experience as persons living with and being treated for HF. We needed the patients to identify the problem and evaluate our intervention, but we also needed to consider the ethical dilemmas of conduction research with vulnerable patients. The recommendation on only selecting patient in stabile health condition was not possible, as this study involved life-threatening illness with an unpredictable trajectory. In addition, as shown in the background section fatigue and anxiety is a real problem for people with HF, it would be unethical to convince patients to participate in multiple project meetings[108]. I therefor chose to include patients at strategic points in the project and ensure that their voices were acknowledged throughout the project. An example is how patients' narratives guided the workshop and development of the PC intervention, as I will present in a later chapter.

As suggested in the background section, the discourse and understanding on HF does not necessarily involve death as an outcome. On the other hand, PC is understood as a terminal care for the dying person. This meant that ethical considerations on offering PC in the beginning of a HF trajectory had to be discussed. In addition, during my initial conversations with HF patients, it became clear that they did not recognize the term ‘palliative care’. I therefore chose to focus less on this term in conversations with patients. Patients did not always recognize even the term ‘heart failure’, so I tried to use their own words instead. Often these were simply ‘heart troubles’, ‘heart condition’ or ‘reduced heart function’.

An example of a consideration of power and individual vs. common good is from the pilot. I, as researcher had the idea that we would use the world café method[88] joining professionals and patients in the evaluation process. However, this was changed as a patient expressed her concern for a joint debate. It can be interpreted, that this patient had defined the roles of the professionals as an authority, and the role of patient was less powerful. Turning to ethical considerations on respect for person and community I decided that in this case another method could be used instead ensuring respect for the individual patient. I will elaborate on other power issues in the chapter Discussion on method.

The rationale to involve professionals was based on their specific roles in the treatment of HF and their understanding of HF or PC. We needed professionals to produce knowledge on how to address the problem and develop an intervention fitting for this specific real-life setting.

Although professionals had been involved in developing the PC intervention and understood the methods involved, one nurse later shared a concern. During my observations, she asked a question that reflected an unease that I would be evaluating her personally. I ensured her that my emphasis was not on her person neither personally or professionally. My focus was on the content of sessions. This made her feel more at ease.

An example of a discussion during the research process regarded the narrative approach in the PC intervention. Would this approach be to confronting? Does patients want to share from their everyday life with strangers? Is it okay to talk about death with people who might very well have years before death is eminent? I looked for answers from other researchers, both in literature and through discussions face to face and discussed it with the project group. Their understanding informed my understanding, and I believe that exploring the patient experience is not only essential; it is ethically the right thing to do. Both international and national literature recommends integration of PC at every step of the disease progression as PC needs emerge.[39,59] In order to recognise these PC needs we must explore patients experiences. Furthermore, it is a given that a person-centred approach recognizes the person involved.

In qualitative research, it is considered good practice to add some kind of participant validation. How, is a matter of epistemological considerations,[110,111] but it might be argued that in AR this is elementary, as the research process is shared by participants and researcher. During the project, we had several meetings in the project group consisting of interdisciplinary professionals (more on this in the Pre-phase chapter). This enabled a back and forth discussion on findings and interpretations. To give an example, in the development phase, I provided the professionals with a synthesis of findings from the first part of the workshop. This synthesis was used to continue the development of the PC intervention, but also provided the professionals with the opportunity to correct me if, I had misunderstood something.

In the studies where participants were patients, I chose another approach. In interpretive research, the dialogue between researcher and participant is part of the hermeneutic process towards understanding. I could use this quite literally across my observations and interviews. The participant observations were validated in my interviews as I could ask about the situations to get a deeper understanding. In addition, I allowed for spontaneous conversations during participant observations. On one occasion a participant asked to see my notes *"just out of curiosity"* she said. Her feedback was a smile and a nod, which I believed authenticated my observations. Even within the interview itself, I chose to ask if I was unsure of the meaning of a statement.

The ethical principles of privacy and confidentiality in the Declaration of Helsinki were applied through the study. However, confidentially is not an easy guide when it comes to qualitative research.[112] As I was aiming to uncover lived experiences, my data included observations and interviews. These holds the subjective experience of participants and their stories were analysed to gain insight. This was evident during the workshop in the development phase, were I presented patients narratives to the professionals. However, I presented the narratives with as little characteristics as possible to avoid recognition of the patients.

Confidentiality proved even more difficult in regards to the professionals. Their involvement in this project were known in the department and I could not guarantee that they remained anonymous to their colleagues. In dissemination of results from the workshop it was even necessary to provide the reader with knowledge on the participants profession, as this showed that an interdisciplinary approach was necessary. However, both patients and professionals agreed that I could disseminate findings including quotes both locally and internationally, and no authentic names or unnecessary details were presented.

Ethical considerations are very important and considerations on formal approval is obligatory. The study protocol was send to the Regional research ethics committee, and they ruled that a formal approval was not required due to the nature of the study. The study was registered (REG-108-2017) and approved by the Danish Data protection agency (see Appendix C) as well as by the involved departments at the hospital.

Pre-phase

This pre-phase can be understood as the construction level of the AR cycle. As shared in the foreword this project started with a clinical frustration that HF patients had unmet needs. Also, as mentioned earlier the literature confirms the severity of HF[7,8] and the problems with foreseeing the illness trajectory.[17–19] The clinical symptoms and the unpredictable nature of HF often manifest in psychosocial needs throughout the illness trajectory,[34] for which PC is appropriate.[35] However, the access to PC is still favouring cancer patients[13,14] and knowledge on how and when to offer PC to the HF patient is missing,

Action research involving key actors have been argued to be part of the growing field of implementation research with an aim to: "*understand and work in 'real world' or usual practice settings, paying particular attention to the audience that will use the research, the context in which implementation occurs, and the factors that influence implementation".*[113 pg. 4]

These arguments formed the wish to integrate PC in the standard HF treatment and for working together with patients and professionals to do so.

The steps of articulating a research protocol, apply for ethical approval, obtain funding and enrol in the PhD school were supported by peers from REHPA, The Danish Knowledge Centre for Rehabilitation and Palliative Care as well as PROgrez, a research group at Næstved, Slagelse and Ringsted hospitals. A supervising partnership was formed between REHPA, PROgrez and the HF clinic.

Visiting the Heart Failure Clinic

The setting for most of this PhD study included the standard treatment sessions at the outpatient HF clinic. The standardized treatment is informed by the Danish Health Authory[51] and main elements are shown in Figure 4.

Although I know many of the professionals at the HF clinic, due to earlier employment at the cardiac hospital ward, I am not accustomed to this specific setting. Hence, to get a sense of the setting and establish a relation with professionals, I spend a few days at the HF clinic before commencing any studies. Data were not gathered systematically, but rather through informal talks and simply being present. Reflective notes were made during or after observation. No systematic analysis were carried through, only reflections as to what milieu I would be conducting research in.

During these days at the clinic, I observed challenges with complying with the regional guidelines. As an example, patients sometimes waited up to 12 weeks before starting the standard treatment sessions although their doctor had prescribed follow-up within two weeks. Another challenge observed was time with the patients. On occasion, a session with a nurse lasted no more than 10 minutes. The nurse conveyed feeling stressed and frustrated. Time constrictions meant that they prioritized medical treatment and physical symptoms over other issues.

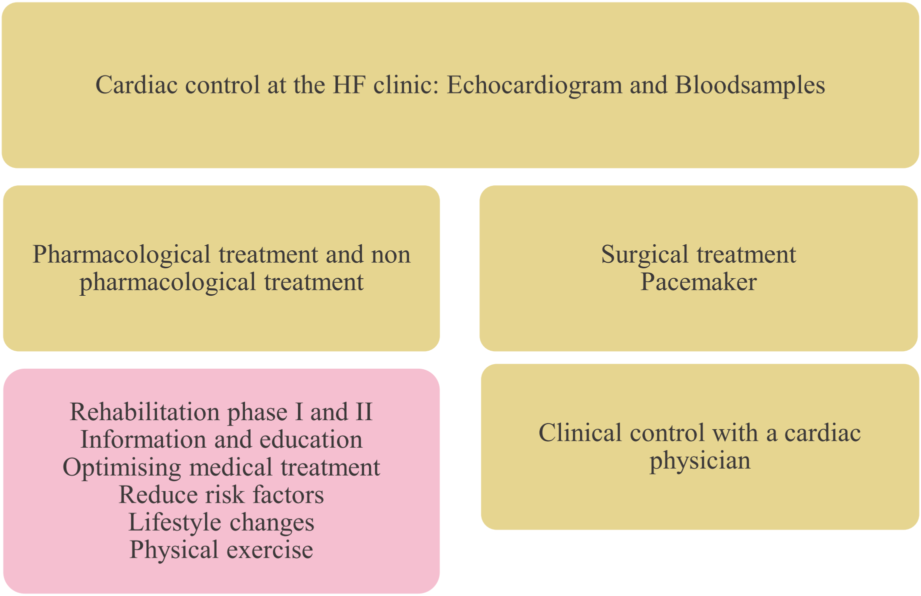


Figure 4: Standardized treatment informed by The Danish Health Authority[51]

A nurse told me that it was important to quickly establish a relation with the patient and provide them with information that would make them able to act on dangerous signals or symptoms. From what I saw, the nurses were quite good at this. They greeted patients with a friendly attitude but also with focus on professional priorities. Sometimes this led to a feeling that psychosocial needs were not recognized or accommodated. The professionals' experiences of not recognizing psychosocial needs of the HF patient was consistent with the patients' experiences.

During my visits at the clinic, it became clear that the professionals had a strong clinical and theoretical foundation in cardiology. PC on the other hand, was understood as terminal care. Hence, more PC knowledge and competences were needed.

Putting Together a Project Group

When establishing a project group I looked for guidance in both AR, PC and HF theory. It is essential to address the organizational structure when conducting AR.[114] The reason is that relevant actors must be identified and included in research phases. These relevant actors were informed through both PC and HF theory promoting an interdisciplinary approach.

The project group consisted of a cardiologist, two cardiac nurses from the clinic, one cardiac nurse from the hospital ward, a nurse leader from PC, a physiotherapist, a hospital chaplain and myself. In addition, an occupational therapist was invited, but declined and a dietician was invited but never responded. Later, two PC nurses and a social worker would join, the nurse from the cardiac ward as well as the PC leading nurse pulled out and the physiotherapist changed several times. In the case of the physiotherapist, the change was due to organizational structure in the department of physiotherapy. The individual professionals were initially approached directly by me but chosen in collaboration with their leaders.

As mentioned, I chose to only include professionals in the project group. Besides the explanation provided under ethical considerations one more should be mentioned. The professionals in the group were the same nurses, doctor and physiotherapist that patients could meet in their treatment. Studies have argued that this can create a conflicting role.[108,115] To create a sense of distance I therefore, chose to divide professionals and patients.

Another argument was the consideration that research must not do harm.[102] Although difficult to imagine I felt obliged to ensure that patients could share their experience without worrying that it would affect their treatment or relationship with their nurse or physician. A patient stating that she would feel very uncomfortable if she had to evaluate the intervention in a shared group with professionals later supported this decision.

Summary of Pre-phase

The pre-phase provided two main points for the further process: 1) A requirement of integrating PC with its person-centred approach in current standard treatment sessions. 2) Building additional understanding of PC. Furthermore, this phase supported the arguments of AR inspiring the overall methodology as nurses showed frustrations with current sessions and a desire to change practice.

Phase I – Identification

Table 4: Design for phase I

Phase	Research question/objectives	Methods	Data	Analysis
Phase I. Identifying knowledge and needs of PC in HF	What characterizes personal narrative interventions in hospital-based palliative care?	International literature study following the guidelines for an integrative review	24 Quantitative or qualitative research articles	Systematic qualitative analysis with a narrative synthesis
	From a local context, what does it mean to live with HF and what needs of support do the patients express?	Local interview study through semi-structured individual interviews	6 interviews	Thematic analysis guided by narrative theory

The aim of this first phase was to understand needs for people living with HF in our local setting and to explore characteristics and feasibility of narrative interventions in a hospital setting. Details of the studies can be found in Papers I and II, while a visual overview of design is portrayed in Table 4. This chapter will provide a summary on the studies with focus on the process and findings for phase II.

Assimilating Current Knowledge Through an Integrative Review

As mentioned, I wanted to start the PhD process with a review study to assimilate current scientific knowledge on narrative interventions for our supplementary phases. For this, I chose the integrative review design.[84] This design allowed us to examine the characteristics of narrative interventions in PC and provided a synthesis of the literature. This section provide an outline of the study presented in Paper I.

Data Collection and Search Strategy

After discussing possible search terms with a research librarian, I performed an initial search through PubMed and used this to adjust the search terms and strategy (see Table 5). PudMed, Embase, Cinahl, PsychInfo, SocINDEX and Scopus was chosen as the most relevant databases due to their domain interest.

Inclusion criteria for articles were as follows: 1) present findings from primary research; 2) include palliative care interventions using personal narrative; 3) research conducted in a hospital setting; and 4) include patients with a life-threatening illness who needed palliative care.

As recommended in order to minimize bias, two researchers reviewed each article. Articles were divided among the three reviewers for individual screening and critical assessment. We then critically assessed full-text articles based on the eligibility criteria followed by a discussion of research rigor using the Critical Appraisal Skills Program CASP.[116]

Table 5: Search strategy terms (Roikjær et al. 2019)

#1	Hospice Care [Mesh, Title/Abstract]
#2	Terminal Care [Mesh, Title/Abstract]
#3	Palliative Medicine [Mesh, Title/Abstract]
#4	Palliative Care [Mesh, Title/Abstract]
#5	Supportive Car* [Title/Abstract]
#6	Advance Care Planning [Mesh, Title/Abstract]
#7	End of life care [Title/Abstract]
#8	Palliative care nursing [Mesh, Title/Abstract]
#9	Psychosocial Support [Mesh, Title/Abstract]
#10	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9
#11	Narrative Therapy [Mesh, Title/Abstract]
#12	Narrative Method* [Title/Abstract]
#13	Narrative approach* [Title/Abstract]
#14	Narrative design* Title/Abstract]
#15	Narrative intervention* [Title/Abstract]
#16	Narrative theor* [Title/Abstract]
#17	A good death [Title/Abstract]
#18	Living and dying [Title/Abstract]
#19	Dignity therapy [Title/Abstract]
#20	Story telling [Title/Abstract]
#21	Life review* [Title/Abstract]
#22	#11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21
#23	#10 AND #22

Data Analysis

Inspired by Miles et al.,[85] we followed the steps of data reduction, data display, data comparison, conclusion drawing and verification. The data reduction was managed by dividing the primary sources into the following subgroups: the voice of the patients; feasibility and acceptability; and effect and efficacy. Each subgroup were analyzed thematically and finally the findings were summarized and presented in a narrative style.[84]

The first author and co-authors independently extracted data with a previously designed and piloted data extraction tool. We extracted information on author, year, participants, design, setting, methods and results from each included paper. Further, we extracted data on intervention characteristics like framework, facilitator, place and ethical considerations.

Findings

Out of 480 articles, we found 24 eligible for this review: eight qualitative, 14 quantitative and two mixed methods. The articles provided evidence on the interventions dignity therapy, legacy building, outlook, short-term life review and life review.

Data analysis resulted in five themes: ‘Core principles’, ‘Theoretical framework’, ‘Content of narrative’, ‘Outcome’ and finally ‘Acceptability and Feasibility’.

Core principles included a main objective of addressing psychosocial and existential suffering. All studies used a procedure manual and a facilitator that guided the patient on reflecting on their life and current situation for meaning making. Nearly all were audio recorded and transcribed into a version that would then be given to the patient.

The theme of Theoretical framework included the findings of interventions as brief psychotherapeutic sessions based on reminiscence theory and empirical work on either dignity or end-of-life experience. All interventions have a sense of meaning as a core concept.

Six studies explored the content of the patients’ narrative. These narratives includes stories of upbringing, accomplishments, defining events, lessons learned, regrets, legacy and advice to loved ones.

Outcome of the studies was measured through different methods. Qualitative evidence supported clinical application for patients nearing death as a means of enhancing their quality of life. However, statistical significance on psychosocial and existential distress was not proven.

The acceptability of narrative interventions was positive and consistent, but feasibility had several challenges. Recruitment and dropout were the main problems. The participants in the included studies were primarily receiving specialized PC in their terminal phase. The few studies that included a general setting found it difficult to adjust to the practices of that specific setting.

Reflections for Phase II

What we learned from this review was that although we had gathered evidence from a hospital setting, we had insufficient evidence from a general PC setting. We also found that the interventions assessed were very resource consuming and problematic in terms of flexibility to practice. With the aim of integrating our PC approach in the standard treatment sessions, we needed to find a more adaptable method.

As I was conducting research for my PhD protocol, I came across the S’ approach in PC and I immediately was attracted to this. It acknowledged the use of narratives as a way to apply a person-centred approach of PC and had been tried in a clinical setting.[117] This approach was developed by the Swedish Professor of Palliative Care Britt-Marie Ternestedt and colleagues to ensure individualized person-centred care and a good death.[118] They found inspiration in the works on an ‘appropriate death’ conducted by Psychiatrist Avery D Weisman. His work build on six questions that explored psychological and social information about the life of recently deceased persons. From this model, Ternestedt and colleagues formed the S’ approach. The conception is that ‘Symptom control’, ‘Self-image’, ‘Self-determination’, ‘Social relationships’, ‘Strategy for the future’ and ‘Sense of coherence’ are all criteria for a good death. By exploring resources and/or needs in each of these domains, clinicians can reflect on how to best support their patient. In short, the S' approach acknowledges a need to know more about the patients to better support their needs.

In Denmark, this approach have been promoted by hospice nurse Annegrethe Venborg.[119] She defines the S' Dimensions like this: Symptom control aims to provide relief according to patients' needs. Needs can be assessed through screening tools like the EORTC QLQ-C15-PAL[120]. Self-image is how the patient describe himself, and how illness have affected this image. Self-determination involves wishes and expectations on decision-making. Social relationships are the relations the patient finds important and how these relations support or challenge life with illness. Strategy for the future is how (and if) the patient accept his new situation, does he need practical support or guidance? Last, Sense of coherence involves the need to experience coherence and meaning with everyday life. This entails existential needs. At Hospice Djursland, Venborg and colleagues have developed an inspirational S' question guide to help facilitate a personal story for each S' dimension.[119pg155]

The S' approach is a model translating a holistic and person-centred PC approach to a clinical setting. Hence, the S' approach accept that documentation is an essential part of clinical practice and suggest a checklist for how to work with the six S' domains in PC. In this approach, I found a method that focused on the person suffering from life-threatening illness at the end of life.

I as researcher, decided that we would use the S' approach as a starting point for the development of our intervention. However, research on the S' approach originates primarily from a specialised PC setting and considerations about transferability into a general hospital setting was required.

Identifying Needs Through an Interview Study

As this PhD strive to develop meaningful integrated PC for patients with HF, an important step was to explore the patients' subjective experiences of living with HF. I present the findings from this study in Paper II, but provide the reader with a summary of the methods and process as well as additional reflections in this section.

Setting and Participants

The setting of this study was different from the others as patients had been living with HF long enough to have been hospitalized at least two times. Patients were recruited while hospitalized due to HF. Using convenience yet purposeful sampling a nurse at the ward invited patients to participate in an interview study to better understand life with HF. Over a period of two weeks, the recruiting nurse asked patients admitted at her station with the diagnosis HF. Besides talking the study over with the cardiac nurse, the patients were given an information sheet and were encouraged to ask questions if any emerged. Before the interview, patients signed an informed consent form.

Inclusion criteria were: 1) Admission due to HF at least two times 2) No cognitive impairment 3) A willingness to share from everyday life with HF 4) Not currently receiving palliative care.

Unfortunately, the nurse did not keep a detailed record of why patients refused to participate, but the overall reasons were 'not interested' or 'to tired'. The reason 'to tired' could literally mean fatigue due to the HF but it could also mean a feeling of being overwhelmed and a need to prioritise. In all 10 patients were invited and six accepted participation. All but one interview took place at the patients' homes. As I wanted patients to share from their life with HF as well as treatment, I found it best to distance myself from the hospital, providing a familiar place to share experiences either positive of negative.

Data Collection

For this study, I used semi-structured interviews. A Danish interview guide is presented in Appendix D. The interview style was open and inviting, providing an atmosphere that would enable the patient to tell their stories. I allowed relatively long pauses to avoid interrupting the patient's train of thought. I began and ended each interview with a few minutes to thank the patient for participating. In some cases, these minutes were extended with small talk to establish trust. These were not recorded. Interviews had a mean duration of 44 minutes with a range from 28 minutes to one hour and 32 minutes.

Interviews were audio recorded and transcribed ad verbatim. In addition, as I transcribed the interviews myself it allowed for simultaneous notes in the margin. These notes could concern the atmosphere, tone of voice or tears to name a few. These notes were helpful in the analysis as their provided me with a feeling of the setting and atmosphere during the interviews.

Data Analysis

My analytical approach was described in a former chapter, and will only be briefly mentioned here. The semi-structured interview guide informed data analysis that followed a qualitative interpretive approach to data analysis and presentation described by Kvale & Brinkmann.[121] Data was coded and analysed solely by me. Themes were derived from the coded data and later themes and my interpretation of meaning were discussed with supervisors and analyzed with theory.

One example is the theme of 'Unacknowledged psychosocial and existential needs'. This theme was guided by my presupposition and semi-structured interview guide, but an interpretation of why these needs went unacknowledged were derived through theory. Arthur Frank[77] provided me with an understanding that the illness narrative can help patients find their way in a suddenly foreign landscape. But, patients didn't share their narrative with the professionals, and so they were left with unacknowledged needs.

Findings

Four central themes were found during the analysis: Understanding heart failure, A Sisyphean struggle with exhausting cycles of relapse and progress, Difficulties adjusting to limitations and last, Unacknowledged psychosocial and existential needs.

The first theme disclosed that patients had a hard time explaining both the diagnosis HF as well as life with HF and often attributed age for their fatigue or shortness of breath. Patients understood their HF illness through a sense of loss and challenges and not through diagnoses or clinical symptoms. In addition, they often had other diagnoses intertwined in their illness experience.

The Sisyphean theme conveyed the shared challenge of overcoming a relapse, both physically and mentally. Often the acute phase of treatment was a positive encounter. Professionals were competent and acted swift and with authority. However, patients spoke of surprise when their second event occurred as they thought they were successfully treated. If a third event occurred, patients felt disheartened as one patient conveyed with these words:

> *"That adversity I would say - it is the hardest to endure" HFp1*

These events made it difficult for the patients to balance a life between fear of a new event and a need to live life, leading into the theme: *Difficulties adjusting to limitations*. However, patients experienced no room to talk about existential or psychosocial challenges and felt alone with these, as conveyed in the last theme.

Again inspired by Arthur Frank, Illness always calls for a story but what happens when patients can't share their story? This quote show how a patient perceived her everyday psychosocial issues to be without value for the nurse and treatment:

> *"They can't use that, can they? - it's not right to come and talk about these things - at least it doesn't feel like that" HFp2*

I interpreted this quote as the dominating disease perspective being projected onto the patient. She did not feel that it was okay to talk about her psychosocial troubles in this setting. In my understanding of Kleinman, if the patient perspective of illness is neglected, the treatment can lose meaning for the patient. An outcome can be an unsuccessful integration of treatment and everyday life with HF.

These findings were supported from other studies on life with HF,[122,123] and argumentation for an approach that allowed for existential and psychosocial issues and facilitated a more nuanced understanding of HF was formed.

Additional Reflections

One interview was conducted at the hospital by the patient’s request, as he was still hospitalized. His story presented differently than the others. Using Franks theory of narratives I interpreted this interview as a chaos narrative.[77] The patient had difficulties structuring his story and it felt like he said whatever came to mind. Again turning to Frank this is because this patient was in the midst of the chaos of illness. It could have been interesting to interview this patient again, but he died of HF.

Summary of Insights for Phase II

The literature showed that a narrative approach proved clinical valuable in relieving existential and psychosocial suffering and was acceptable to patients. However, many resources went into conducting and transcribing narrative sessions. This would not be feasible to integrate in current standard treatment session at our local hospital. However, the S’ approach seemed pragmatic and feasible. The interview study showed an understanding of living with HF as a continuous Sisyphean struggle and patients feeling alone with psychosocial and existential problems. Furthermore, this study showed how the dominating professional perspective in standardized HF treatment made the patient feel that a dialogue on problems that could not be translated into a clinical symptom, were not welcomed.

Phase II – Development

Table 6: Design for phase II

Phase	Research question/objectives	Methods	Data	Analysis
Phase II. Developing a general PC intervention in HF	Increase palliative care skills and knowledge in cardiology	Seminar focusing on palliative care to the heart failure patient Study trip to hospice		
	Generate new insights to develop a palliative care intervention in a cardiac hospital setting	Interdisciplinary workshop based on dialogue	Field notes from workshop sessions	Thematic analysis guided by dialogical theory

This second phase entails different levels and aims. On an overall PhD study level, we aimed to integrate PC in HF. A corresponding objective was to prepare professionals and the organization to integrate a PC approach including the patient perspective of life with HF.

On a method level, we aimed to develop an intervention that would meet principles and needs discovered concerning integrating PC in standard HF treatment as well as acknowledge existential and psychosocial needs by adapting a narrative approach.

The design and development was qualified through a seminar, a study trip and two workshops. This phase was undoubtedly the most challenging of this PhD, as I had no experience with leading a project group or with facilitating a workshop. This chapter will provide you with an overview of each step in the process as shown in Table 6. Paper III provides additional details on the workshops where tension between perspectives facilitated new insight.

Learning About Palliative Care

The unconstructive cycle of lack of PC competences and accessibility in cardiology were a necessary concern when planning action. We needed to address how to teach and inform professionals. Discussions with my supervisors inspired from AR theory formed the learning strategy, but later the workshop showed additional needs for communicative skills and supervision.

With this learning strategy we aimed to

- Provide professionals with an increased understanding of PC based on the WHO definition.
- Introduce the S’ approach as a clinical model in PC
- Enhance the ability to identify PC needs
- Form a collaboration between PC and cardiology

Seminar

Speaking with peers in the field of PC and cardiology, we came to realize that the lack of PC competences in cardiology (and vice versa) were not restricted to this local hospital, but rather shared by the whole region. In 2017 REHPA and I, had been involved in organising a national seminar in collaboration between the medical societies DSC, Danish Society of Cardiology and DSPaM, Danish Society of Palliative Medicine. [124] Unfortunately due to an implementation of a new IT system in the hospitals of Region Zealand, hospitals in this region were not able to join the national seminar. We therefore decided to arrange a one-day seminar for interdisciplinary professionals working in either palliative care or cardiology in Region Zealand inspired by DSC and DSPam.

Figure 5: Panel debate during seminar

The aim was to join and share research and clinical experience between cardiology and palliative medicine, to educate professionals about PC and provide an opportunity to discuss possibilities and limitations of integrating PC in a cardiac setting. The seminar became a joint adventure between the cardiac department at Slagelse hospital, the cardiac department at Roskilde University hospital and REHPA. Registered nurse Gitte Ingwersen and Postdoc Heidi Bergenholtz provided practical support during the phases of both planning and executing the seminar.

One hundred and four interdisciplinary professionals participated in the seminar and provided an important base for advances in PC for the HF patient. All participants from the project group (as described earlier) were present, either as audience or as presenters.

Besides research knowledge and clinical experiences, the seminar provided a platform for debate allowing for dialogue between perspectives from PC and cardiology (see Figure 5).

The program can be seen in Appendix E.

Study Trip

In order to develop clinical skills and knowledge on the content of PC, I arranged for the two intervention nurses to go on a one-day study trip to Hospice Djursland were the S' approach is implemented. Here the intervention nurses had a chance to see the approach in a clinical context and gather experiences. Before going, they each read the book by Annegrethe Venborg[119] providing them with a better understanding of the rationale of the S' approach. The book also provides a description of needs encountered when living with (and dying from) life-threatening illness. Furthermore, the book provides recommendations on how to identify and address these in PC. They each followed a nurse during her daily routine, met some of the patients and attended an interdisciplinary conference guided by the six S' dimensions. They also received inspirational material on how the S' approach could be applied in a clinical setting.

Reflections on Learning Strategy

Data on the learning strategy was not gathered systematically, but I will present our reflections. The combination of a seminar where current experiences and challenges across the region were shared and discussed, combined with a study trip to Hospice Djursland for developing a clinical experience of the S' approach, proved valuable. It enhanced an understanding of the need for PC in HF treatment and the ability to identify PC needs.

In regards to the seminar, our concerns (Gitte, Heidi and myself) were to balance a program for an interdisciplinary audience between two medical fields. A panel debate facilitated by clinical cases from members of the audience enabled our aim of joining perspectives from both medical fields. The seminar also had a direct positive outcome on this PhD, as a social worker and PC nurse present on the day ended up joining my interdisciplinary project group.

The study trip to Hospice Djursland received mixed evaluations from the two intervention nurses. Their main concern was the difference between the two settings. The hospice setting is organised to provide relief and care, whereas the setting at the HF clinic is organised to provide efficient medical treatment and cure. Would it even be possible to work with the S' approach in the HF setting? Once again this made me, as researcher, attentive to the fact that we would not be able to transfer the S' approach directly from a specialized setting to the HF clinic.

In hindsight, I should have been more attentive to prepare the nurses for the trip. However, the nurses did assemble material and experiences and shared their knowledge and understanding of the S' approach in the workshop.

Workshop Using Dialogue to Join Different Perspectives

The aim of the workshop was to generate insight for an integrated PC intervention, join different perspectives and enable relational engagement in the project group. This section will provide an overview of design and findings. For additional presentation of this study, please see Paper III.

Setting and Participants

The setting was a meeting room centrally located at Slagelse hospital. This venue was chosen due to convenience for participants to join, but it also provided an absence of context to either PC or cardiology. I organised the room with a large oval table in the middle and provided props like post-it notes and a projector for presentation. Furthermore, in order to set a warm and friendly atmosphere I provided coffee and tea as well as lunch and afternoon snacks.

Participants were the interdisciplinary professionals as described in the pre-phase section of forming a project group, eight in total. Patient were not involved, but findings from the interview study in phase one were presented with patients' narratives and quotes.

Data Collection and Analysis

As mentioned in the chapter on AR this study is based on the theory that tension can be used to facilitate a productive dialogue.[86] For the workshop, I found inspiration in Labonte's idea of using narratives to prompt a dialogue.[87]

Table 7: Workshop playbooks

Workshop 1 - playbook

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

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

10:30-11.30 The workshop manager presented an outline of the action research project, the overall aim of developing and integrating 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 presented the interview study with focus on patient narratives

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

Workshop 2 – playbook

09.00-09.30 Coffee and breakfast

09.30-10.00 The workshop manager presented 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 regard to designing the intervention are delegated

Table 7 provides an overview of the workshop playbooks. I opened the first part of the workshop with a presentation of preliminary findings from phase one supported by patients narratives. This presentation sparked a dialogue around *What happened? Why did it happen?* and *What can we learn from this?* The participants were encouraged to use examples from their clinical experience. The objective was to voice different perspectives on needs concerning PC in HF for a constructive dialogue.

The second part of the workshop began with the synthesis of generated insights from day one followed by a dialogue on *What can we do about it?* The objective here was to voice principles and ideas for developing a PC intervention and addressing PC needs in a HF clinic.

The data included a combination of observations and extracts of dialogue from the workshop. These were transcribed into fieldnotes. A thematic analysis focused on meaning was then undertaken.[97,121] The analysis was inductive and iterative but guided by the overall aim of producing knowledge for a new PC intervention (see Table 8). Furthermore, my new found understanding of Kleinman's theory on illness and disease[44] was used to understand and illustrate the different perspectives present in the data material whereas Tsoukas's theory on dialogue[86] was used in the discussion of findings. An example is the central theme of reframing. This exact term is borrowed from Tsoukas and captures the discourse used to push a constructive dialogue forward and build a bridge between the perspectives from cardiology and PC. In that sense, the themes were flexible up until dissemination as this allowed for a hermeneutic process not only based on my presupposition but also on theory.

Findings

The principal ideas for this PC intervention were: 1) To operationalize the WHO definition of PC, 2) To integrate patient and professional perspectives using dialogue and personal narratives, 3) To integrate the PC intervention in the standard treatment and care of the HF patient to enable largescale implementation.

The analysis derived three general themes: 'Recognition of differing perspectives', 'Building bridges between perspectives' and 'Planning action for general palliative care in heart failure treatment'.

Recognition of differing perspectives exposed a need to recognize and include the patient perspective in future general PC for HF. The analysis revealed that the professional outset for assessing problems and planning treatment came from a disease perspective. However, the professionals agreed that this was not sufficient as they sometimes experienced patients neglecting symptoms and problems due to HF. They decided that a meaningful PC intervention had to derive from patients' perspectives and needs.

Building bridges between perspectives uncovered a necessity to connect objectives and perspectives across HF treatment and PC as both had value in providing total care for the person suffering from HF.

Finally, the last theme included the perceived challenges of applying principles from PC in a cardiac setting. New insight, competence and interdisciplinarity were necessary in order to include the patient perspective and provide person-centred PC. However, this was not sufficient. It was argued, that nothing would change unless the project had organizational support.

Table 8: Example of derived themes of workshop data

Quotes	Central theme	General theme
‘We try to educate patients to take care of their disease’ (nurse 1). ‘Our main focus is to optimize medical treatment’ (nurse 2). ‘In physiotherapy we try to guide them [patients] in exercises aimed at their problems’ (physiotherapist).	A dominant perspective in a hospital setting	Recognition of differing perspective
‘Sometimes I feel like they only attend to please me’ (physiotherapist). ‘I just don’t understand why they don’t react. It’s like the alarm doesn’t ring’ (nurse 1).	Frustration of noncompliance	
'You are first and foremost **a person** with an illness - you are not the disease’ (chaplain). ‘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’ (chaplain). ‘People die as they have lived’ (PC nurse).	The patient perspective	
‘You have to go through your own recognition, and this happens through your emotions’ (chaplain). ‘A poem reads: at birth you cry and those around you smile. Live your life so that when you die you smile and those around you cry’ (nurse 1).	Reframing	Building bridges between perspectives
‘We cannot solve everyone's problems’ (PC nurse). ‘HF is more than clinical symptoms, and we need to argue that treatment does not end just because the medical treatment does’ (physician).	Adjusting objective	
‘I find it difficult to talk about death when treatment is just beginning’ (nurse 1). ‘There must be a call to a life that is still worth living’ (chaplain).	Setting	Planning action for general palliative care in heart failure treatment
‘We need lessons in communication’ (nurse 1). ‘I am unsure how to actually start the conversation’ (nurse 2). ‘The conversation has to be dialogue based’ (PC nurse).	Competences	
‘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).	Organization	

A main concern from the cardiac nurses were how to balance the sessions between hope and reality. The original inspirational question guide from the S' approach aimed to provide a good death for the terminal patient could not easily be transferred to this specific setting with newly diagnosed HF. The professionals argued for a focus on the patient's life with HF rather than on death and dying. However, a consideration for death as a possible outcome was necessary. They came to the agreement that the person-centred focus in the S' approach could support the inclusion of the patient perspective and bridge objectives from PC and HF treatment. Hence, they decided to keep the narrative S' approach as a foundation for the PC intervention including the person-centred dialogue and interdisciplinary conferences. The hospital chaplain took on the task of amending the inspirational questions to better fit the HF setting.

In addition, the nurse leader from PC argued to apply the EORTC QLQ-C15-PAL[120] questionnaire (see Appendix F. The EORTC QLQ-C15-PAL is defined as a patient reported outcome measure (PROM)[125] used in specialized palliative settings for assessing both physical and psychosocial symptoms and functioning. It is also used in research to measure outcome on quality of life. In a Danish setting it has been recommended as a clinical tool for cancer, chronic obstructive lung disease and HF.[126] The PC nurse argued that by incorporating the EORTC QLQ PAL-15 questionnaire from the specialized setting, we integrated the PC terminology and assessment of PC needs. In this context, the professionals agreed to include the EORTC QLQ-C15-PAL in the intervention to identify PC needs and screen for perceived quality of health. Before every session, the patient would be asked to fill out and bring the EORTC QLQ PAL-15 questionnaire.

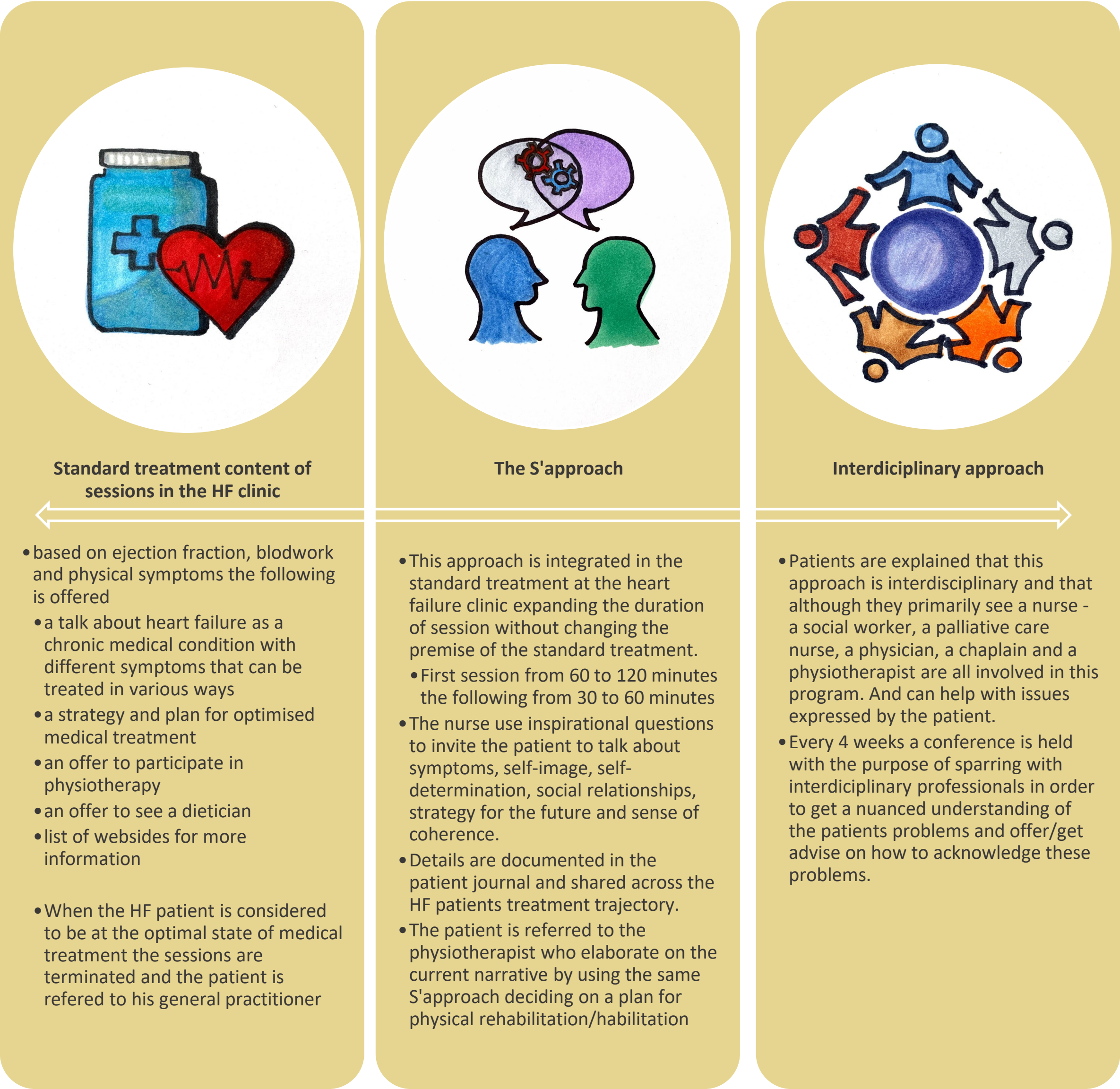
Designing a Palliative Care Intervention in a Heart Failure Clinic

I began to develop the PC intervention based on findings supporting an intervention centred on three key element: standardized HF treatment, S' approach sessions with nurses, and interdisciplinarity. When developing the intervention, I continuously compared my ideas with identified needs from patients and professionals. When questions or doubt arose, I called upon members of the project group or supervisors for support. An example is this: During the workshops, the cardiac nurses had requested supervision and additional skills in terms of communicative style. Hence, I planned an afternoon and asked the hospital chaplain to hold a practical session with focus on communication. Furthermore, the chaplain would provide supervision in the beginning of the integration process.

The narrative approach would be integrated in standard treatment trajectory that already holds the elements of a talk about clinical symptoms and HF, a plan for optimal medical treatment and rehabilitation.[51] In the standard sessions, patients are encouraged to bring a family member during sessions. This harmonizes with the family approach in PC and nurses made sure to invite family members for the integrated session. In addition, the sessions would apply the S' approach guided by the inspirational S' question sheet and the S' dimensions of Symptoms control, Self-image, Self-determination, Social relationships, Strategy for the future and Sense of coherence. The work from Hospice Djursland provided the foundation, but the question guide was adjusted by the hospital chaplain to fit the HF setting (see Appendix G). Integrated in the standard HF sessions, the nurse would invite the patients to share experiences, worries or thoughts from their lifeworld. These narratives would be compressed and recorded under S' dimensions in the patient's file. These files were accessible for an interdisciplinary team and the physiotherapist would continue documentation here. In addition, the EORTC QLQ-C15-PAL would be applied as a way to measure and record patient reported quality of life.

The first session was scheduled to take two hours making it possible for the intervention nurse to ask exploratory questions and provide the patient with an opportunity to share stories from his life. The following sessions would be scheduled for one hour and planed according to needs, either biomedical or needs of a more psychosocial or existential character. The amount of sessions for each patient would be formed by the standardized HF treatment plan where sessions at the clinic are concluded as soon as the medical treatment is finalized. However, as this was a research setting it allowed for some flexibility in terms of sessions. Both how often and on occasion the amount of sessions. An argument for offering an additional session could be an existential problem that needed further consideration.

Every four weeks an interdisciplinary conference would be held between the two cardiac intervention nurses, a physiotherapist, a cardiac physician, two PC nurses, the hospital chaplain and a social worker from a PC setting. This conference would commence with a presentation of new patients using the S' dimensions hereby ensuring to present both physical, psychosocial and existential problems. Different perspectives on the problems would facilitate an analysis and further strategy for care and treatment. The strategy would be documented in the patients file for further use. As integration into the standard sessions was a requirement, the sessions would end when the patient's program at the HF clinic completed and treatment transferred to the general practitioner (GP). The finished design for the PC intervention is shown in Figure 6.



Standard treatment content of sessions in the HF clinic

- based on ejection fraction, blodwork and physical symptoms the following is offered
  - a talk about heart failure as a chronic medical condition with different symptoms that can be treated in various ways
  - a strategy and plan for optimised medical treatment
  - an offer to participate in physiotherapy
  - an offer to see a dietician
  - list of websides for more information

  - When the HF patient is considered to be at the optimal state of medical treatment the sessions are terminated and the patient is refered to his general practitioner

The S'approach

- This approach is integrated in the standard treatment at the heart failure clinic expanding the duration of session without changing the premise of the standard treatment.
  - First session from 60 to 120 minutes the following from 30 to 60 minutes
- The nurse use inspirational questions to invite the patient to talk about symptoms, self-image, self-determination, social relationships, strategy for the future and sense of coherence.
- Details are documented in the patient journal and shared across the HF patients treatment trajectory.
- The patient is referred to the physiotherapist who elaborate on the current narrative by using the same S'approach deciding on a plan for physical rehabilitation/habilitation

Interdiciplinary approach

- Patients are explained that this approach is interdisciplinary and that although they primarily see a nurse - a social worker, a palliative care nurse, a physician, a chaplain and a physiotherapist are all involved in this program. And can help with issues expressed by the patient.
- Every 4 weeks a conference is held with the purpose of sparring with interdiciplinary professionals in order to get a nuanced understanding of the patients problems and offer/get advise on how to acknowledge these problems.

Figure 6: Integrated PC intervention

Phase III - Integration

Table 9: Design for phase III

Phase	**Research question/objectives**	**Methods**	**Data**	**Analysis**
Phase III. Integrating the PC intervention	Piloting an integrated PC approach in HF Integrating the final PC intervention	Interview sessions inspired by the World café method	1 patient interview + 1 group dialogue with the interdisciplinary project group	Qualitative analysis guided by Kvale for condensing meaning into units

Inspired by AR this project development was not a linear process, but rather a continuation of cycles providing insight for further action. Although I present each phase under individual headlines, the reality was that steps often overlapped. Furthermore, as I have chosen to pilot the intervention I have an additional step to present. This step forms a bridge between development and integration. I have chosen to present it under the integration process as settings and methods fits well there. The design for phase III is summarized in Table 9.

Piloting a Palliative Care Intervention

The purpose was to pilot the PC intervention hereby continuing the AR inspired cycle with an evaluation and new plan for action towards a meaningful PC intervention. In the bigger picture of this PhD, this was only a small part. However, as this process has not been described in any research paper, I have chosen to provide considerable detail in this section. The focus was to evaluate on experiences with the PC intervention and acceptability of a narrative approach in sessions. However, the pilot also enabled reflections on feasibility such as recruitment.

Setting and Participants for the Pilot

Inclusion criteria for participating in this pilot were: 1) a newly diagnose of HF 2) follow-up treatment at this local HF clinic 3) informed consent to participate in the PC intervention with integrated narrative sessions. The only exclusion criteria was if the patient already followed a PC offer due to other illness. In case patients did not speak Danish, we arranged for an interpreter.

In general, patients are referred to the HF clinic in two ways 1) through their GP or 2) through the cardiac ward at the hospital.[51] The patients might present themselves differently as one have experienced an acute event for which a hospital intervention was needed. The ones referred directly to the HF clinic, most likely had no acute event but rather symptoms evolving over time for which their GP had prescribed an echocardiogram at the HF clinic to either confirm or deny the suspicion of HF. We wanted to include both groups of patients hence; our recruitment strategy involved both settings.

Due to a tight time schedule, the recruitment period was fixed to December 2018. Supported by a physiotherapist at the cardiac ward and cardiologists at the HF clinic, eight patients were found eligible to participate. Each patient were provided with an information letter describing rationale and content of the study as well as the opportunity to talk the study over with me as a researcher. However, the recruitment was slow and only four patients agreed to participate. Most gave no reason to decline participation. One simply said *"I have nothing to talk about"*. All included participants were recruited from the cardiac ward. Unfortunately, two patients dropped out in the beginning of the pilot as shown in Table 10.

Table 10: Data on pilot participants

Participant	**Pp01**	**Pp02**	**Pp03**	**Pp04**
Sex	Female	Male	Female	Male
Age	84	56	84	72
Sessions	3	14	(1 phone session)	14
Dropout reason	'I can't find the strength'		'I just can't manage'	

The Pilot Intervention Protocol

As patients accepted the invitation to participate in the pilot, their first session was scheduled within two weeks as recommended. The patient received an automated electronic mail with details on when and where the sessions would occur, as it is standard procedure at the hospital. In addition, they received a letter inviting them to use the sessions to share issues or events from their life (see Appendix H). Finally, they received the EORTC QLQ-C15-PAL questionnaire,[127] which they were asked to fill out before the sessions. The nurse would transfer the patients' answers into the IT system and were able to follow the progress, stagnation or decline in patients perceived physical symptoms, activity and quality of health.

During the pilot, the hospital chaplain supervised sessions in order to provide feedback to the nurses on their communicative style and narrative approach.

The first follow-up sessions often occurred within one week, but as issues were talked over and the medical treatment adjusted with satisfaction the time between sessions became longer. The interdisciplinary conference was held every four weeks as described. However, due to clinical workload the nurse from the hospital ward and the cardiac physician were infrequently present.

Evaluating the Piloted Intervention

This action inspired evaluation was aimed to provide feedback on the pilot PC intervention in order to make informed decisions.[90] It was designed as a study in two parts using qualitative inquiry to explore experiences with the PC intervention. I will use this section to elaborate on methods and findings.

The evaluation was guided by the iterative motions for an AR analytical approach and inspired by the methodology of world café as defined by Brown and Isaacs.[88] The world café method uses dialogue within one group to spark dialogue in another group within the same setting. In the beginning of this pilot, a patient told me that she would not like such a setup, as she would feel at unease to share her thought directly with the professionals. We found it possible to shape the evaluation in respect to this. Therefore, we decided to keep the two groups divided and adapt the method to a focus group design instead. The program can be seen in Appendix I and Figure 7 shows the hospitable setting.

Figure 7: Hospitable setting

Part One – Patient Experience of the Pilot Palliative Care Intervention

In the first part, we wanted to give a voice to patients and hear their experiences with this pilot intervention. To elaborate, we wanted a personal account of patients' experiences, with the social interaction and reflection that takes place in a group.

Our ‘group’ altered into a dyad due to dropouts and then, on the day of interviews only one patient joined. This meant that we had the choice of cancelling or continuing with only one participant changing the method to individual semi-structured interview. We chose the latter, arguing that the patient’s experiences were essential to hear, and the timeline did not allow for rescheduling.

Data Collection and Analysis

A HF patient and two researchers were present. Charlotte Simonÿ facilitated the interview. I recorded the session through observational notes and with audio.

Immediately after the interview Simonÿ and I discussed quotes and extracts from the interview using Kvale's analysis approach with identifying themes supported by meaning units.[121] We wrote central themes on papers and scattered them on the conference table. Then we turned perspective from parts to whole and discussed how each theme presented the patients story. When we were content with our thematic analysis, we chose to go for a walk once again talking over the themes presented by the patient.

Findings from Part One of the Pilot

We found the central themes of 'Evaluation – Reflection', 'Dialogue – Solo performance', 'Uncertain – Insecure', 'Professionalism – Humanity', 'Value – Dignity' and 'Healing – Death' (see Figure 8).

The first thing the patient conveyed was how he felt uplifted by the intervention. He described a balance between professionalism and humanity making him feel recognized. He shared how uncertainty about the future and treatment made him insecure, but the nurse would listen to his stories of life, hardship and symptoms and support him. *"if there is anything else you need, then I will try to help, she said"* and that made him feel safe. He knew where to turn in case of doubt of problems and he knew that he was welcome.

The sessions with the nurse enabled a reflection on his life and he was determined to get through this. He spoke of his wife's death and nothing could be worse than that. He would get past this. The patient conveyed a continuum between healing and death and will not settle somewhere in between. He believes that body and psyche is connected and this same view was perceived in the sessions with the nurse.

However, the patient also pointed out that he needed the treatment to be evaluated along the way and for this; he preferred a session with a cardiologist. He expressed a heartfelt connection with the nurse and her ability to speak with him and not simply to him. She always met him with compassion and dignity. However, the dialogue was restricted to the nurse. This made it feel like a solo performance. He would like a greater interdisciplinary approach.

Part Two – Professionals Experience of the Pilot Palliative Care Intervention

The second part of this sub-study was a group dialogue with the interdisciplinary project group. Unfortunately, the chaplain and professionals from PC were not able to join due to other priorities and illness. In addition to professionals, we were two researchers present. Again, Charlotte Simonÿ facilitated the dialogue and I observed and recorded.

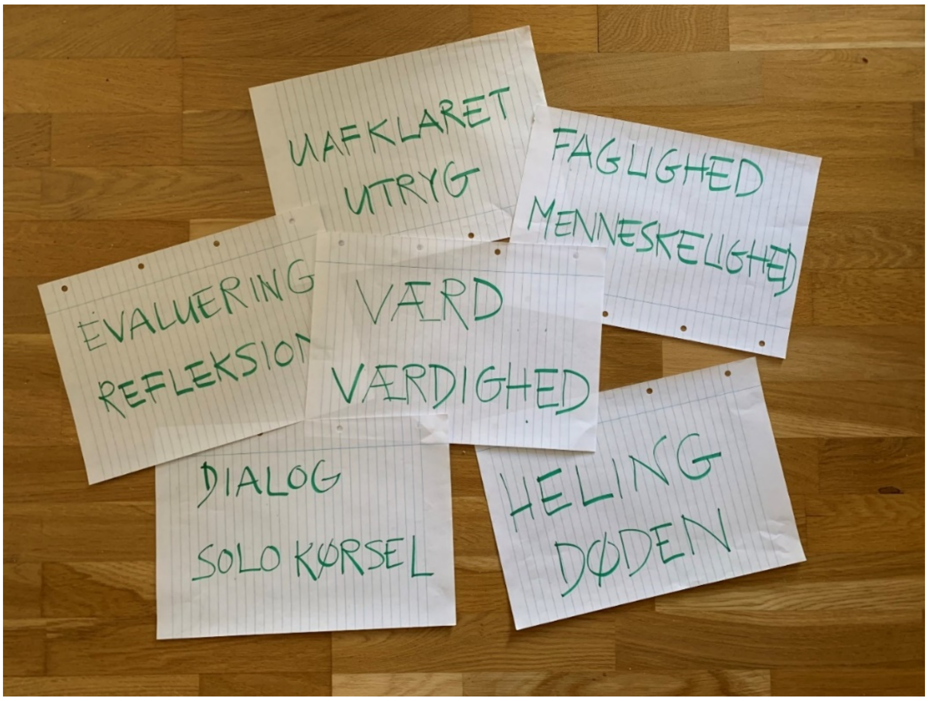


Figure 8: Themes from the patient interview

The aim was to bridge the experience between patient and professionals making them reflect on the intervention. Simonÿ presented the findings from the patient interview in a narrative style supported by the themes laid out on the table and asked the group to discuss each theme.

Data Collection and Analysis

Data was recorded through observational notes and audio recording. Themes derived through a qualitative content analysis. A summary of themes for planning action is presented as finding.

Findings from Part Two of the Pilot

As a whole the group perceived the patients experience to be both praise and critique. The critique was met with a need to explain. The praise with a frustration that this would not be possible in standard care. However, with a focus on *"what can we do about this?"*, the dialogue moved onward.

Two themes arose from this dialogue. One was 'Intervention vs standard care', the other 'Hope and death'.

The first theme included a dialogue on issues arisen from the patient interview. The patient experience of mono-disciplinarity was considered a necessary concern. PC is interdisciplinary and this intervention was designed to reflect that. The group decided to pay more attention to presenting the intervention with its interdisciplinary aspects.

The need for a session with a cardiac physician was already an option, and could be scheduled if necessary. However, such needs had to be recognised.

This theme also projected how the intervention patient had completely different conditions than patients receiving the standard HF treatment. The additional time allowed for patients to talk about life and worries enabling an integration of the patient perspective. The possibility to schedule sessions depending on the patients' needs was also quite different from standard procedure. The group interpreted that this must have an influence on whether or not the patient feels safe and cared for.

This leads into the theme of hope and death. The group discussed the experience of living with HF. Within this situation is the likelihood that patients will encounter scary events and existential challenge. This uncertainty cannot be removed. However, with the PC intervention professionals experienced being able to better identify and address existential issues and support healing. They experienced a need to recognise the existential struggle between a hope of healing and a fear of dying.

Summary of the Pilot Study

The evaluation part of this phase showed that the developed PC intervention was meaningful to the patient and brought a sense of safety in an uncertain life with HF. However, the patient conveyed the experience of a monodisciplinary approach, which needed to be addressed in the larger intervention study.

The professionals conveyed that the PC intervention provided a setting where they could support the HF patient with not only clinical symptoms but also existential issues. They also point to the fact that the premise of the intervention differs to that of the standard HF treatment trajectory. This is often the case in intervention studies. However, in this particular study, the aim is to develop PC practices in the HF clinic and sustainability is a concern. The professionals believed (and so did I) that when this approach of inviting the patient to share from his everyday life became more familiar the follow-up session would actually not take longer than the standard session. On more than one occasion a nurse told me that it was actually very difficult to 'turn off again' and she often applied this person-centred approach in her standard sessions. We therefore felt confident that this should be tried out with a larger group of patients.

Integrating a Palliative Care Intervention in a Heart Failure Clinic

In this part, the objective was to integrate the adjusted PC intervention in the HF clinic. The intervention occurred as in the pilot with a few alterations. Due to the patient experience of a monodisciplinary approach, the following changes were implemented: 1) when patients were invited to join the integrated PC intervention in HF treatment they were explained that the narrative sessions would be with the nurse. 2) The nurse would pay attention to how she presented the project as integrated PC and HF treatment involving an interdisciplinary group. She would focus on presenting it as a unit and be sure to express all elements as available to the patient.

Setting and Participants

Inclusion criteria for participating were adapted from the pilot: 1) a newly diagnose of HF 2) follow-up treatment at this local HF clinic in Slagelse 3) informed consent to participate in the integrated PC intervention 4) Not presently in a PC program.

During the pilot, we found that patients turned down the offer of participating, and we needed to change our recruitment strategy. Discussing the problem with my supervisor Henrik Ryde, he argued for a personal involvement from me as the researcher of the project, and although this provided two patients from the cardiac ward the recruitment were still going to slow.

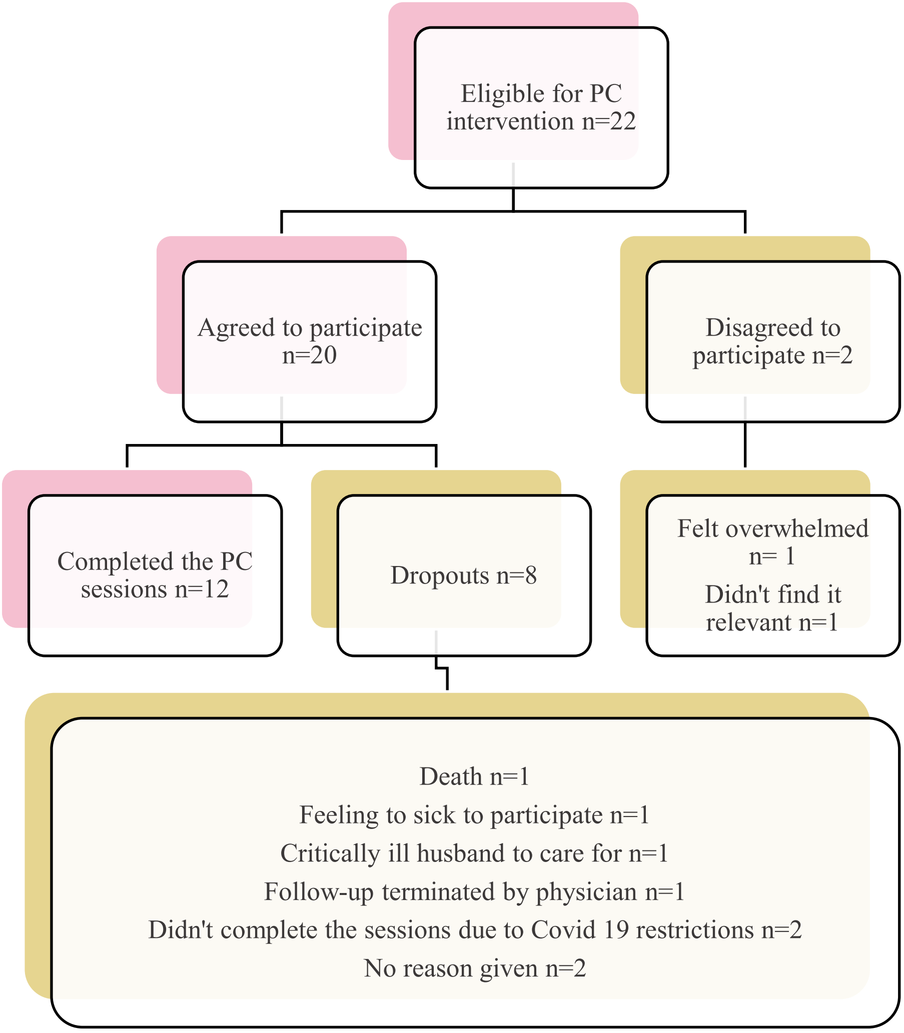


Figure 9: Inclusion for Integrated PC Intervention

Once again taking this up with the project group an intervention nurse suggested that I waited until patients were referred to the HF clinic. She would, then be able to provide a recruitment list that concurred with inclusion criteria. This was the key to unlocking recruitment, and provided patients from the different referral groups as mentioned in the pilot section.

In hindsight, it makes sense. When the physiotherapist or I approached the patients in the hospital, patients were overwhelmed and could not make a decision regarding future sessions. Their focus was on the acute treatment. However, when they had been home for a few days, they started considering the next step in their recovery.

Patients were recruited over six months from March to August 2019. I went through the list in consecutive order arranged by date of referral. I then approached patients by phone or in person, inviting them to join the integrated PC study. A letter with details on the study was given to the patients. They were encouraged to discuss potential pros and cons about participating with family, professionals or me before deciding. In all, 22 patients met the inclusion criteria, 20 agreed to participate in the PC intervention and 12 completed the intervention including the semi-structured interviews with me (see Figure 9).

Demographic data as well data on number of sessions and additional diagnosis is shown in Table 11.

Table 11: Data on intervention participants

Participant	**P1**	**P2**	**P3**	**P4**	**P5**	**P6**	**P7**	**P8**	**P9**	**P10**	**P11**	**P12**
Sex	F	M	F	M	M	M	M	F	F	M	M	M
Age	60s	50s	80s	70s	60s	50s	70s	70s	80s	40s	70s	70s
NYHA	III	I	II	I	II	I	II	I	III	II	II	I
EF	35%	25%	15%	40%	30%	35%	15%	25%	30%	20%	40%	25%
Married/ partner	Yes	No	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	yes
Other Diagnosis	MI	VAB AF	NST COL	BPH	NST	SCA	ASHD	NP	ASH DRI		CHD	AF HT
Sessions	10	13	7	7	5	3	8	13	10	7	6	6

MI= mitral insufficiency, EF= ejection fraction, VAB= valvula aortae bicuspidalis, AF=atrial fibrillation, NST=non ST elevation acute myocardial infarct, COL=chronical obstructive lung disease, BPH=benign prostate hyperplasia, SCA=sudden cardiac arrest, ASHD=arteriosclerotic heart disease, NP=nephropathy, RI= renal insufficiency, CHD=coronary heart disease, HT=hypertension

Phase IV - Evaluation

Table 12: Design for phase IV

Phase	Research question/objectives	Methods	Data	Analysis
Phase IV Evaluating the PC intervention	What does the HF patient find significant in integrated PC sessions using a narrative approach?	Local interview study through semi-structured individual interviews.	12 interviews	Thematic analysis guided by narrative theory
	To explore the content of the sessions	Observational design	Approximately 37 hours of participatory observations	Thematic analysis guided by theory on the S' approach
	Evaluation from interdisciplinary group	Feedback group meeting	1 hour group dialogue	Qualitative content summary

Inspired by Øvretveit's definitions on evaluating change, I took on a descriptive approach to explore the content of sessions in addition we evaluate on intentional change to organisation.[91] As shown in Table 12, I have applied the methods individual interview, participatory observations and dialogue. What patients found significant was the central objective hence, the main study. This study is presented in Paper IV and summarized in this chapter.

Participant Observation – Exploring the Sessions

The complexity of evaluating value in health research made us (my supervisors and myself) decide to include participant observations. The aim was to explore the patient experiences by observing what occurred during the PC sessions.[94]

I will present this study in the following sub-sections and include an extract from my field notes for transparency.

Settings and Participants

Participants in this study were the same as described in the previous section on integrating the PC intervention in standard HF treatment.

I had chosen to sit as a spectator in a corner of the nurse's office and told the patient that I would simply be observing and taking notes. As family members were often present, I asked for their permission to record the sessions.

The observations took place from April to December 2019 during integrated PC sessions at the HF clinic. I planned to be present in at least two sessions with each patient. However, one patient only had three sessions and I never accomplished observing sessions with him.

Data Collection and Analysis

Just under thirty-seven hours of observation accounts for the data for this study. I recorded data through notes and wrote descriptive field notes after each intervention session. As my focus was on activities and the person-centred approach, I chose a qualitative content analysis guided by the S' dimensions as well as our intervention protocol. For managing data, I used the software program Nvivo12 pro.[98] I will present findings in a narrative form supported by observations.

Findings

I found three themes corresponding to our PC intervention plan: 'Talking about life with HF', 'Talking about lived life' and 'Talking about medical treatment'.

Talking About Life with Heart Failure

The first session always initiated with a talk of the disease HF, patients' experiences leading up to the diagnosis and their thoughts on getting the diagnosis. This enabled an illness story and reflections on the patient's perspective of getting ill. It also provided an understanding of the strategies patients used to cope with HF. A strategy could be denial. One patient outright denies being ill, and bases her dismissal on the lack of symptoms. However, most accept the diagnosis and wants to find a way to balance life between the threat of illness and hope of life, as they know it. This following quote shows how nurses tried to provide information with hope:

> *"A lot of people get better. Fortunately, you don't have a lot of symptoms. However you are only 40 – we want to take care of your heart – it has to work for many more years" N1*

The following sessions often opened with *"how have you been doing?*" supported by the EORTC-QLQ-C15-PAL questionnaire. This allowed for stories from the patients everyday life. For example, one shared an experience from her birthday party. She had had an amazing time and had enjoyed being with her family and friend. She had even indulged in a glass of wine, but this had resulted in dizziness and a recognition that she had limitations. She finishes this sentence with a vibrant laughter. Her choice of opening with a joyful occasion is interesting. It might be a coincidence but it conveys something meaningful for her. The dimension of *Sense of coherence* is concerned with uncovering perspectives of existential and meaningful character. In this case, the patient seems quite able to find meaning and celebrate life despite illness.

Another patient shared an intensive feeling of fatigue and a continuous lurking anger, despite no objective clinical symptoms. This enabled a talk of symptoms and *Symptom control* in relations to everyday HF. Furthermore, this patient spoke with apparent sorrow about his daughter who were going through a devastating divorce. The nurse aided a reflection that these symptoms might also connect to this situation.

Venborg argues that *Symptom control* must consider the person within the patient defined by his or hers *Self-image, Self-determination, Social relationships, Strategy for the future and Sense of coherence*.[119] Our study confirmed this argument by showing that symptoms are complex and must be understood with consideration for the other S' dimensions. Through this narrative approach, patients appeared supported to share about themselves instead of being restricted to the clinical symptoms.

Talking About Lived Life

A second part of a session entailed talks of a more 'life story' character. As the first session was scheduled for two hours and the following for one hour, this provided time for the patient to share stories that reflected him or her as a person. This could be stories from childhood, adulthood or from times of hardship. The following is an extract from my data:

The patients starts talking about his childhood. It was a different time then, and children grew up early. He himself chose to move away from home when he was 13 to live at a boarding school. It was his own choice, he never felt pushed by his parents. However, he should have never done that. The bullying was terrible at that place. His tone of voice makes me think that he is indignant. He never were the bully but often the victim. He wish that he had stayed in the municipal school. Here he actually had a friend. They connected in first grade and have been friends ever since. His face lit up in a smile that quickly withered. The patient takes a deep sigh and continues: "or I had a friend". He lowers his head and pauses. Then he explains how the friend moved to Vancouver many years ago. They kept in contact over phone and mail, and remained friends. "He shot himself 3 years ago".

The room goes silent. Then the nurse says: "that must have been very difficult" and she continues by asking: "how do you react when you experience such difficult situations?" The patient answers that, unfortunately he has a tendency to go sit in a corner and contemplate of life and problems. Fortunately, his wife is more prone to action and helps him through the bad times.

This extract shows how the narrative approach can enable a more nuanced picture of the patient and from where his perspective is formed. By asking to how he reacts when he is faced with hardship, the nurse used the story to get to know the patient. He conveys that his wife supports him when he is in need, disclosing a bit about his *social relations.*

Talking About Medical Treatment

A third part of the sessions was concerned with the medical treatment, prognosis and plan as part of the standardized HF treatment and care. In general, I observed that nurses listened with curiosity to the patients stories. They kept eye contact as much as possible, they allowed for pauses and they asked follow-up questions. Yet, when this medical part came up, I observed a distinct change in the situation. The nurse commonly changed her exclusive focus on the patient and turned to the computer. Here she could find data on the patient's bloodwork and see results from prior procedures or sessions. Often this made the patient also look towards the computer screen. In one session, I observed a family member rice from her chair to see the information given on the screen.

In what order these parts were arranged seemed to depend on the patient. Most often, the plan for medical treatment came last circling back to *symptom control* and life with HF. However, if the patient initiated the sessions with clinical issues from his everyday life a natural movement into treatment occurred.

Another important finding is what I did not observe, moving a bit more into a process evaluation thought. Nurses did not use the inspirational S' question guide in a stringent form. They used the EORTC-QLQ-C15-PAL questionnaire. This is interesting because during the workshop professionals and in particularly the nurses, requested a pragmatic guide to use during sessions.

To sum up, the observational data showed how sessions with a person-centred PC approach joined a perspective on the everyday life of the patient as well as a medical perspective focused on treatment. The sessions also seemed to integrate the different S' dimensions although the nurses did not necessarily follow the structure of the S' question guide. The first session were the most structured session as the nurses invited the patient to talk about aspects from the different S' dimensions. This allowed nurses and patients to discuss PC needs and resources. Especially the psychosocial and existential domains were considered an extension of the standard sessions. Patients would share issues related to the fact that they had a life-threatening illness, and these were recognized by the nurse, as PC needs. Some experienced that talking to the nurse was enough, others accepted an invitation to talk to the hospital chaplain, or that the nurse would refer the issues to a social worker.

In following sessions, The EORTC-QLQ-C15-PAL appeared preferred over the S' question guide. Nurses seemed to focus on the question of perceived quality of life and simply chose to explore from here. This created a flowing dialogue focused on the person. Furthermore, it provided nurses with an understanding of the patients' current needs in terms of physical, psychosocial and existential problems in life with HF. The understanding derived from this study became a presupposition for my interview study.

Interview Study – Exploring What the Patients Find Significant

The qualitative interview has the ability to provide exclusive insight in to the patients' perspective as they narrate from their experience. A common aim in health research is to add value and quality to health interventions.[128] Integrating real-life experiences, as evidence in both health research and care has been argued essential in order to improve patient outcomes and ensuring a positive experience of care.[128]

In a new research and care field like general PC integrated in HF treatment it is necessary to explore the patient experience and use this understanding in development of practice. With this interview study, we aimed to explore what patients found significant in the PC intervention as part of our evaluation. As I had also conducted participant observations I had already established a relationship with all but one of the interviewees. In addition to my semi-structured guide I used these prior observations in my interviews. This allowed me to ask patients about a specific situation getting a deeper understanding of the experience.

Setting and Participants

Participants in this study were the same as completed the intervention as described in Table 10.

Data Collection

I chose an open-ended interview style and listened actively in order to provide a milieu allowing for narratives. With attention to enable a calm and safe environment as well as a sense of neutral grounds, I conducted most interviews in the patients' home. Most patients chose to have their spouse present and with the same argument as before, this was endorsed. This distance to the hospital setting also aided a sense of neutrality. However, three patients wished that the interview took place at the HF clinic proceeding their last session. Interviews were audio recorded and had a mean length of 61 minutes. Saturation, consistent with our aim, sampling plan and inclusion criteria seemed achieved by the 10th interview.[129] The participants in this study were a heterogenic group in terms of age, gender, social environments, stages of their illness and variety of needs for which a person-centred PC approach would be helpful. However, data saturation is difficult to judge hence, this might be a limitation in our findings. The individual interviews were transcribed ad verbatim by a data manager or myself.

A semi-structured interview guide can be seen in Appendix J. Although the guide starts with questions concerning background, the key question, *"please tell me your experiences with the sessions at the HF clinic"* guided the interview.

Data Analysis

The software program Nvivo12 pro[98] was used for managing and coding data. The following analytical steps were incorporated: 1) organizing the data 2) familiarizing ourselves with the data 3) coding the data and 4) create themes.[97] The qualitative thematic analysis, informed by Kvale and Brinkmann focused on meaning making.[121] It was derived through an iterative hermeneutic process of going back and forth between parts and whole and discussed with supervisors.[121] As usual when starting an analysis I started the process with an open mind, reading the manuscript and jotting down immediate thoughts. Then I coded data. This time my data was not experienced from a blank slate rather, the insight I had procured during the preceding studies guided my coding scheme and derivation of themes. Again, themes were presented to colleagues as I found this to be a way of stepping out of the detail of an interview into a wider interpretation of the whole data set, and make me aware of additional important themes. Table 13 provides an example of meaning units in the general theme 'Integrating perspectives of HF into everyday life'.

Findings

As a whole, the analysis revealed that the integrated narrative PC intervention was successful in uniting patient and professional perspectives hence, providing person-centred care. Furthermore, the intervention proved meaningful for patients in terms of integrating treatment and everyday life with HF.

Table 13: Example of Thematic analysis in Interview study

Quotes	**Central theme**	**General theme**
"it's like... You can never be prepared 100%" P4 "It brings me comfort that my family is financially secured in case I die – to know that my bereaved are comfortable and won't need that struggle on top of everything else."P6	Preparation	Integrating perspectives of HF into everyday life
"I give it less and less attention – I mean it has to get some consideration - you can never let it go completely. It is present but it must not dominate (life)."P6 "It's like Winnie the Pooh is saying 'the rest of the days you have to live' and that is so true"P8	Attunement	

Physical symptoms, anxiety and worries in everyday life were concerns for many patients. The sessions with the S' approach enabled a safe atmosphere to convey worries and share stories. This provided comfort due to a sense of coherence and meaningful understanding of HF. The thematic analysis led to three themes that support the overall findings: 'Sessions bring comfort', 'Telling your story provides a sense of meaningfulness' and 'Integrating perspectives of heart failure into everyday life'.

The first theme of 'Sessions bring comfort' showed how patients felt cared for and this enable them to share their personal experiences, thoughts or worries. The nurses appeared willing to address any issue either practical or existential and patients perceived this as competence and concern. The patients articulated how they felt a sense of comfort after sessions:

> *"I am always completely relaxed after seeing Helen (fictive name for the nurse). Before I get there, I am in a state of oh oh (swirls her head around making frantic gestures with her arms)". P9*

The second theme, 'Telling your story provides a sense of meaningfulness' demonstrated how telling stories from everyday life brought about a sense of recognition and coherence for most patients:

> *"It is significantly meaningful, both in regards to medicine and that stuff but also in how one understand... how should I put it... the whole thing". P4*

Patients shared stories of difficult loss, complicated relationships or more obvious illness related stories of prior illness, hospitalization and fear of dying.

The last theme, 'Integrating perspectives of heart failure into everyday life' revealed that sessions supported the integration of the patients embodied understanding of HF with a medical perspective. An example is how patients felt supported in balancing the fear of a new cardiac event with living life:

> *"It's like Winnie the Pooh is saying 'the rest of the days you have to live' and that is so true"P8*

Our study propose that standard HF treatment trajectory is quite successful in addressing physical symptoms, but the S' approach provides a wider definition of suffering and includes psychosocial and existential symptoms. However, not all participants experienced psychosocial or existential problems in this study. This suggest that a screening for psychosocial and existential suffering as triggers for a person-centred PC approach could be helpful when designing general PC. At least one such screening tool is already used in the standard HF treatment: The Hospital Anxiety and Depression Scale (HADS).[130] Another more comprehensive suffering tool is the Pictorial Representation of Illness and Self Measure (PRISM).[131] Nevertheless, a review on available suffering assessment tools in PC conclude that the evaluation of assessment can be made easier.[132]

Interdisciplinary Feedback Meeting

Inspired by an AR analytical approach with iterative motions between plan, act and evaluation, I held a feedback meeting with interdisciplinary professionals to conclude the intervention.

Setting and Participants

Present for this feedback meeting were seven participants: a physiotherapist, a PC nurse, a cardiac physician, the hospital chaplain, the two cardiac nurses and myself. Due to personal issues and changes in organisation and priorities, this group only represented four professionals from the original interdisciplinary project group who supported the process of developing the PC intervention. Due to convenience, the meeting was held at a conference room in the PC unit.

Data Collection and Analysis

This feedback meeting using dialogue was designed without an interview guide, as I did not want to restrict professionals to how far my creativity could stretch. I simply invited the professionals to share thoughts on the intervention and process. However, in case I needed to facilitate the dialogue, I had prepared bits from my observations and individual interviews with patients. The meeting was audio recorded and analysed for qualitative content guided by the overall question *“what was the impact on the professionals?”* inspired by Øvretveit.[91] In total, I had one hour and six minutes on tape. Findings are presented in a summary style supported by quotes for transparency under the themes ‘Impact on a professional level’, ‘Thoughts on an organizational level’ and ’Concerns on feasibility’.

Findings

Impact on a Professional Level

Professionals shared what impact they believed the intervention had on them as professionals. A participant initiated the dialogue with a comment that this approach was interesting, as it provided a new reflection on how decisions were made. The patient perspective was vital to ensure that decisions were based on dialogue rather than forced on the patient. This is an example of how a person-centred approach both include and facilitate shared decision-making.

This view initiated a dialogue on perspectives. Especially how the approach in this intervention made it possible to explore a wider understanding of living with HF. Patients presented many different issues of many different characters, but not necessarily something that could be translated in to clinical symptoms of HF. A nurse talked about a divorce that had an understandable impact on a patient. She felt satisfied that she was able to provide a calm place for him to talk about this.

Another participant conveyed that she had learned a lot about the existential troubles arising when people get *“ill in the heart”*. She interpreted that persons with heart illness are burdened in a double meaning, as we in our culture understand the heart as part of our identity. The aim of joining the patient perspective with the professional perspective as in this intervention allowed for a recognition of the whole person, supporting patients in moving forward on existential matters towards a meaningful life.

Thoughts on an Organizational Level

To facilitate a dialogue on interdisciplinarity I paraphrased a conversation with a patient. Her illness was advanced and difficult to manage leaving her with PC needs of both physical, psychosocial and existential character. She told me that she had the experience of a unified PC program with coordinated care including doctor, nurse, physiotherapist and hospital chaplain. The group received this evaluation with appreciation and interpreted that the relations they have built with each other through the seminar, workshop and interdisciplinary conference meetings had made a difference. However, a cardiac nurse conveyed that the focus on strategy for treatment in the conference felt forced. The conferences worked best when the focus was on discussing an acknowledgement of PC needs beyond a medical nature, as these were already considered successfully managed in the HF clinic.

In the physiotherapy, they experienced that more patients were sent for an initial talk on the best physical exercise strategy. The nurses had experienced being more inclined to refer patients to the chaplain in case of existential needs. However, they highlighted an important lack of continuum and cooperation from the cardiac ward to the HF clinic. One even pointed out that, the feedback meeting was without representation from the hospital ward.

The lack of continuum in the HF trajectory was perceived to affect the patient experience as they were sent home with no *"safety net",* and sometimes waited months in *"no man's land"* before the treatment was continued. On this same note they compared the intervention to 'reality' where they also send patients home without a sense of continuity: *"I will send you a time as soon as I have one. If I find anything out of the ordinary with these tests, I will call you. Otherwise you won't hear from me".* They all agreed that this did not provide a sense of safety or care. The intervention had provided a setting where patients could come every week if necessary. This supposedly had enabled a strong relationship between patient and professional. In addition, it made professionals allow for a dominating patient perspective in one session, as another session could be scheduled immediately allowing for a professional perspective. Yet, the group expressed that the reality of the organisation does not allow for flexibility and they are forced to reject issues that does not translate into relevant clinical symptoms.

Øvretveit argues that an evaluation always involves comparison between a before and after.[90] This is evident during this dialogue as the group keeps comparing to what they call 'reality'. To give another example, the group described how the intervention confirmed care as a key dimension in health services. However, in reality this would not be feasible. The focus in reality is primarily on cure and the hospital feel more like a factory then a health care facility *"patients have production numbers and not names"* one argued. This was recognised with a comment from another participant. He raised the problem that HF patients are probably one of the most challenged patient-groups in cardiology, still the focus remains on medical issues and less on existential issues. They spoke of a constant battle to include care into a system focused on cure, but argued that this is a necessary battle as the intervention had shown them.

I interpret these comments and the continuous comparison between the interventions using the S' approach and the reality as a new insight and acknowledgement. An acknowledgement that pain and suffering is not restricted to physical pain and an acknowledgement of a good life as meaningful and not only functional. There is a need to recognize total pain and to care for the person behind the patient to help him or her find meaning. In the case of PC in HF, an unreliable life-threatening illness, this acknowledgement is essential. Without 'care' there can be no 'palliative care'.

Concerns on Feasibility

Besides a concern on the organisation being able to include care, there was a concern that the intervention might have been offered to early in the course of illness. One argued that these patients often live a full life. She suspected the patients focus was on receiving medical treatment making them able to *"live their life* *again".* She continued by arguing that medical treatment is quite effective and she experienced people *"returning to life".* She believed that considerations on end-of-life care does not present simultaneously with diagnosis. Everyone agreed that discussions on end-of-life care are very important, but maybe not at this early stage.

Another participant disputed this view. He argued that cardiac professionals might not be good enough to talk about HF as a life-threatening illness. His experience is that patients react completely different when receiving a cancer diagnosis, because the public acknowledge that you can die from cancer and the patient expect a talk about this. This is supported in the research literature.[21,28,34] HF patients do have the same psychosocial needs but the access is restricted compared to cancer patients. However, the literature also suggest that these needs may present themselves at different times than we are accustomed to with cancer.[34]

Nurses in particular conveyed a pragmatic concern about the documentation of patients' narratives in the IT system 'Sundhedsplatformen'. Due to multiple sessions, the written narrative became extensive. This required additional time and the narrative was difficult to recap. A nurse was concerned about how partners in the primary sector, like the patient's GP would manage this. *"We know that we can skip over the narrative and go straight to the information"* she said. This is an interesting choice of words *the information*. What she meant was the objective information of for example blood samples and the medical treatment. This is of course a vital information for the GP, but I find it interesting that she does not think that the personal narrative could be useful for the GP. However, I do not think this is what she actually meant. What I take away from this comment is rather that the narrative itself is important in a person-centred approach, but the documentation of the narrative in a medical journal format is challenging.

Another practical problem with the S' approach was the dimensions. Nurses found it difficult to split the narrative into different dimension. Again a very interesting and informative finding. The holistic style of PC as applied in the S' approach was not easily divided and documented under specific S' dimensions. On the other hand, the S' approach provided a compromise and a pragmatic level to the narrative. During the workshop, the interdisciplinary group expressed a need for a pragmatic model with inspirational question. Yet, in practice they primarily used the self-reported quality of life scale in the EORTC-QLQ-C15-PAL as a starting point for the narrative.

Summary of Findings Through Phase IV

Guided by Øvretveit's purpose of action evaluations[90] this evaluation phase aimed to understand outcomes of the PC intervention on different levels.

Patient interviews showed that PC through the person-centred S' approach integrated in sessions at the HF clinic was significant in various ways. First, it made patients feel a calm and safe atmosphere with a nurse who were truly interested in them. Secondly, a PC approach showed an ability to bring comfort to lived physical, psychosocial and existential issues. Last, it made patients able to combine their embodied understanding of HF with a medical perspective hereby, integrating treatment in their everyday life.

The observational study supported the findings of sessions combining a perspective on the everyday life of the patient as well as a medical perspective focused on treatment.

The feedback meeting conveyed how professionals perceived the intervention to have had an impact on their professional stance. They were in agreement that care is an essential part of health service. Furthermore, they found that care could best be provided if there was a balance in the patient and professional perspective. The S' approach demonstrated how a person-centred approach could be integrated in sessions at the HF clinic. However, the practical structure of writing the narrative was difficult to adapt to a medical journal format, and considered difficult to integrate in the reality of the HF clinic.

Discussion

Main findings of this PhD study have been addressed individually in the four published papers. This chapter will discuss how main findings fits together in the fields of narrative theory, palliative care and cardiology. It will also present methodological considerations in terms of research rigour and quality.

Discussion of Findings

A general Palliative Care Approach by the Use of Narratives

In phase I, findings from the interview study showed that people living with HF in Region Zealand, experienced a Sisyphean struggle,[133] including not only physical health needs but also unacknowledged needs of psychosocial or existential character for which the total pain concept in PC is helpful. This resembles findings from international studies.[32,122,134,135] Furthermore, we found that patients had a hard time understanding the term heart failure. This is also confirmed in research literature.[21,28]

I asked the question of why such needs went unacknowledged in a standard HF treatment trajectory and found that it could be due to a dominating disease perspective focusing on clinical symptoms, diagnosis and effective medical treatment. The findings also showed that it could be because patients refrain from talking about existential issues. This is a bit of a 'chicken and the egg' dilemma. Does the patient refrain from talking about existential problems because they are not acknowledged or are they not acknowledged because they are not shared? By means of Kleinman's definition of illness perspectives as formed from how patients understand and talk about symptoms, how the disease is viewed in our culture and his or hers individual lifeworld,[44] we can get an understanding of why. HF is not generally recognized as a life-threatening illness like cancer, patients keep quiet about their symptoms and professionals refrain from talking about death and dying. In addition, professionals in this PhD study conveyed that the organizational focus on cure made it very hard to provide care with focus on existential and psychosocial problems related to illness. I argue that when it comes to HF patients, this leading focus on cure is problematic, as HF is a life-threatening chronic syndrome for which there is currently no cure and where death is a likely outcome. This is supported in the building literature on PC for life-threatening illness.[39,41,136,137]

The premise of this PhD study was that a narrative PC approach would focus on suffering including that of existential and psychosocial character because the narrative provided a method to front the embodied patient perspective and provide person-centred care.[44,64,77,78] Based on narrative theory and findings in this PhD, I argue that narratives have great potential in a general PC approach for the HF patient.

A main characteristic for interventions facilitating a personal story is the use of a guide with open questions. This was found both in the review study[138] and in S' approach literature.[119] A systematic model was arguably necessary when borrowing a concept from socio-narratology and psychotherapy to be used in health care system.[138] The interdisciplinary group followed this logic and we (researcher and professionals) decided to apply the S' approach. The inspirational S' question guide was adjusted to include symptoms that did not necessarily focus on terminal care and death but rather on a more inclusive PC focus on life with an illness where death is a likely outcome. Yet, the EORTC-QLQ-C15-PAL appeared to replace the S' question guide during clinical sessions. If this was because the S' question guide became familiar to the nurses or if the simpler EORTC was preferred I cannot say.

Venborg writes that the S' approach should not constrict the clinical practice, but rather provide person-centred palliative care. She argues that a vital point in the S' approach is that the professional is provided with a narrative of the patient's situation, symptoms and needs and can use these as a guide in treatment.[119] Would it be possible to do without a guide for the narrative? Findings from our review study[138], suggested that a guide was necessary but it also concluded that a narrative intervention must be flexible and amend to the practices of the setting. The workshop strengthened this idea.

In a Danish context, nurse researcher and cultural sociologist Pia Ramhøj has contributed with her understanding of the potential of narratives in nursing and research.[139] She confirms care as a core element of nursing and as such, nursing is not only a consideration for technical or procedural tasks. It is very much also a consideration for patients' wellbeing. She continues by defining knowledge on the patient's lifeworld and life situation as a prerequisite for care. Nevertheless, at every project meeting with professionals in this project, they conveyed their concern and frustration that care had been detached from this hospital setting. They even reflected that this PhD project had made them recognize that.

Ramhøj, acknowledge that health care is provided in an arena of both system and lifeworld, and argues that if the patient is not to be reduced to objective data, it is essential that we listen to the patients' narratives and open up for the embodied patient perspective. She even describes narratives as a natural extension of the nursing tradition.[139] Evaluating on this general PC intervention, patients conveyed feeling recognized as they could share stories from their life and their experienced problems. Thus, narratives are not only possible but also necessary in health care if the aim is to provide person-centred care. However, what kind of room is there for person-centred care in a hospital setting like the HF clinic?

During the workshop, cardiac nurses asked for additional training in a narrative communication style, as this was not familiar to them. They are educated in asking structured questions that allow for thorough medical anamneses, but feel insecure when the dialogue focuses on the patient's lifeworld. This seems in direct contradiction with Ramhøj stating that narratives are a natural part of nursing yet; it highlights the need to address the culture within the HF clinic. Advances in cardiac technology and pharmaceuticals are vast and have had a positive effect on overall death from cardiac diagnoses.[140] Yet, when it comes to including the scope of care the same advances are not as evident.[141] It seems like the technological system is progressing much faster than the consideration for patients' lifeworld hence, down-prioritizing care.

I will use an example from the findings to strengthen this argument. Nurses found the IT system 'Sundhedsplatformen' as a barrier to documentation of the narrative. A recent evaluation of this system found that it did not support documentation such as nurses considerations regarding patients' needs.[142] It was primarily used to logically check boxes concerning objective issues such as blood pressure, temperature or diureses.[142] The EORTC-QLQ-C15-PAL on the other hand, is already included as a standard patient reported outcome measure (PROM) in Sundhedsplatformen, making it easy for nurses to document these scores. My concern is that if the IT systems only allows for objective clinical issues to be recognized and documented, then this sends a message that nothing else is important and the patient might actually be reduced to objective data as Ramhøj warns. However, in this study, it seems that nurses used the S' dimensions as an approach to PC and to understand the patient's total life situation, but maybe the EORTC questionnaire provides a better way of documenting needs for further action.

The discussion of lack of care in hospitals as the professionals conveyed has also made it to the news. A newspaper article from 2017 argue that spiritual care has increasingly been pushed out of the specialized hospitals were knowledge is based on scientific objective findings.[143] Professor in spiritual care Niels Christian Hvidt, argue that spiritual care is needed as it can help build a bridge between the patient perspective and the professional perspective.[143] This was supported in our findings were the hospital chaplain and PC nurse formed a bridge between the embodied perspective conveyed in patients' narratives and the medical perspective from cardiac professionals.

It seems difficult to find a balance between system and lifeworld as technology and quality measured in efficiency has more credit than the value of meaning making and understanding. This brings on the next question. If the system is challenging the narrative as a prerequisite for person-centred care, then how can a general PC approach be integrated in a HF clinic?

Integrating a general Palliative Care Approach in a Heart Failure Clinic

To answer this question we have to consider the inspiration by actions research, and revisit what constitutes PC in the intervention and how this differs from standard HF treatment.

The AR inspired activities, such as the learning strategy, the workshop and the feedback meetings provided insight that allowed for a collaboration between the medical perspective in cardiology and the person-centred approach acknowledged in PC. Based on these findings we developed a narrative PC intervention including dialogue and interdisciplinary conference meetings that provided a way of joining the patient illness-oriented perspective with the professional disease-oriented perspective. The PC approach in this study consisted of an acknowledgement of total pain in relation to life-threatening illness and the prospect of dying of HF.

The AR design puts forward a bottom-up approach, which in this study maybe was closer to "user-involvement". I will elaborate on this in the discussion of validity, reliability and generalizability. However, one example is how this whole project started with a clinical frustration that needs of HF patients were often neglected, and a wish to 'do better'. Another example is how the EORTC-QLQ-C15-PAL was included in the intervention based on influence from the head PC nurse. A bottom-up strategy is supported in a study from 2014[144] focused on barriers and facilitators to implementation of organisational changes in PC. Important facilitators are knowledge and awareness, usefulness of change and attitude of professionals. This support my findings. In addition, the authors found important barriers to be the organizational and political context.[144] They conclude that change in care processes would be easier to integrate if the underlying understanding of care corresponded.[144] In this PhD with an aim of integrating general PC in a specialised cardiac HF clinic, we did not have that favouring prerequisite. However, the workshop and continuous dialogue among members of the interdisciplinary group formed a bridge between objectives and perspectives from cardiology to palliative care. An illustration of this is the use of patients' narratives in the workshop.

Using stories to trigger and achieve change is not new in AR as dialogue is a prerequisite in democratic change development.[86,87,145] During the workshop, patients' narratives made the tension between perspectives explicit and open for dialogue. Further, this process of being involved in understanding the problems and discussing plans of action led to relational engagement and a feeling of responsibility among interdisciplinary professionals. Corresponding, professionals argued that interdisciplinarity was built from their relational engagement formed through this AR inspired approach.

In both PC and HF literature interdisciplinarity is recommended.[42,146] Our research contributes to that recommendation as interdisciplinarity made it possible to discuss and understand different perspectives. However, interdisciplinarity was challenged by the organisational conditions. Throughout this project, the group constellation changed several times making it difficult to convey interdisciplinarity. This also came across in the PC intervention. Many patients did not experience the interdisciplinarity, as they did not feel the need to talk to a chaplain or see a physiotherapist. However, some patients do convey a more nuanced understanding of the interdisciplinarity in the intervention and mentions that conversations with the chaplain or a physiotherapist had meant a great deal to them.

The dialogue on what constitutes PC was also enabled from AR activities. During the workshop, a nurse asked *"but why is it palliative care? Why is it not just care?"* At the time, I simply rephrased the WHO definition, but as we (research and interdisciplinary group) moved along in this study, the same question recurred repeatedly making it apparent that a discussion was needed.

In PC, pain is understood in accordance to the patient's whole life situation. Hence, PC aims to relieve physical, psychosocial and existential suffering and problems in life with life-threatening illness. What seems to mud the waters is that general PC is provided early in the illness trajectory and not by a special unit. In PC literature, there is an ongoing discussion on early PC, what is it and when should it be offered?[147–150] However, there seem to be an acceptance that an early acknowledgement of PC is not to be questioned, it is necessary also when it comes to HF.[147,150,151] In this study, we wanted to integrate a PC approach in the current sessions in the HF clinic making it even more difficult to distinguish between one and the other. In addition, I made the ethical choice to focus less on the term PC and more on the meaning of life and needs when faced with life-threatening illness. A narrative review from 2020[150] looked at barriers to early utilization of PC in HF. The author argues that the term 'palliative' is perceived as a stigma by both professionals, patients and family members as it is related to death, and many prefer using the term 'supportive care' instead.[150] This is almost the same discourse dilemma as I have accused the efficient IT system to cause. By not being explicit about PC, it becomes invisible, and by not being explicit about HF being a life-threatening illness with death as a likely outcome, the reasoning for PC in HF diminishes.

The Standardized Plan for HF treatment aims to obtain and preserve functionality hence, increase the patient's quality of life, independence and autonomy.[51] The plan emphasises the involvement of the patient but this involvement seems based on a patient-centred approach with emphasis on the professional perspective. Strengthening this statement are findings throughout this PhD. The professionals from the HF clinic in particular highlighted that the person-centred approach in PC were different from their normal practice. For example, they asked for a workshop on communication allowing for a patient perspective to unfold and for supervision during session to learn from examples. Furthermore, a total care argument was formed across the interdisciplinary group throughout the AR inspired activities and process. For example, by evaluating the PC intervention against standard sessions it became clear that the person-centred approach allowed for the recognition of total pain symptoms and lifeworld of the patients.

This shift in approach was also visible in findings on patients' experiences. The first interview study suggested that patients were not able to share symptoms or problems that could not be translated into clinical symptoms. This left them with unacknowledged needs. In the evaluating interview study,[152] the experience was different. Patients found the integrated PC and HF intervention significant in relieving problems of psychosocial or existential as well as physical character. Applying a narrative PC approach and providing a safe atmosphere to share stories and incorporate the patient perspective showed to have a significant meaningful impact on patients as it supported the patients in restructuring their 'map'[77] and continuing their 'journey' through life.[70]

During the evaluation phase, I observed that nurses left the inspirational S' question guide as the sessions progressed. Instead, they simply used the EORTC-QLQ-C15-PAL. This substitution was not articulated but seemed to occur almost as a common sense movement. Would the use of the EORTC-QLQ-C15-PAL questionnaire have had the same outcome on its own?

Looking at literature on PROMs like the EORTC they have been predicted to transform health care,[153] as well as improve quality of care.[154] With the advances in IT systems the collection and reporting of PROMs have been simplified,[155] which is also reflected in findings from this PhD. In a policy document on the Danish health care system goals[156] one specific goal is increased patient involvement for which patient reported outcome measures (PROM) have been argued to play a vital part.[157,158]

However, an evaluation on the same national health care goals in 2019 showed that patient involvement had no positive trend in Region Zealand and scored worse than the rest of the country.[159] Does this mean that a PROM is not enough or that Region Zealand just have not used PROMs? I cannot give an answer to this. Nevertheless, I can provide my own thoughts on the subject based on this PhD.

I do not think the EORTC would have had the same outcome on its own. Some patients even found the questionnaire silly, arguing that it was a waste of time checking the same boxes for every meeting. I interpret that it was the combination of education on PC and the S' approach along with the interdisciplinary meetings that provided room for the narrative and person-centred approach in the HF clinic.

Looking at the S' approach and the open ended questions guiding the narrative, I among others,[119,160,161] would argue that the S' approach takes total pain and the patients lifeworld into account. This provides for a thick narrative, but documentation showed difficult. Findings on this PhD indicates that the EORTC questionnaire is especially valuable as a translation tool from narrative to documentation in the system, but less valuable for the patient.

To sum up, it seems that the EORTC functioned as a bridge between system and lifeworld; ensuring a person-centred approach into the HF clinic. However, simply transferring PROMs from specialized PC is insufficient. Integration of a PC approach in a HF clinic requires a cultural change. A PhD from 2016[162] suggesting that the culture and organization of PC in hospital medical departments was missing an overall policy and goals of care, supports this statement. However, it seems a bit discouraging if general PC have not advanced more in the last 5 years. The current strategy to improve health care in Denmark is centred around the policy: *"better quality in treatment and rehabilitation with focus on the results that has meaning for the citizen"*.[159] This still leaves out palliative care, and with the focus on PROMs, this might also limit the patient's personal narrative.

Discussion on Method

Reflections on Research Rigour

In the Danish code of conduct for research, three principles underpin integrity: honesty, transparency and accountability. As mentioned earlier, my analysis and interpretations of the qualitative data must be considered through my ontological position and horizon. Ensuring trustworthiness, I have tried to make transparent choices throughout this project substantiated by arguments.

This study was framed by hermeneutic epistemology and inspired by AR methodology. Furthermore, it applied qualitative methods, as the focus was on patients' perspectives, lived experiences and organizational development. AR guided a study divided into four phases, and in each phase methods were carefully chosen with consideration for the research question and aim (see Table 3). Through every phase, we questioned methods and design to strengthen quality. For guidance we used Mason's questions:

- Are the concepts meaningful?
- Are the methods appropriate?
- Is research designed and carried out carefully, accurately and well?
- Is data analysed carefully, accurately and well?
- Are conclusions supported by data analysis?
- Are conclusions more widely applicable?[93pg 36]

An example of such a question was on how to measure the PC intervention. Adding additional recognition, care and time to an already established treatment plan will most likely have a positive outcome. In regards to this, measuring patient satisfaction will not be that interesting. However, what is interesting in an explorative study is the significance for the individual patient on his/hers life and everyday life. What does it mean for the patient if general PC is integrated in the HF clinic? This is what I have tried to answer through this PhD.

Validity, Reliability and Generalizability

Validity is an internal assessment of quality and about showing appropriateness.[163] Was the research questions, methods, data and findings throughout this AR inspired study appropriate for the aim of integrating PC in HF?

Through this PhD process, I have been contemplating whether to define the study as AR or as clinical development supported by theory and research. The circle shown in Figure 1 resembles an acknowledged conceptual model for a learning strategy in clinical development,[164] and I have not been able to involve patients or professionals in every decision throughout this PhD. However, I remain confident that my guidance by AR is both accurate and relevant. The definition of AR as situated between insight and a change process as well as between theory and practice development,[82] supports this confidence. Moreover, this dissertation is based on theory and research with the aim of changing practice through meaning making and understanding. This methodology proved able to produce insight and generate new knowledge on integrating PC for the HF patient. An example of this is how we through a workshop used Kleinman's theory to gain insights on perspectives and used this new knowledge in developing practice.

AR is a methodology for which both quantitative and qualitative methods can be applied, but with my focus on lived experiences, qualitative methods were the most appropriate. Each phase joined different methods much like triangulation. In phase I, I aimed to identify needs and current knowledge. For this, I chose an interview study as well as an integrative literature review. In phase II, I aimed to develop a PC intervention, for this I used workshop with a dialogue guided by theory. In phase III, we piloted the PC intervention and evaluated through interviews on both individual and group level. In phase IV, I chose an observational design as well as interviews, again on an individual level to explore the lived experience from patients and on a group level with interdisciplinary professionals to gain feedback on acceptance and feasibility. The congruence between findings from the different qualitative methods strengthens the internal validity. Using Gadamer's concepts of a hermeneutic circle, dialogic process and fusion of horizons,[163] this whole PhD can be seen as a way to move closer to a hermeneutic understanding of how to integrate PC in HF and why.

Inclusion of participants is also a question of validity. With an aim to join perspectives, it should be obvious that we needed a variation of perspectives. This was considered through the sample strategy. Purposeful sampling, meaning sampling in accordance with inclusion and exclusion criteria, ensured that the participants (either patients or professionals) had relevant experiences that could help answer research questions.

The interview study during phase I, included patients that had been hospitalized with HF on several occasions. This proved to be a good strategy as patients could give rich information on the experience of living with HF, the unmet needs in treatment and the Sisyphean struggle it entailed. Details on why patients had declined were not sufficiently gathered and this should be considered a study limitation. Such details could have made us wiser on recruitment barriers.

During both the pilot study and the intervention study, recruitment was a problem and dropouts high. The recruitment strategy had to be altered however; the inclusion and exclusion criteria remained the same. As mentioned, we encountered problems in the evaluation of the pilot. The strategy was to enrol enough patients to conduct a group dialogue. This was not possible. Due to organizational conditions, the research plan was delayed leaving little time for including patients. Furthermore, we encountered a 75% dropout, leaving us with only one patient to share his lived experiences of the piloted PC intervention. However, this patient provided thick description of his lived experiences for the following group dialogue with interdisciplinary professionals. Maybe this particular design, using group interview and dialogue, was not the right strategy. As mentioned, HF patients can have days where fatigue or other symptoms seem overwhelming, and this evaluation design left little flexibility in terms of rescheduling.

The experience of recruitment challenges and dropouts did not change our inclusion and exclusion criteria for patients participating, however as mentioned it did change our recruitment strategy. Based on findings and feedback from professionals our sample strategy might be considered a limitation. The broad inclusion criteria based on time of diagnosis proved a challenge in terms of experienced PC needs. A more purposeful sampling strategy to target HF patients based on psychosocial or existential needs could be considered in future studies.

Another reasonable discussion is the majority of men among patient participants. This is not surprising as women tend to develop HF at a later stage than men[165] and therefore may be more inclined to turn down a research participation offer. However, it has been questioned if female researcher are able to conduct meaningful and respectful research with men.[166] This study never had sexes or gender norms as a research interest, although maybe it should have. Research have shown that life situations for men and women are different and that the majority of studies on HF are dominated by men.[167] The majority of men in this study could be considered a limitation. In addition, it is necessary to mention that the majority of professional participants were women. Again not surprising given that health care is a field dominated by women. This could also be considered a limitation.

Although our integrative review study did not include participants, it very much so had a systematic sample strategy. Yet, when I first began building the search strategy, the idea was to focus on HF. This was not feasible as I only found four papers and none remained after applying the inclusion and exclusion criteria. This meant that we had to widen our scope and choose life-threatening illness over HF. I am not sure whether to call this a limitation or a strength. Thinking about generalizability, we could argue that this was in fact a strength. In any way, it proved that research, which could contribute to the knowledge on interventions using a narrative approach in PC and HF, was needed.

Through the phases, participants in the interdisciplinary group changed several times. Bringing so many different health care fields together showed challenging as I had no control over the individual organizational priorities within each field. This is a clear study limitation. Nevertheless, the twelve different participants all contributed with their experiences and competences. A main strength of this interdisciplinary was that we were able to use it actively to create tension, facilitate a productive dialogue, and produce insight.

The emphasis on dialogue and reflections through this PhD was inspired by the AR cycles of planning, acting and evaluating. As we began the workshop in phase II, the interdisciplinary project group was introduced to findings from the first two studies. This was done to centralize the patient's voice on issues that mattered to him or her, and drive change from here. Between first and second part of the workshop a summary of the dialogue was presented to the professionals. This was done to validate trustworthiness of findings. Professionals found the summary recognisable and valid.

Findings from the patient interview studies were not send back to patients for a control of meaningfulness. However, as a way to strengthen the initial analysis I would ask patients to elaborate on statements I was uncertain about during the interview. In a similar notion, the group sessions with professionals always entailed a validation of data as the interviewer (either Charlotte Simonÿ or myself) would ask exploratory questions or questions that would open for another perspective.

In qualitative research, reliability lies within consistency.[163] Meaning that reliability concerns the generated data and conducted analysis as well as presentation of findings. The analytical process has been addressed both in scientific papers and through this dissertation and a thematic analysis presenting the qualitative content in data was used consistently. In study I, we were at least two reviewers on all articles. In case of doubt or difference of opinion a third reviewer was consulted. In the other studies, I used a constant comparison of parts and whole throughout analysis to strengthen the reliability that what I found, was indeed conveyed in the data. Further, the analysis were discussed with supervisors. However, I was the only data coder, which is a limitation. In future studies, I will consider a collaborative analysis including additional coders. For transparency, I presented findings in a narrative style supported by quotes or field note data. In addition, I have provided examples of my analytical process in this thesis. As I have mentioned, my interpretation is formed by my presuppositions and as such, another qualitative researcher might have found another way to construct themes or another theory to apply to findings. This is recognised as a premise for qualitative work,[163]

To evaluate reliability of this PhD, it is helpful to address issues of power. As mentioned in the chapter on ethical considerations, the principles of respect for persons is understood more broadly in AR. Power plays an essential role in this and knowing the power relationships within a group can be beneficial.[104] A way to understand roles and power in AR is through the work of AR researchers John Kretzman and John McKnight, who developed a theory of assets-based community development.[105] They argue that a primary building block for change is located within the community and under the control of the community. Another building block is located outside the community and outside the control of the community.[105] As mentioned several times, this study is merely inspired by AR and have not applied an AR strategy throughout the study. However, acknowledgement of power and power relations have been reflected on in this PhD.

To give an example, I must elaborate on my positions in the fields of PC and HF. I consider myself both an outsider and insider to the specific HF clinic. I did not know the field in detail, but as I had previously been employed at the hospital ward, I knew the professionals from the cardiology setting. I have never conducted research in PC nor do I have clinical practice in this specific field. The argument of a PC approach evolved as I tried to understand the clinical frustration expressed by a cardiac nurse. This meant that in many ways my power as a researcher in this field was low.

In the same way, I have been away from cardiology for six years. Six years is a long time with the fast advancement of technology and medical treatment. The choice of engaging professionals were not just based on methodology and ethics, in some ways it was necessary. I needed knowledge and experience from others to be able to develop an intervention that would be acceptable and feasible in a real-life setting. This was made clear to the participants. It was also made clear that they were invited because they each had strengths and knowledge essential to the study. Hence, had the power of influence.

However, the power from outside our little community representing the interdisciplinary group, the patients and my team of supervisor were even stronger. The larger organization of the department, the hospital and the health care policy in Region Zealand were not sufficiently engaged in this project. This proved to be a limitation with consequences for organizational change.

In terms of patients, I explained how they could contribute to knowledge and why it was important to findings. In the case of professionals this meant that during team meetings with the interdisciplinary group, I functioned as a facilitator and as a team member with a research focus. The workshop is a good example of this. I facilitated a dialogue using patients' narratives but the insight produced during the workshop was the result of a democratic process. The balance between researcher and interdisciplinary team member and project manager was however a challenge. Especially the workshop proved challenging as I tried juggling being both researcher, interdisciplinary team member and workshops manager at the same time. This could be considered a limitation. However, this experience brought a new insight and for the following pilot, I asked Charlotte Simonÿ to facilitate interviews and dialogue.

Another power concern in AR relates to who owns the data that is produced.[104] At the beginning of the process, I had the idea of bringing professionals into the dissemination of results. Unfortunately, as this is a PhD study with formal demands of scientific research papers, the professionals felt unequipped to participate. Instead, I have been talking at seminars, provided afternoon courses on general PC to non-malignant illness, and when this PhD is finished, we have planned that I attend a meeting at the Department of Cardiology and discuss the findings with professionals and leaders. This ensures that the knowledge produced is not only conveyed in scientific circles but also at a clinical level. Paper II in this PhD is purposely targeted a Nordic journal for both researchers and practitioners in the field of PC.

Dissemination of findings to the participants have not been as strategic, but considerations have been made. I have invited everyone to the defence, and provided them with feedback when we met. However, many had concerns about an English presentation, as they do not feel eloquent in English. This is one of the reasons, that I have wished for a Scandinavian assessment committee. If I am able to defend this PhD in Danish, it will be easier to reach also the patient audiences.

Nevertheless, I was the main researcher and essentially had the final say as I conducted analysis and disseminated findings. Based on my level of presuppositions in this study, I would argue that the hermeneutic circle towards understanding happened through dialogue with patients and professionals and of course through a scientific discussion with my supervisors.

Generalizability is whether you can make a wider claim based on your findings. As this PhD is inspired by AR with an objective to explore lived experiences, it is in its nature situation specific and not generalizable. However, some findings might be useful in similar settings.

I have already discussed the conditions under which this project has been done and whether or not findings are sustainable in this particular outpatient cardiac setting. However, such conditions might be different in other cardiac settings. Maybe PC is already an educational topic, or the organisation allows for more flexibility.

Maybe a narrative approach is more likely to be used in an in-patient setting at the cardiac ward. Therefore, transferability to other settings must consider such differences.

Overall, this research have presented knowledge on what patients found significant in the integrated PC intervention in the HF clinic as well as how interdisciplinary professionals experienced being involved in the development of a PC intervention based on patients' needs and narratives. This all happened at the same hospital, the same clinic and among the same patient group which of course may be a limitation to generalizability. Yet, the professionals were an interdisciplinary group coming from different settings at the hospital. Professionals from the interdisciplinary group conveyed that they used the narrative communicative style on patients outside this research sample. One even claimed that such an approach is difficult to 'turn off', and all agreed that the recognition of the patient perspective is worth fighting for. This indicates some level of change and the possibility of transferring new insight on the necessity of the patient perspective inside the organisation.

Conclusion

The aim of this PhD study was to develop, integrate and evaluate the significance of a general palliative care intervention in a heart failure clinic based on patients' narratives. This was achieved through qualitative methods with an inspiration from action research methodology.

In Phase I, we concluded that HF patients experienced unmet psychosocial and existential needs; possibly do to a dominating medical perspective from professionals in HF treatment trajectory (Paper II). Based on the integrative review (Paper I) we concluded that personal narratives are and can be used in a hospital setting to relieve psychosocial and existential suffering, although the scope was limited to a specialized setting. It also concluded that a narrative approach must be flexible enough to adjust to the practices of the setting and to the patient's life.

The AR inspired methodology and activities proved valuable in making meaning of the patients' narratives and discussing plans of action led to a feeling of shared responsibility among interdisciplinary professionals. The intervention included the standardized HF treatment sessions, a palliative S' approach to total pain through patients' narratives and interdisciplinary conference meetings (Paper III).

Findings from the evaluation phase showed that a general PC approach using patients' narratives was meaningful, acceptable and possible in a HF clinic given the right conditions. Patients found the S' approach significant as it provided a sense of comfort, a sense of meaningfulness and integrated perspectives of HF into everyday life (Paper IV). Hence, this PhD supports the potential of integrating PC in HF. However, as this study has completed, so has the structured PC approach in the HF clinic and resources are allocated to other tasks concerning HF treatment.

Although this PhD facilitated change on a professional level, it did not succeed to do so on an organizational level, which frames the possibilities of change. An important lesson learned through this PhD project has been to pay more attention to visions and priorities in the organisation you aim to change. Although trying to invite leaders to join in dialogue throughout this project I failed to sell the importance of this project and approach. This specialized cardiac hospital setting does not presently prioritize a lifeworld rationale.

Future Considerations

PC is appropriate and necessary in HF treatment trajectory and it is essential to be aware of possible PC needs from the beginning of HF. This is acknowledged in both research literature[168,169] as well as international guidelines on HF or PC.[40,42,59] However, there is a divide between perspectives and objectives in PC and HF treatment. This PhD bridged such a divide and showed that a person-centred approach could join the fields of early PC and HF treatment. Hence, this PhD supports the integration of general PC in HF treatment trajectory.

Yet, integration in clinical practice proved difficult. Outside the research setting providing insight, knowledge and resources in terms of time and flexibility, patients and professionals still experience a setting where care is dispensable; and care is a prerequisite of the total care idea in PC. Even when suffering from severe and complex symptoms, patients may not be referred to specialized palliative care, as a new report in Denmark has just confirmed.[14] This calls for further consideration on integrating PC in a HF setting.

One such consideration is knowledge and discourse. It seems necessary to change the discourse on HF and acknowledge that this is a life-threatening illness with a high rate of mortality for which PC is needed. In this study, professionals from PC conveyed that this intervention had made them recognize that although the trajectory of illness differs from cancer, the HF patient still experience PC needs.

Another consideration is the logic of the organisation. The dominating system logic must open up for a logic built on meaning making from the patients' lifeworld. This was also achieved in this project, but it was restricted to the study setting and was not sustainable. Considerations on time and flexibility in organization is also important. Patients need a safe and calm atmosphere to share from their life, and this demands an engaged professional and a flexibility in terms of how often or for how long sessions can be scheduled. These cannot be achieved without organizational support. Then, is the system logic in the HF setting undesirable? On the contrary. It is essential if we are to provide efficient treatment to the vast numbers of people suffering for cardiac conditions. Nevertheless, it is a paradox that a narrative PC approach proved valuable for both patients and professionals yet cannot be prioritized in a HF clinic. If arguments of value is restricted to efficiency, we seem to lose the argumentation for care in the HF setting.

The progress in integrated PC in HF treatment trajectory might not be explicitly evident, yet things may change. Internationally studies have been providing arguments on providing earlier involvement of PC in HF.[170,171] And the debate on promoting PC as an integrated part of standard HF treatment and care is showing in cardiac literature.[150,172] As mentioned in the background section, the acknowledgement of integrating PC for advanced HF has also been published in a Danish context.[40,173] Still I argue, that PC will not be feasible in cardiology until meaning making and understanding of the patient perspective is also made an explicit priority in both health care policy and the hospital as an organization.

A possible move forward could be to integrate PC for the HF patients closer to his and hers everyday life organised in primary health care in the municipality. A PhD from 2017[174] succeeded in developing an educational programme for professional caregivers in primary health care sector. Providing them with abilities to identify, initiate and evaluate PC services. This PhD project experienced commitment from all organizational levels and the author, argue that this made a difference in the implementation phase. Unfortunately, I did not have the same experience. Organizational leaders in the cardiology department changed during this PhD hence, so did the premise of our study.

Professionals' experiences on the difficulties in documenting a narrative and needs might also soon be resolved. At Holbæk Hospital, IT staff is working on building a new S' approach framework for the specific IT system 'Sundhedsplatformen' used at Region Zealand. Yet, when and how much documentation of the patient narrative is necessary should also be considered. For the patient, the documentation might be less important than the opportunity to share his or hers perspective.

One last important consideration is that of interdisciplinarity. Integration of PC in a HF clinic entails the essential element of interdisciplinarity. In future considerations it would be beneficial to have more focus on this. This study included an interdisciplinary seminar, workshop and conferences, which strengthened a PC approach in the HF clinic. However, the conference itself were not sufficiently evaluated in this study, leaving question unanswered.

Future Research

Several new research ideas was generated through this PhD process inspired by AR.

First, by the time we were at phase IV evaluating the PC intervention, only ethnic Danes remained. This is a problem as a recent cohort study[175] shows a higher incidence of heart diseases among non-Western immigrants compared to Danish-born. To get a more nuanced picture of the significance of integrated PC in HF, further research could target these non-western immigrant populations.

Second, as change is a process that takes time, it could be interesting to do a follow up study, exploring if change endures on a micro level enabling nurses to join perspectives despite the organisations dominating focus on cure from a professional perspective.

Third, as mentioned the setting of the highly specialised HF clinic might not be the best place to integrate PC for the patient suffering from HF. An AR study in primary health care could provide a different and hopefully more successful integration of general PC.

Fourth, some patients in this study were reluctant to participate in research activities with professionals. Future research could benefit from applying methods with the strategic aim of improving collaboration for change. Inspiration can be found from the Experienced Co-design[176] building on participatory action research, user-centred design, learning theory and narrative based approaches to change.[176]

Last, to change a cardiac practice it presumably takes more than an explorative study inspired by AR. Cost benefit studies or comparative RCT studies could complement our findings and build on the argument of providing general PC for the HF patient.

Summaries

English Summary

Patients with heart failure might experience unmet psychosocial and existential needs from the diagnosis onset, for which person-centred palliative care have shown relief. Compared to malignant disease the access to palliative care is restricted for the HF patient. In addition, the palliative care understanding, skills and competences in cardiology needs improvement.

This dissertation is based on a research project conducted at a local hospital in Region Zealand.

The overall aim of the PhD study was to develop, integrate and evaluate the significance of a general palliative care approach in a heart failure clinic based on patients' narratives.

Inspired by action research, the study was conducted in four phases following a pre-phase.

In the pre-phase, I contacted the cardiac management at Næstved, Slagelse and Ringsted Hospitals and formed a partnership between cardiology, REHPA and PROgrez. In addition, I spend a few days at the heart failure clinic and had informal talks with nurses. This made me realise that a learning strategy on person-centred palliative care was needed.

In the first phase, I identified unmet needs for patients living with heart failure. Moreover, I interpreted the dominant professional perspective from cardiology as a barrier for the heart failure patients to express needs. In collaboration with co-authors of study I, we identified the potential of using a narrative approach in palliative care interventions. As the findings from study I could not be transferred directly to our setting, we (researcher and professionals) chose to work with the S' approach.

The second phase of the project was the development phase. A seminar, a study trip to Hospice Djursland and a workshop provided education on palliative care and the possibility to discuss perspectives across palliative care and cardiology. Furthermore, it produced insight into the development of a person-centred palliative care intervention based on narratives.

In phase three, we piloted the intervention and with a few adjustments, we integrated it in the current standard treatment trajectory of heart failure.

The last phase was the evaluation phase, in which I used both observational design, in-depth interviews and feedback meetings to understand the significance and barriers of person-centred palliative care in a heart failure clinic.

Findings from the project have been reported in four scientific papers. Papers I and II present findings from phase one, Paper III from phase two and Paper IV from phase four.

Paper I is a systematic conducted integrative review study. It examined the use of personal narratives in palliative care interventions for people with life-threatening illness in a hospital setting. The study is based on 24 research papers: eight qualitative, 14 quantitative and two mixed methods. Providing evidence on dignity therapy, legacy building, outlook, short-term life review and life review. Data analysis showed that common to these interventions is a shared theoretical understanding and therapeutic aim. In addition, we found that a clinical application in a hospital setting was acceptable but flexibility regarding the setting and the needs of the patient is necessary.

Paper II reports from a qualitative study of the experience of living with heart failure and current treatment. This study is based on six individual interviews. Data analysis showed an understanding of living with heart failure as a continuous Sisyphean struggle with unmet psychosocial and existential problems. In addition, this study showed how the dominating professional perspective in standard heart failure treatment discouraged the patient to convey needs of such character.

Paper III reports from the workshops during the development phase. Data consisted of notes, field notes and summaries from two workshop days. The method used tension as a facilitator for dialogue and this enabled the process of generating insights into different perspectives. Furthermore, it created relational engagement among interdisciplinary professionals and ownership with the development process. The analysis showed that integrating palliative care principles into cardiology is a complex issue. Acknowledging such considerations, we designed an intervention centred on the elements of standard heart failure treatment, integrated palliative care sessions applying a narrative approach and monthly interdisciplinary conferences.

Paper IV reports on an outcome evaluation study focused on the lived experience of the heart failure patient. This study is based on 12 individual interviews. The study showed that heart failure patient found the integrated palliative care intervention significant in various ways. They felt recognised and ultimately they felt supported in both physical, psychosocial and existential problems.

In conclusion, the findings of this PhD study indicate that a narrative palliative care approach in a heart failure clinic was meaningful, acceptable and possible given the right conditions. Professionals conveyed a change when it comes to including the patient perspective in care and treatment. However, on an organizational level, changes have not been persistent and a palliative care approach has not been fully integrated. For an organizational change, policy makers must first recognize lifeworld rationale as valuable arguments in health care. Because there is no reason to doubt the importance of person-centred palliative care in a life-threatening illness like heart failure. Hopefully, this PhD can help contribute to such a debate.

Dansk Resumé

Patienter med hjertesvigt oplever udækkede psykosociale og eksistentielle behov helt fra diagnosestart. Disse behov kan lindres med en palliativ indsats. Sammenlignet med malign sygdom er adgangen til palliation dog begrænset for patienter med hjertesvigt. Derudover mangler der viden og palliative kompetencer indenfor kardiologi.

Denne afhandling er baseret på et forskningsprojekt udført på et lokalt hospital i Region Sjælland.

Det overordnede mål var at udvikle, integrere og evaluere betydningen af en basal palliativ tilgang i en hjertesvigtsklinik baseret på patienters fortællinger.

Inspireret af aktionsforskning blev undersøgelsen opdelt i fire faser efter en før-fase.

I før-fasen kontaktede jeg kardiologisk ledelse på Næstved, Slagelse og Ringsted hospital og dannede et partnerskab mellem kardiologi, PROgrez og REHPA. Derudover tilbragte jeg et par dage på hjertesvigtsklinikken, hvor jeg havde uformelle samtaler med sygeplejersker. Dette fik mig til at indse, at en læringsplan for en personcentreret palliativ indsats var nødvendig.

I første fase identificerede jeg udækkede behov for patienter, der lever med hjertesvigt. Derudover tolkede jeg det dominerende professionelle perspektiv fra kardiologi som en barriere for at hjertesvigtspatienterne udtrykker deres behov overfor professionelle. I samarbejde med medforfattere af studie I, identificerede vi potentialer ved at bruge en narrativ tilgang i palliative interventioner. Da resultaterne fra studiet ikke kunne overføres direkte til hjertesvigtsklinikken, valgte vi (forsker og professionelle) at arbejde med S' tilgangen.

Anden fase af projektet var udviklingsfasen. Et seminar, et studieophold på Hospice Djursland og workshops muliggjorde en metode til at diskutere perspektiver og gav indsigt der kunne bruges i udviklingen af en personcentreret palliativ intervention.

I fase tre afprøvede vi interventionen gennem et pilot studie, og efter et par justeringer integrerede vi den i nuværende standardbehandling af hjertesvigt.

Den sidste fase var evalueringsfasen, hvor jeg brugte både observationsdesign, dybdegående interviews og tilbagemelding fra den interdisciplinære projektgruppe til at forstå betydningen af og barriere for at integrere en personcentreret palliativ indsats i hjertesvigtsbehandling.

Resultater fra projektet er rapporteret i fire videnskabelige artikler. Artikel I og II præsenterer fund fra fase et, Artikel III fra fase to og Artikel IV fra fase fire.

Den første artikel var et systematisk gennemført integrativt litteraturstudie. Her undersøgte vi brugen af personlige fortællinger i palliative interventioner for mennesker med livstruende sygdom på et hospital. Undersøgelsen er baseret på 24 forskningsartikler: otte kvalitative, 14 kvantitative og to mixed-method. Det bidrog med evidensbaseret viden om dignity therapy, legacy building, outlook, short-term life review and life review. Dataanalysen viste, at fælles for disse interventioner er en psykoterapeutisk teoretisk forståelse og målsætning. Derudover fandt vi, at en klinisk anvendelse i en hospitalssetting var både gennemførlig og acceptabel, men krævede fleksibilitet med hensyn til praksis og patientens behov.

Artikel II rapporterer fra en kvalitativ undersøgelse af oplevelsen af at leve med hjertesvigt og den nuværende behandling. Denne undersøgelse er baseret på seks individuelle interviews, og dataanalyse viste en forståelse af at leve med hjertesvigt som en kontinuerlig Sisyfos-kamp med udækkede psykosociale og eksistentielle problemer. Desuden viste dette studie, hvordan det dominerende professionelle perspektiv i standard hjertesvigtbehandling fik patienten til at fortie behov af en sådan karakter.

Artikel III rapporterer fra en workshop i udviklingsfasen. Data består af noter, feltnotater og resuméer fra de to workshop dage. Metoden brugte spænding som en facilitator for dialog, og dette muliggjorde processen med at generere indsigt i forskellige perspektiver. Desuden skabte det et relationelt engagement blandt tværfaglige professionelle og ejerskab med udviklingsprocessen. Analysen viste, at integrering af palliative plejeprincipper i kardiologi er et komplekst emne. Med hensyntagen til sådanne overvejelser designede vi en intervention centreret om elementerne i standard hjertesvigtbehandling, personcentreret palliativ indsats gennem en narrativ tilgang og månedlige tværfaglige konferencer.

Den sidste artikel rapporterer fra en evaluering af resultatet med fokus på hjertesvigtspatientens levede oplevelse. Dette studie er baseret på 12 individuelle interviews. Studiet viste, at hjertesvigtpatienter fandt den integrerede palliative intervention signifikant på flere måder. De følte sig anerkendt og støttet i både fysiske, psykosociale og eksistentielle problemer.

Afslutningsvis viser resultaterne af denne ph.d. undersøgelse, at en narrativ palliativ tilgang i hjertesvigtsbehandling var meningsfuld, acceptabel og gennemførbar under de rigtige forhold. Professionelle inkluderer nu patientperspektivet i pleje og behandling. På organisatorisk niveau har ændringer dog ikke været vedvarende og en palliativ indsats er ikke blevet integreret. For at opnå en organisatorisk ændring må sundhedspolitikere først anerkende livsverdens rationaler som værdifulde argumenter i sundhedsindsatsen. Forhåbentlig kan denne ph.d. bidrage til en sådan debat.

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Paper I

The use of personal narratives in hospital-based palliative care interventions: An integrative literature review

Roikjær SG, Missel M, Bergenholtz HM, Schønau MN, Timm HU

Palliat Med. 2019 Dec;33(10):1255-1271. doi: 10.1177/0269216319866651. Epub 2019 Aug 1. PMID: 31368845.Paper II

Review Article

PALLIATIVE MEDICINE

Palliative Medicine
1–17

DOI: 10.1177/0269216319866651
journals.sagepub.com/home/pmj
SAGE

The use of personal narratives in hospital-based palliative care interventions: An integrative literature review

Stine Gundtoft Roikjær[1,2,3], Malene Missel[4], Heidi Maria Bergenholtz[3,5], Mai Nanna Schønau[4,6] and Helle Ussing Timm[1,3]

Abstract

Background: People living with life-threatening illness experience unmet existential needs despite the growing research and clinical field of palliative care. Narrative interventions show promise in managing these problems, but more knowledge is needed on the characteristics of narrative interventions and the feasibility of using personal narratives in a hospital.

Aim: To review the literature on personal narratives in hospital-based palliative care interventions and to strengthen palliative care practices.

Design: We conducted a systematic integrative review with qualitative analysis and narrative synthesis in accordance with PRISMA where applicable (PROSPERO#:CRD42018089202).

Data sources: We conducted a systematic search in PubMed, Embase, Scopus, Cinahl, SocINDEX and PsychInfo for primary research articles published until June 2018. We assessed full-text articles against the eligibility criteria followed by a discussion of quality using the Critical Appraisal Skills Programme.

Results: Of 480 articles, we found 24 eligible for this review: 8 qualitative, 14 quantitative and 2 mixed methods. The articles reported on dignity therapy, legacy building, outlook, short-term life review and life review. Data analysis resulted in five themes: core principles, theoretical framework, content of narrative, outcome and, finally, acceptability and feasibility.

Conclusion: Various types of systematic palliative care interventions use personal narratives. Common to these is a shared psychotherapeutic theoretical understanding and aim. Clinical application in a hospital setting is both feasible and acceptable but requires flexibility regarding the practices of the setting and the needs of the patient.

Keywords

Hospital care, narrative, palliative care, psychological well-being, quality of life, review, storytelling

What is already known about the topic?

- Psychosocial and existential care are important elements in palliative care, but patients still experience unmet psychosocial and existential needs.
- Narrative interventions in palliative care seem promising in managing psychosocial and existential problems.
- No synthesis currently exists on the use of personal narrative interventions in hospital interventions.

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[1]Clinical Studies, University of Southern Denmark, Odense, Denmark
[2]Department of Medicine 2, Naestved, Slagelse and Ringsted Hospitals, Slagelse, Denmark
[3]Knowledge Centre for Rehabilitation and Palliative Care, REHPA, Nyborg, Denmark
[4]Department of Thoracic Surgery, Rigshospitalet, Copenhagen, Denmark
[5]Department of Medicine and Surgery, Holbaek Hospital, Holbaek, Denmark
[6]Department of People and Technology, Roskilde University, Roskilde, Denmark

Corresponding author:
Stine Gundtoft Roikjær, Department of Medicine 2, Naestved, Slagelse and Ringsted Hospitals, Ingemannsvej 30, 4200 Slagelse, Denmark.
Email: sgro@regionsjaelland.dk

What this paper adds?

- This article reviews the literature on using personal narratives in hospital-based palliative care interventions.
- This review finds that palliative care interventions using personal narratives share a common psychotherapeutic understanding, but different systematic interventions exist.
- This review finds that facilitating personal narratives serves a function in affecting the individual's sense of meaning and is both acceptable and feasible in a hospital setting.

Implications for practice, theory or policy

- This review finds that using personal narratives in hospital-based palliative care can be managed in a hospital setting but requires a systematic approach and consideration for practice and individual needs.
- This review recommends further research to focus on the theoretical foundation, ethics, outcome and general palliative care.

Introduction

Palliative care is an approach that aims to enhance the quality of life of people with a life-threatening illness by relieving physical, psychosocial and existential problems and by supporting patients and families in preparing for death and coping with grief.[1] Historically, palliative care has been interlinked with the hospice philosophy.[2] The original definition of palliative care focused on patients with cancer who did not respond to curative care.[3] In 2002, this definition broadened to include all patients living with life-threatening illness.[4] Furthermore, palliative care is now recommended to be implemented along with curative care.[1] At the curative stage, people living with life-threatening illness are primarily in contact with a hospital, and thus, the hospital faces a task in planning and implementing a palliative care strategy in addition to their conservative tasks.

Although the field of palliative care is continually growing, most current research still focuses on relieving the physical problems of people with cancer and is most often restricted to specialized palliative settings. The lack of palliative interventions in hospitals has partly been credited to the historical context of hospitals and the culture of medicine as a curative discipline, resulting in a lack of skills in palliative care and a knowledge gap in research.[5,6] Furthermore, the specific research focus on physical problems has left patients with unmet emotional needs and experiencing a lack of psychosocial support.[7]

These gaps in palliative care might have contributed to the growing interest in narrative interventions.[8] Narrative theory has its theoretical roots in socio-narratology and psychotherapy.[9,10] The concept of 'narrative' represents different operational methods to provide meaningful patterns to experiences, events or even ideas. This study uses 'personal narratives' as the individual patient's story reflecting and representing his or her experiences in life and illness constituting 'the self'.[11] A narrative intervention is an intervention based on these personal narratives.

Narrative interventions have shown promise in addressing existential and psychological domains, but, to our knowledge, personal narrative interventions have not been systematically reviewed in relation to palliative care in the specific setting of the hospital.[8,12,13] We therefore aimed to review and synthesize current evidence on using personal narratives in palliative care interventions conducted in a hospital-based setting for people with life-threatening illness by answering these research questions: (1) What characterizes personal narrative interventions in hospital-based palliative care? (2) What is the purpose and significance of personal narrative interventions for the patients? (3) How does general palliative care provide for using personal narratives?

Methods

Design

We chose the integrative review design[14] to examine the characteristics of narrative interventions in palliative care and provide a holistic and critical synthesis of the literature because of its ability to search, assess and synthesize different types of research designs on a topic for further use in clinical practice.[14]

This study reports on findings in adherence to the preferred reporting items for systematic reviews and meta-analyses (PRISMA)[15] statement where applicable and has been registered on PROSPERO: https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=89202.

Information source and searches

We performed the initial literature search using PubMed to provide background knowledge on the narrative methods used in palliative care. Table 1 lists the search terms and strategies.

We analyzed articles from this initial search regarding search terms, index words and text words, and afterwards discussed with a research librarian. We then adjusted the

Table 1. Search strategy terms.

#1	Hospice Care [Mesh, Title/Abstract]
#2	Terminal Care [Mesh, Title/Abstract]
#3	Palliative Medicine [Mesh, Title/Abstract]
#4	Palliative Care [Mesh, Title/Abstract]
#5	Supportive Car* [Title/Abstract]
#6	Advance Care Planning [Mesh, Title/Abstract]
#7	End of life care [Title/Abstract]
#8	Palliative care nursing [Mesh, Title/Abstract]
#9	Psychosocial Support [Mesh, Title/Abstract]
#10	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9
#11	Narrative Therapy [Mesh, Title/Abstract]
#12	Narrative Method* [Title/Abstract]
#13	Narrative approach* [Title/Abstract]
#14	Narrative design* Title/Abstract]
#15	Narrative intervention* [Title/Abstract]
#16	Narrative theor* [Title/Abstract]
#17	A good death [Title/Abstract]
#18	Living and dying [Title/Abstract]
#19	Dignity therapy [Title/Abstract]
#20	Story telling [Title/Abstract]
#21	Life review* [Title/Abstract]
#22	#11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21
#23	#10 AND #22

final search terms and keywords to each of the chosen databases: PubMed, Embase, Cinahl, PsychInfo, SocINDEX and Scopus. We searched in December 2017 with an update in June 2018. Furthermore, we screened the reference lists of all included studies for additional studies accompanied by manual searching and expert guidance. We limited the review to studies published in English, Danish, Swedish or Norwegian.

Study selection

To minimize bias, two co-authors reviewed the articles. We sorted the articles into three piles and divided them among the reviewers (the co-authors) for individual screening and critical assessment. The first author screened and assessed all articles. We initially screened the articles by titles, abstracts and then full text. We critically assessed full-text articles based on the eligibility criteria followed by a discussion of research rigour using the Critical Appraisal Skills Programme (CASP),[16] at least the first author and one co-author. In case of discrepancies, we included a third reviewer.

The articles included met the following inclusion criteria: (1) presented findings from primary research, (2) included palliative care interventions using personal narrative, (3) were conducted in a hospital setting and (4) included patients with a life-threatening illness who needed palliative care. We excluded studies involving children and young adults, since research shows that the organization and service of palliative care for children differs from that of adults.[17,18] We also excluded studies exclusively conducted in community-based settings and hospice. The PRISMA flow chart shows the details of the search and screening process (Figure 1).

Quality assessment

Because this review aimed to synthesize data for further use in clinical practice and included both quantitative and qualitative studies, we chose the CASP in the quality assessment process. The CASP addresses research from a clinical perspective and uses a checklist to systematically discuss three broad questions: Are the results of the study valid? What are the results? and will the results help locally?[16] The CASP checklists were conducted individually and then discussed by the first author and the respective co-author.

Data analysis

The analysis followed the framework of Miles et al.,[19] with the steps of data reduction, data display, data comparison, conclusion drawing and verification. As recommended by Whittemore and Knafl[14] for conducting an integrated review, we initiated the data reduction by dividing the primary sources into subgroups. We performed a unique thematic analysis under each subgroup and finalized the review by synthesizing the important elements of each subgroup into an integrated summation of the use of personal narratives in hospital-based palliative care interventions.

We chose to classify the subgroups under the headings: the voice of the patients, feasibility and acceptability, and effect and efficacy. The first author and co-authors independently extracted data with a previously designed data extraction tool. We piloted the data extraction tool on articles from each subgroup and, after small adjustments, completed the remaining data extraction. We extracted information from each included study on such characteristics as author, year, participants, design, setting, methods and results. Furthermore, we extracted data on the intervention characteristics: framework, facilitator, place and ethical considerations.

Results

Study characteristics

We included 24 clinical studies: 8 qualitative,[20–27] 14 quantitative[28–41] and 2 mixed methods[42,43] (Table 2). Among these, six sets of articles reported results from the same intervention and population. Hack et al.[21] reported on qualitative findings from Chochinov et al.,[35]

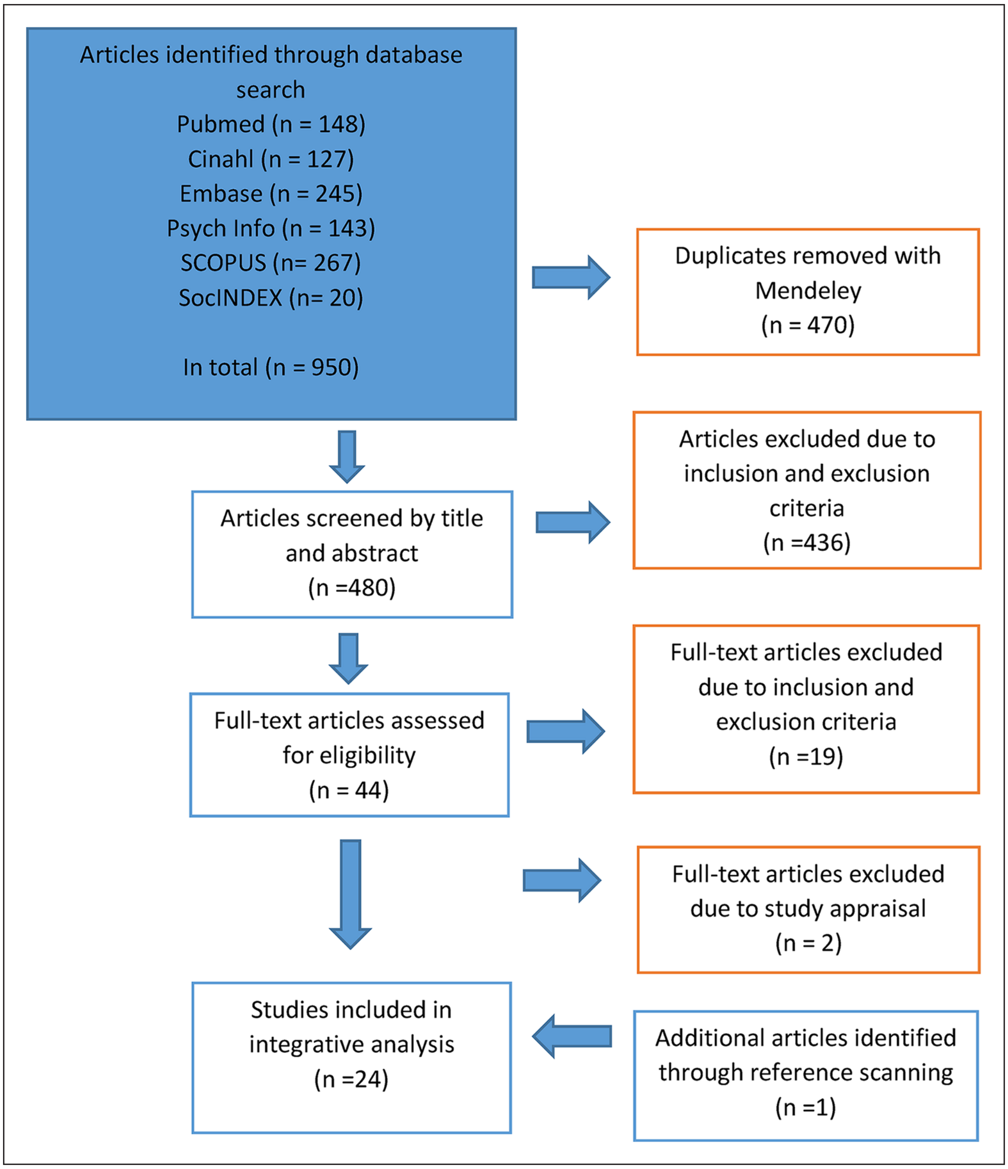

Figure 1. PRISMA flow chart.

Steinhauser et al.[25] reported on qualitative findings from Steinhauser et al.,[40] Dose and Rhudy[20] reported on qualitative findings from Dose et al.,[30] Vuksanovic et al.[27] reported on qualitative findings from Vuksanovic et al.,[41] Julião et al.[39] reported on secondary outcomes from Julião et al.[38] and Hall et al.[22,36,42] reported from the same randomized controlled trial (RCT). Furthermore, the same research team led by Ando et al.[31–33] was responsible for the studies conducted in Japan and Houmann et al.[23,37] for the studies conducted in Denmark. In total, the articles reported on five narrative interventions in hospital-based settings from 17 populations: life review,[31] short-term life review,[32,33] outlook,[24,25,40] legacy building[28] and dignity therapy.[20–23,26,27,29,30,34–39,41–43]

Of the 24 studies, 6 were conducted in the United States;[20,25,28,30,34,40] 3 in the United Kingdom;[22,36,42] 3 in Australia;[24,27,41] 3 in Japan;[31–33] 2 in Portugal;[38,39] 2 in Denmark;[23,37] 2 in Canada and Australia;[21,29] 1 in Canada, the United States and Australia;[35] 1 in Canada[26] and 1 in Germany.[43]

The quantitative studies used either RCT[31,33,35,36,38–41] or pre–post intervention design.[28–32,34,37] The dignity therapy intervention had the highest number of study samples and was carried out in the United States,[20,28,30,34,35]

Table 2. Summary of included studies ($n = 24$).

Reference, reviewer.	Study aim	Intervention, design, sample size	Population, setting	Outcome/objective	Methods	Results	Study appraisal CASP
The voice of the patients							
Dose and Rhudy[20] Reviewers: S.G.R. + M.M.	To identify what individuals with advanced pancreatic or lung cancer describe during dignity therapy (DT) as important to them when they are facing the possibility of personal mortality but not immediate end of life.	DT. Qualitative descriptive approach as part of a mixed method study. $N = 20$	The United States. Pancreatic or lung cancer within 12 months of diagnosis. Outpatient chemo suite. General palliative care (GPC).	Explore the content of the narrative.	Qualitative analysis of the unedited DT interview transcript. NVivo 11.0 software. Content analysis.	Family was the context of all themes. Emerging themes: defining events; accomplishments; Gods plan; lessons learned; message of hope. Few participants spoke of their illness! DT was an opportunity to talk about life, not illness.	Focused issue. Design and methods are well-fitted for the purpose of exploring the patient perspective. Authors used consent analysis techniques. Analysis and codings are described. All themes and their interrelatedness are described. No theoretical discussion of findings. Demonstrate a possibility to provide a DT intervention for patients in complex treatment regimens for those still undergoing active treatment for advanced cancer.
Hack et al.[21] Reviewers: S.G.R. + M.M.	To capture the voices of the dying, to hear what matters most to them as they reflect on their lives as death approaches.	DT. Qualitative analysis of DT transcripts from a larger RCT. $N = 50$	Canada and Australia. Terminally ill patients. Cancer centres and community hospitals. Specialized palliative care (SPC).	Explore the content of the narrative.	50 random DT transcripts were read and coded using content analysis and constant comparing analysis techniques with a grounded theory approach.	The reflections of the patients are imbued with their core values. The most prominent core values were family; pleasure; caring; a sense of accomplishment; true friendship; rich experience. These are described in the context of personal account, significant life event and illness experience. Furthermore, the narrative elicited a variety of functions of affirmation, personal ethic, wishes, contentment, turning point, regret, gratitude and role identification as the most prominent.	There is an in-depth description of the coding process, analysis and of who did what. Findings are discussed in terms of value theory, the role of DT and values clarification.
Hall et al.[42] Reviewers: S.G.R. + M.M.	Explore in detail the impact of DT on distressed cancer patients.	DT. Case study from a completed phase II mixed-method RCT. $N = 3$	The United Kingdom. Advanced cancer patients. Hospital. SPC.	Explore the patients' main dignity-related problems.	Patient Dignity Inventory (PDI). Survey questionnaire. Interviews. Three patients with the highest level of dignity-related distress who received DT were explored in depth. Two recipients of the generativity document were interviewed.	The women were experiencing a wide range of problems and appreciated the opportunity to talk about their concerns to the therapist. Some of these problems could be expected to be helped by DT, however, most could not. Patients felt that DT had helped them and their families, but DT is not suitable to relieve physical symptoms or social problem. Some problems returned, and new problems emerged as the women's condition deteriorated.	Argue for the use of case study. Outcome measures are described. The authors refer to their other studies to get the details of the methods used.
Hall et al.[22] Reviewers: S.G.R. + M.M.	Explore intervention and control participants' perception of benefits of taking part in an evaluation of DT within the frame of the underlying model of the intervention.	DT. Qualitative study. $N = 45 + 4$ husbands, 3 sisters, 1 daughter and 1 friend.	The United Kingdom. Cancer patients from a phase II RCT (Hall et al.[36]). NHS Hospital trust UK. SPC.	Explore the patients' perception of benefits.	Semistructured interviews and a framework approach to qualitative analysis.	Support for 5 out of 7 themes from the DT model: generativity; continuity of self; maintenance of pride; hopefulness; care tenor. All but generativity were evident in both groups. Emerging themes in intervention group: reminiscence and pseudo-life review (LR). In control group: making a contribution. Both groups perceive similar benefits from taking part of the study.	The authors have discussed their own role by stating that qualitative interviews and questions about dignity and illness-related issues gave patients in both groups the opportunity to talk about the problems – and this might explain the participants' experienced benefits in both groups. The study is very much based on empirical findings and empirical discussions. Theoretical perspectives could have broadened our understanding of the findings. Four authors were involved in agreeing on the analysis.
Keall et al.[24] Reviewers: S.G.R. + H.B.	To explore the perception that individuals with life-limiting illnesses have about their lives, both positive and negative, and their message to future generations.	Outlook. Qualitative analysis of the intervention interviews. $N = 11$	Australia. Adults with a life-threatening diagnosis and <2 years life expectancy. Hospice and tertiary referral hospital. SPC.	Explore the content of the narrative.	Interpretive phenomenological analysis (IPA) was used in the analysis.	Eight subthemes under three overarching themes. 1) LR: Self-identity; accomplishments; conflicts; regrets. This overarching theme included the ways in which the participant described themselves and their interactions with others, memories, achievements and regrets. 2) Current situation: current quality of life (QoL); losses as a palliative care patient; current goals. This theme included what contributes to their QoL and what has a negative effect on them. 3) Legacy/principles: principles; legacy. This theme included advice for future generations and how the participants wished to be remembered.	Ethical considerations only discussed briefly. No discussion of the role of the palliative care nurse who undertook the intervention. IPA is described and the analysis is detailed. A possible bias is that only the ones who are comfortable with their life may be willing to discuss it with a stranger. Four out of 11 accepted the audio recording.

(Continued)

Table 2. (Continued)

Reference, reviewer.	Study aim	Intervention, design, sample size	Population, setting	Outcome/objective	Methods	Results	Study appraisal CASP
Steinhauser et al.[25] Reviewers: S.G.R. + H.B.	To report the development of the intervention as well as qualitative findings on pilot RCT on Outlook.	Outlook. Pilot RCT with qualitative analysis of intervention interviews. $N = 18$	The United States. Life-threatening illness <6 months life expectancy. Palliative care setting: hospice, homecare, rehabilitation centre, inpatient units at University medical centre. SPC.	Describe the development of their conceptual model. Explore the content of the narrative.	Intervention discussions were audio recorded, transcribed and analyzed using grounded theory methodology.	Life story: Most participants tell stories of birth and childhood. Both positive and negative. Illness was often framed as an interruption in the story. *Cherished times* always included social connections and *accomplishments* were divided between work/careers and education, children, financial stability, work with the church and ability to cope with illness. Forgiveness: *Things done differently and regrets* focused on relationship, education and health in an overall arc of important life lessons. *Forgiveness asked and offered*; most said they did not have need to ask or offer forgiveness. *Peace*; 1/3 were not at peace and themes included fear, sadness, loss, and the inability to fulfil previous roles. Heritage and Legacy: *Lessons learned;* lessons taught in childhood and intrapersonal themes. *Lessons to share with loved ones*; often advice designed to steer children from bad choices. *Advice to other generations*; often pertained to interpersonal relationship with larger issues of finding god, promoting peace or expanding ones view. *Legacy*; most participants relayed personal characteristics by which they wanted to be remembered.	Ethical issues not discussed. Since this is the qualitative findings from a larger RCT it is not stated clearly what the aim of this particular study is. The researcher's role in the study is not discussed. Discusses findings with the theory of both Frankl and Rousseau, Cassell's and Byock's theory of suffering as a result as threats to our integrity, as well as Giddens.
Tait et al.[26] Reviewers: S.G.R. + M.N.S.	To systematically examine the thematic dimensions and recurrent narrative features that emerge in narratives told in response to the DT protocol.	DT. Qualitative design with interviews and a framework of rhetorical genre studies. $N = 12$	Canada. Patients at the end-of-life interviewed by resident physicians. Palliative care setting in two University of Toronto academic hospitals. SPC.	Explore the content of the narrative.	Semistructured DT interviews. Rhetorical analysis with a constant comparative approach and group discussions of emergent thematic patterns.	Three narrative types emerged: 1) Evaluation narratives. Subthemes: 'Recounted narratives' (their heritage, their parents, their upbringing) 'Maturation' (marriage, children, spouses, careers) 'Social lives and travels' 2) Transition narratives. Impact of past events on the context of dying. 3) Legacy narratives. Subthemes: 'Newfound perspectives' 'How patients believed their loved ones should conceive of time'. 'Advice on how loved ones should move on with their lives'.	Lacks in-depth description of the analysis process, but position the study within the theoretical framework of rhetorical genre studies. Researchers have not critically examined their own role, potential bias and influence during analysis and selection of data. Convenience sample. Discussion draws on narrative and rhetorical theory.
Vuksanovic et al.[27] Reviewers: S.G.R. + M.M.	To explore, compare and better understand the content of standard DT, waitlist DT and LR. Part of a larger study (Vuksanovic et al.[41])	DT. LR. Interview transcript was analyzed using qualitative methods. $N = 56$	Australia. Adults with advanced terminal disease <12 months life expectancy. SPC.	Explore the content of the narrative.	The framework method for analysis of qualitative data. LR interview transcripts. DT and waitlist DT legacy document.	Themes prevalent in all groups: belief, values, memories, and important relationship with the majority also indicating at least some sense of meaning and acceptance despite disappointments, regret and the impact of illness. Themes most prevalent in legacy documents: Sense of legacy, fighting spirit, and hope. Themes most prevalent in LR interview transcripts: relationship regrets, self-blame, unfinished business, and aftermath concerns. Themes of spirituality, illness impacts and unfinished business were relatively less common in waitlist DT participant. 93.3% of family members reported DT to be helpful.	It is not easy to distinguish between primary and secondary outcomes. The legacy creation component of DT was facilitative of exploration of resilience, hope and enduring sense of legacy but possibly to the detriment of deeper exploration of themes such as interpersonal regrets, unfinished business and concerns about the aftermath. The study is valuable when deciding which intervention to use to meet the individual patient's needs and wishes and therapeutic goals. Primarily a deductive approach. Briefly mention Erikson in the discussion section.

(Continued)

Table 2. (Continued)

Reference, reviewer.	Study aim	Intervention, design, sample size	Population, setting	Outcome/objective	Methods	Results	Study appraisal CASP
Feasibility and acceptability							
Bernat et al.[28] Reviewers: S.G.R. + M.M.	To assess the feasibility and acceptability of a web-enhanced and abbreviated DT intervention to determine if it could be a user-friendly alternative to traditional DT.	DT + Legacy building (LB). Feasibility and acceptability study. Pre–post intervention. $N = 16$.	The United States. Cancer. <50% chance of 1 year survival. Recruitment rate 36.4% GPC.	Feasibility. Acceptability. Existential well-being. Dignity.	Percentage of completion of surveys. Percentage of participants who completed a legacy project and percentage of participants who used the web portal. Survey questionnaire. Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale (FACIT–Sp.) PDI.	69% completed legacy projects. Patient satisfaction with intervention and the final legacy project was high; Intervention: M = 8.82, SD = 1.08 Final legacy project: M = 8.55, SD = 1.13 45% used the web portal to finish their project – others used WORD. 80% of the participants that used the web portal reported dissatisfaction. No significant outcome on well-being and dignity.	Patients received US$25 gift cards for completing surveys. Qualitative inquiries into web skills before the intervention might have provided better acceptability and satisfaction with the portal. Small sample. Recruitment rate was low (16%) and the protocol had to be adjusted accordingly. Participants reported high levels of existential well-being and low levels of dignity-related distress at base – hard to show improvements.
Chochinov et al.[29] Reviewers: S.G.R. + M.M.	To establish the feasibility of DT and determine its impact on depression, dignity, anxiety, suffering, hopefulness, desire for death, suicide and sense of well-being.	DT. Pre–post intervention study. $N = 100$	Canada + Australia. 97% cancer, 3% non-malignant with a life expectancy <6 months. SPC.	Feasibility, depression, dignity, anxiety, suffering, hopefulness, desire for death, suicide, sense of well-being, QoL and symptoms.	Baseline psychometrics. Single-item screening instruments. Seven-point scale. A 2-item QoL instrument. Satisfaction survey. Wilcoxon signed-rank test.	Qualitative finding: Refusal rate 19.6%; Withdrawal 22%; 91% reported feeling satisfied or highly satisfied; 86% that DT was helpful or very helpful; 76% that it heightened their sense of dignity; 68% that DT increased their sense of purpose; 67% that DT heightened their sense of meaning; 47% that DT increased their will to live. Quantitative outcomes: Significant improvement in suffering; $p = 0.023$ Depressed mood $p = 0.05$ Improvement in dignity $p = 0.085$ No improvement in hopelessness, desire for death, anxiety, will to live and suicide.	Authors account for some factors that can have a negative effect on the result, but not for any that could have had a positive result. No follow-up. Negative results are only reported in the text, not with statistical numbers. Correlations are reported. No confidence intervals are given. They report qualitative findings in percentages and without a qualitative method.
Dose et al.[30] Reviewers: S.G.R. + M.M.	To determine feasibility and acceptability of a DT/life plan intervention for patients with advanced cancer.	DT + life plan. Pilot descriptive study. Pre–post. $N = 18$	The United States. Life expectancy > 6 months. Pancreatic and non-small lung cancer – 12 months after diagnosis and still in treatment. GPC.	Feasibility. Acceptability.	Demographic data. Was it worth it questionnaire 1–5 with 5 indicating greater acceptability. CONSORT flow diagram.	Acceptability: Satisfaction with process 3.89 (Pancreas) 4.78 (Lungs) Recommend to others 4.22 (Pancreas) 4.89 (Lungs) DT helpful to develop life plan 3.78 (Pancreas) 4.11 (Lung) Feasibility: 45 patients approached – 20 declined – 7 withdrew – 18 completed. Study completion rate was 90%.	Missing detailed description of the life plan element. Because treatment schedules varied depending on chemo-therapy regimen or delays related to treatment toxicities, the study procedures were adapted to meet the goal of accommodating treatment schedules. Some participants have phone interviews others face to face. All participants accounted for.
Houmann et al.[23] Reviewers: S.G.R. + M.M.	To test the acceptability and feasibility of the DT question protocol (DTQP) among Danish health professionals and cancer patients, and to obtain preliminary estimates of patients' uptake for DT.	DT. Feasibility study. Qualitative design. $N = 20$ (patients) $N = 10$ (health professional)	Denmark. Patients with incurable cancer. Healthcare professionals (HCPs). Hospice, hospital department of palliative medicine and a hospital department of oncology. SPC. GPC.	Comprehension, acceptability and relevance.	Interviews. Implementation of DT. Examining the acceptability of the DTQP for patients. Systematic content analysis.	Professionals had both positive and negative views on DT. The positive was that the questions were found relevant and important. The negative was grouped into six concerns: too existentially confronting issues; cognitively challenging issues; unacceptable self-praise; overlap; inappropriate word /phrasing; interference with the lives of others. The patients have similar concerns, except very little patient data supported the professionals' concern regarding existentially confronting questions. Questions were understood and accepted; however, the findings suggest that Danish patients are resistant to talk about things perceived as self-praise and had difficulties relating to the title DT.	Confusing explanation of participants, the numbers 25, 20 and 18 are stated as the included. Professionals' perception of DT was exclusive on the DT questions guide as they had never used them first hand. Therapist and patients seemed to be hesitant to some questions. Therapist-to-therapist variation can influence a feasibility study.

(Continued)

Table 2. (Continued)

Reference, reviewer.	Study aim	Intervention, design, sample size	Population, setting	Outcome/objective	Methods	Results	Study appraisal CASP
Mai et al.[43] Reviewers: S.G.R. + M.M.	To translate the DT questionnaire protocol and test the feasibility and acceptability of DT in an inpatient setting.	DT. Mixed-method multicentre study with questionnaires and semistructured interviews. HCP, $N = 12$ Patients (PT), $N = 30$ Family members, $n = 30$	Germany. Patients with terminal illness with life expectancy between 2 weeks and 12 months. SPC.	Feasibility and acceptability.	DTQP. Semistructured cognitive interviews. DT patient feedback questionnaire. DT family feedback questionnaire. Focus groups. Field notes, audio recording. Qualitative content analysis. SPSS.	HCP: five categories of comment on DT and DTQP: negative aspects of DT; positive aspects of DT; dignity therapist; conducting DT; and the DTQP. HCP further agreed that DT was feasible in a PCU setting and could be an essential part of PC for the patient if it was conducted with compassion. PT: four categories: the title, the DTQP, the wording, and the set of questions. PT had both positive and negative remarks. Some felt that questions could lead to openness about cancer, could preserve pride, and should be widely offered. Negative remarks were related to the effectiveness of DT or fear of psychological challenges. 18/19 PT evaluated DT as helpful and 18/19 satisfactory. All found it satisfactory in terms of psychosocial care. Family members evaluated DT as helpful, just as important as other aspects of care, and would recommend DT to others.	EORTC translation procedure. Researchers report on their own role as both a colleague and researcher. None of the HCP had conducted DT before evaluating the questionnaire. Participants accounted for. Qualitative analysis with example quotations. Small sample: 30 participants (out of 72 eligible) in DT, 29 in the following cognitive interviews and 19 returned a feedback questionnaire. 26 out of 30 family members provided feedback.
Vergo et al.[34] Reviewers: S.G.R. + M.M.	Assess feasibility of DT relatively early in the disease trajectory and, second, effect on death acceptance, distress, symptoms, QoL, peacefulness and advanced care planning.	DT. Feasibility study with pre–post outcome measures. $N = 15$	The United States. Patients with stage IV colectoral cancer. GPC.	Feasibility, death acceptance, distress, symptoms, QoL, peacefulness, advance care planning.	Success rate of enrolment and a satisfaction survey. Time impact analysis (TIA). Distress thermometer. Edmonton Symptoms Assessment System. 2-item QoL scale. Hypothetical Advanced Care Planning Scenario (H-CAP-S).	In terms of feasibility, 100% reported that they were satisfied or very satisfied with DT. 88% that DT was helpful or very helpful, 78% that it increased sense of dignity, 78% that it increased a sense of purpose, 88% that it increased sense of meaning, 67% that it increased a will to live and 88% reported that it was helpful to family. Lack of dropout shows that DT is at least risk neutral. No significant change in secondary outcomes was measured besides appetite and drowsiness. There was found a change in death acceptance, in non-life-prolonging goals of care and treatment choices over time.	Lacks power for statistical significance of findings. No control group. Cannot determine results to be caused by DT. Lacks a match of expected effect and outcome measures. No control group. Small sample. Reportings of results are poor and nothing is reported on QoL, peacefulness or ACP. However, primary outcome is feasibility.
Effect and efficacy							
Ando et al.[31] Reviewers: S.G.R. + H.B.	To (1) evaluate the treatment efficacy of LR interviews on the spiritual well-being of terminally ill cancer patients and (2) explore any differences in the responses of patients who obtained clinical benefits and those who did not.	LR Pre–post intervention study. $N = 12$	Japan. Cancer. Hospital. SPC.	Overall QoL. Spiritual well-being.	SELT-M (Skalen zur Erfassung von Lebens qualität bei Tumorkranken – Modified version). Statistical analysis: Wilcoxon sign rank test. Text mining and correspondence analysis between the effective and non-effective group	SELT-M: Physical well-being $p = 0.307$. Mood $p = 0.008$; Support $p = 0.237$. Orientation $p = 0.041$; Spirituality $p = 0.023$; overall QoL $p = 0.013$. Text-mining dimensions: +group: positive view of life; pleasure in daily activities and good human relationship; balanced evaluation of life. –group: worries about future caused by disease; conflicts in family relationship problems; confrontation of practical problems.	Small sample size 21 recruited – 12 participated. No control group. 'Many sessions were discontinued' – no further explanation. Limited generalizability to terminally ill cancer. No discussion of bias. Weak results; LR interviews *may* be effective in improving the spiritual well-being of terminally ill cancer patients. LR only effective for patients who have a positive view of life.
Ando et al.[32] Reviewers: S.G.R. + H.B.	To assess the efficacy of the STLR on the spiritual well-being, as well as anxiety, depression, suffering and happiness on terminal ill cancer patients.	Short-term life review (STLR). Pre–post study. $N = 30$	Japan. Cancer. Hospital and homecare clinic. SPC.	Spiritual well-being. Anxiety. Depression Suffering. Happiness.	FACIT-sp. Hospital Anxiety and Depression Scale (HADS). A numeric rating scale. Statistical analysis: Wilcoxon signed-rank test; correlation analysis; intention-to-treat.	$16 \pm 8.2/24 \pm 7.1$; $Z = -4.2$; $p = 0.001$ Total HADS: $17 \pm 8.6/9.5 \pm 5.4$; $Z = -4.1$; $p = 0.001$ Anxiety: $6.8 \pm 4.7/3.0 \pm 2.2$; $Z = -3.8$; $p = 0.001$ Depression: $10.2 \pm 4.7/6.6 \pm 4.1$; $Z = -3.7$; $p = 0.001$ Suffering: $3.4 \pm 1.9/1.8 \pm 1.4$; $Z = -3.5$; $p = 0.001$ Happiness: $4.6 \pm 1.9/5.6 \pm 1.6$; $Z = -3.2$; $p = 0.002$	Small sample size. 35 recruited – 30 participated. No discussion on confounding factors. No follow-up or control group. Limited generalizability. Positive but weak results – no clinical significance. The STLR is feasible, but cannot be established effective with this study. Discusses findings with a theoretical model of stress and coping.

(Continued)

Table 2. (Continued)

Reference, reviewer.	Study aim	Intervention, design, sample size	Population, setting	Outcome/objective	Methods	Results	Study appraisal CASP
Ando et al.[33] Reviewers: S.G.R. + H.B.	Primary: Efficacy of the STLR for enhancement of spiritual well-being. Secondary: Effect on anxiety, depression, suffering and good death.	STLR. RCT. $N = 68$	Japan. Cancer. Hospital. SPC.	Spiritual well-being. Anxiety. Depression Suffering. Good death.	FACIT-sp. HADS. A numeric rating scale. Statistical analysis: ANOVA; correlation analysis	Main effect between groups: FACIT-sp $p < 0.00$ Hope $p < 0.00$ Life Completion $p < 0.007$ Symptom $p < 0.18$ HADS $p < 0.00$ Burden $p < 0.31$ Suffering $p < 0.001$ Preparation $p < 0.37$ Pain $p < 0.091$	No blinding. Similar groups. All participants accounted for. The fact that difficult family problems and severe physical symptoms were exclusion criteria might have affected the results. Limited generalizability to cancer and terminal ill.
Chochinov et al.[35] Reviewers: S.G.R. + M.M.	To determine if DT could mitigate distress and/or bolster end-of-life experience for patients nearing death	DT. Multi-site RCT with three arms. $N = 326$	The United States, Australia, Canada. Terminal prognosis with a life expectancy of 6 months or less. Primarily cancer. Hospital and community-based palliative care. SPC.	Distress. QoL.	FACIT-Sp. PDI. HADS. Items from the Structured Interview for Symptoms and Concerns. QoL scale. Modified Edmonton Symptom Assessment scale. Self-report survey. Statistical analysis: Mann–Whitney *U*, ANOVA, Kruskal–Wallis, Tukey's test, Wilcoxon signed-rank test.	No significant difference across study arms in primary outcome of distress. Secondary outcomes showed DT to be more likely to be experienced as helpful ($p < 0.001$), improve QoL ($p < 0.001$), sense of dignity ($p = 0.002$), change how families see and appreciate them ($p < 0.001$) and be helpful to their family ($p < 0.001$). The DT's ability to mitigate distress is yet to be proven. There is, however, ample evidence supporting DT's clinical application for patients nearing death, as a means of enhancing their end-of-life experience.	It is difficult to get a significant outcome on distress if the baseline of distress is low. Generalizability should be framed in terms of those who maintain their cognitive capacity in proximity of death. The study has primarily involved patients with cancer; application in non-cancer populations has to be explored. Distress was considered important by the researchers; however, the study showed that distress was not a problem from the patients' perspective.
Hall et al.[36] Reviewers: S.G.R. + M.M.	Assess the acceptability and potential effectiveness of DT to reduce distress in people with advanced cancer.	DT. Phase II open-label RCT study. $N = 45$	The United Kingdom. Advanced cancer patients. Hospital. SPC.	1. Dignity-related distress. 2. Hope, anxiety and depression, QoL, palliative related outcome and self-reported study benefits	Palliative Dignity Inventory. Herth Hope Index. HADS. EQ-5D. Two-point Likert-type scales. Self-reporting. Statistical analysis.	No difference in dignity-related distress at any time. A reduction of hope in control group and a slight increase of hope in DT group with an effect size of 0.20 after 1 week and 0.15 after 4 weeks. No difference on other secondary outcomes. The intervention group was more positive than the control group in self-reported benefits.	45 participants of 188 eligible. 27/45 at 1-week follow-up. 20/45 at 4-week follow-up. All patients accounted for. Response rate is low, attrition rates high and baseline levels of distress were low. Assess adherence to protocol. The self-reported benefits measure DT or taking part in the study, making it difficult/irrelevant to use the same questionnaire. Results do not support implementing DT on its own. The influence of DT on more overt distress will need to be determined in patient populations where baseline distress is more pronounced.
Houman et al.[37] Reviewers: S.G.R. + M.M.	To investigate participation in and evaluation of DT and longitudinal changes in patient-rated outcomes.	DT. Prospective evaluation design with questionnaires. (pre–post) $N = 80$	Denmark. Incurable cancer. Hospice and a hospital palliative medicine unit. SPC.	Depression. Anxiety. Dignity. QoL.	Participants screened with Blessed Orientation-Memory-Concentration test. Structured interview for symptoms and concerns items, PDI, HADS, the Palliative Performance Scale–v 2, nine items from the DT patient Feedback questionnaire and QLQ-C15-PAL	At T1, 73%–89% found DT helpful, satisfactory and of help to relatives; 47%–56% reported that it heightened their sense of purpose, dignity and will to live. 25%–43% found life more meaningful and had less suffering. QoL decreased; depression improved in one outcome measurement and sense of dignity and sense of being a burden to others improved. Patients with children and lower performance status, emotional functioning and QoL were more likely to report benefit. Participants who complete DT and both follow-ups had better baseline scores than the one's who dropped out.	The results showed only few positive changes over time. All patients accounted for. A dropout from 80 participants to 31 at the second post measurement due to deterioration and death. Patients who refused to participate were often older and in-patients. No control group. 70 patients did not meet inclusion criteria due to physical limitations – no further explanation. Median time from baseline to T1 = 36 days and from baseline to T2 = 60 days.

(Continued)

Table 2. (Continued)

Reference, reviewer.	Study aim	Intervention, design, sample size	Population, setting	Outcome/objective	Methods	Results	Study appraisal CASP
Julião et al.[38] Reviewers: S.G.R. + M.N.S.	To determine the influence of DT on depression and anxiety in inpatients with a terminal illness and experiencing a high level of distress in a palliative care unit.	DT. Non-blinded phase II RCT. $N = 80$	Portugal. End-stage cancer. Tertiary inpatient palliative medicine unit. SPC.	Depression. Anxiety.	HADS scale at baseline, day 4, day 15 and day 30 post DT. Wilcoxon test. Mann–Whitney test.	DT group: HADS-a median: baseline – 10.0; T2 – 5.0; T3 – 5.0; T4 – 4.0 HADS-d median: Baseline – 14.0; T2 – 10.0; T3 – 10.0; T4 – 10.0 SPC group: HADS-a median: baseline – 9.00; T2 – 9.00; T3 – 9.50; T4 – 10.00 HADS-d median: Baseline – 14.0; T2 – 14.0; T3 – 15.0; T4 – 17.0	Ramdomized through computer. All patients accounted for. Not blinded. Similar groups. Equally treated Diagnosis not explicit. Secondary outcomes presented in Julião et al.[39] Benefits are worth the cost. No causal relationship between DT and the reduction of anxiety can be concluded. Fails to explain how DT is associated with anxiety and depression.
Julião et al.[39] Reviewers: S.G.R. + M.N.S.	To determine the influence of DT on demoralization syndrome, the desire for death and a sense of dignity in terminally ill inpatients experiencing a high level of distress in a palliative care unit.	DT. Non-blinded phase II RCT. $N = 80$	Portugal. Patients with a life-threatening disease with a prognosis of 6 months or less. Tertiary inpatient palliative care. SPC.	Demoralization syndrome, the desire for death and sense of dignity.	Demoralization Syndrome criteria; the Desire for Death Rating scale; PDI.	DT was associated with a significant decrease in demoralization syndrome compared with SPC ($p < 0.001$). DT was associated with a significant decrease in DfD prevalence ($p = 0.054$). Those who received DT showed a statistically significant reduction in 19 out of 25 PDI items.	This study reports on secondary outcomes from Julião et al.[38] Four-day follow-up. 10 patients lost to follow-up
Steinhauser et al.[40] Reviewers: S.G.R. + H.B.	To evaluate the impact of Outlook that promotes discussion of end-of-life preparation and completion on health outcomes in dying persons; pain and symptoms, physical function, anxiety, depression, spiritual well-being and QoL at the end of life.	Outlook. Pilot RCT. $N = 78$	The United States. Life-threatening illness < 6 months life expectancy. Palliative care setting: hospice, homecare, rehabilitation centre, inpatient units at University medical centre. SPC.	QoL, depression, anxiety, functional status, pain and symptoms.	Memorial symptom assessment scale; Rosow–Breslau ADL scale, Profile of Mood States subscale; Centre for Epidemiologic Study of Depression (CESD); QUAL-E; the Daily Spiritual Experience Scale.	Results show very little improvement in any outcomes in the relaxation meditation and no intervention group. In the Outlook group, there were improvements in all the study outcomes: ADLs from 26.1 to 22.7, POMS 6.4 to 3.7, CESD 11.8 to 9.1, and end-of-life preparations improved 3.4 to 3.7.	Large dropout (approximately 50%) Sample size is not large enough to show statistical significance. Post measures did not include daily spiritual experience or family social support measures. Discusses findings with theory on forgiveness and health. Include patients with heart disease, lung disease and cancer.
Vuksanovic et al.[41] Reviewers: S.G.R. + M.M.	Evaluate the legacy creation component of DT by comparing this intervention with LR and waitlist control groups.	DT. RCT study. $N = 70$	Australia. Adults with advanced terminal disease < 12 months life expectancy. Hospital. Hospice. SPC.	Ego-integrity, generativity, dignity-related distress, QoL, well-being. Perceptions of impacts of DT for families.	Brief Generativity and Ego-Integrity Questionnaire, PDI, FACT-G and treatment evaluation questionnaires. A Family Evaluation Form measured family/carers perceptions of impacts of DT.	DT recipients demonstrated significantly increased generativity and ego-integrity scores. No significant change for dignity-related distress or physical, social, emotional and functional well-being among the three groups. High acceptability and satisfaction were noted for participants and families in both DT and LR.	Control group was a waiting list group that received DT after the waiting period. Random allocation between the three groups. All patients accounted for. Inadequate power to detect small effects due to the sample size in each group and only mild to moderate levels of distress at baseline. This study provides knowledge about the specific process of legacy creation and its impact on sense of generativity and ego-integrity near end of life.

CASP: Critical Appraisal Skills Programme; RCT: randomized controlled trial; SD: standard deviation; ANOVA: analysis of variance; ADL: activities of daily living ;POMS: Profile of Mood States; FACT-G: functional assessment of cancer therapy: general; ACP: advanced care planning; DfD: desire for death; QUAL-E: quality of life at the end of life.

Canada,[21,26,29,35] Australia,[21,27,29,35,41] the United Kingdom,[22,36,42] Denmark,[23,37] Portugal[38,39] and Germany.[43] Life review was carried out in Australia[27] and Japan.[31] Short-term life review was only carried out in Japan,[31–33] and outlook was carried out in the United States[25,40] and Australia.[24] Finally, legacy building was carried out in the United States.[28]

The studies using a qualitative approach all used interview design but different methods of qualitative analysis such as content analysis,[20,23] grounded theory,[21,25] constant comparative method,[26] a framework approach[22,27] or interpretive phenomenological analysis.[24] The sample sizes ranged from three participants[42] to an analysis of dignity therapy transcripts with 50 interviewees.[21]

Mai et al.[43] and Hall et al.[42] chose mixed methods in both data gathering and analysis. Mai et al. tested dignity therapy in Germany, and Hall et al. explored the effects of dignity therapy using a case study.

The participants in the included studies were primarily receiving specialized palliative care in their terminal phase, but a few studies[20,28,30,34] were conducted in a general palliative care setting or in a mix of the two[23] while the patients were still undergoing active treatment. Most of the patients were diagnosed with advanced or terminal cancer; other diagnoses are referred to as terminal illness[21,26,27,29,35,41,43] or life-threatening illness.[24,25,40]

Methodological quality

The CASP is not intended to be used as a scoring system but rather as a systematic tool for discussing research rigour. The results of the included studies were all considered valid; all presented clear statement of aims, appropriate methods and design for their research focus. All presented results according to their chosen methods (Table 2).

However, there were some limitations; the quantitative studies[33,35,36,38–41] could not blind their participants because of the nature of the intervention and often lacked power because of sample size. Furthermore, although the qualitative studies chose well-fitted designs to explore the patients' perspectives and described the steps of the qualitative analysis, none addressed the saturation of data and only a few[21,25–27] elaborated their findings with additional theory. Finally, only one study[22] critically examined the role of the researcher.

Core principles of narrative interventions

We present the main findings in accordance with the five analytical themes. These themes differ from the subgroup headings because of the different steps in the analytical process described earlier.

All interventions had the main objective of addressing psychosocial and existential suffering. Some dignity therapy studies[20,26,27] also included a legacy document as an objective. Facilitators guided the patients in reflecting on their life and current situation and making meaning of it through their experienced life story.

All studies used a procedure manual with the elements of semistructured interviews to ensure that the facilitator followed the patient's cues while helping them to structure and organize their thoughts. Nearly all audio was recorded and transcribed except Ando et al.,[31] who recorded the life review through notes during and immediately after the interview. Nevertheless, there are also differences. In dignity therapy, the transcript was edited into a chronological and positive narrative with respect for the patients' wording. This edited version was read to the patients to ensure that they had nothing further to add or omit. Finally, the patients received the document to pass on to people of their choosing. The therapeutic stance of unconditional positive regard reflects the fact that the document is intended for the family or friends.[23] This was not the case for life review,[31] short-term life review[32,33] or outlook,[24,25,40] in which the patients review both good and bad memories. The intervention of legacy building combined the dignity therapy interview with a web portal to create the legacy document.[28] Ando et al.[32] completed their short-term life review by making an album for the participants using keywords from the narrative, and Keall et al.[24] offered the audio recording to the participants, but only 4 of 11 accepted the recording.

In the dignity therapy intervention, the participants receive the session topics and questions beforehand to reflect on and decide what to include in the narrative. This is not evident in life review, short-term life review or outlook. Most interventions had one session with a facilitated interview focusing on life story followed by one or two sessions used for re-evaluating and reconstructing[32,33] or editing and presenting the narrative.[20–23,26,27,29,30,34–39,41–43] The legacy building intervention[28] used three dignity therapy questions in an interview session, and the participants answered the rest of the dignity therapy questions through the web portal. The life review intervention[31] included four interview sessions on childhood, adolescence, adult life and current situation, and the outlook intervention[24,25,40] included three interview sessions on life review, forgiveness and legacy (Table 3).

In general, the sessions took 30–60 minutes and were scheduled 1–3 weeks apart. Furthermore, short-term life review and dignity therapy interventions used additional time to edit the interview into either a narrative or an album. Studies on dignity therapy[23,29,38,39,41] said that completing the narrative takes 2–5 days, but only Hack et al.[21] described in detail that the transcription took 2–3 days and editing 24–48 hours. The dignity therapy interviews were facilitated by a psychiatrist,[29,35] psychologist,[27–29,35,37,41,43] social worker,[28] physician[26,38,39] or

Table 3. Sample questions for interviews.

Short-term life review	Life review	Dignity therapy	Legacy building	Outlook
- What is the most important thing in your life? - What are the most vivid or impressive memories in your life? - In your life, what event or person affected you most? - What is the most important role you played in your life? - What is the proudest moment in your life? - Is there anything about you that your family needs to know? - Are there things you want to tell them and are there things you want them to remember? - What advice or words of guidance do you have for the important people in your life or for younger generations?	Session 1: Childhood - What is the very first thing that you can remember in your life? Go back as far as you can. - Did you have any brothers or sisters? Tell me what each was like. Session 2: Adolescence - When you think about yourself and your life as a teenager, what is the first thing you can remember about that time? - What were the pleasant things about your adolescence? Session 3: Adult life - What was life like for you in your 20s and 30s? - Tell me about your work. Did you enjoy work? Were you appreciated? Session 4: Current situation - How do you feel now when you review those impressive events?	- Tell me a little about your life history, particularly the parts that you either remember most or think are most important? When did you feel most alive? - Are their particular things that you would want your family to know about you, and are there particular things you would want them to remember? - What are the most important roles you have played in your life (family roles, vocational roles, community service roles, etc.)? Why were they so important to you, and what do you think you accomplished within these roles? - What are your most important accomplishments, and what do you feel most proud of? - Are there particular things that you feel still need to be said to your loved ones, or things that you would want to take the time to say once again? - What are your hopes and dreams for your loved ones? - What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your [family member, others]? - Are there words or perhaps even instructions you would like to offer your family in order to provide them with comfort or solace? - In creating this permanent record, are there other things that you would like included?	- What parts of your life do you find most important? - What do you want people to know and remember about you? - Are there particular things you believe still need to be said to your loved ones?	Session 1: Life story - Tell me about your life - What are your cherished times? - Of what are you most proud? - If someone were to make a movie of your life, what would be important to include? Session 2: Forgiveness - If you were to do things again, what might you do differently? - Are there things or times you regret? - Is there anyone to whom you would like to offer forgiveness? - Is there anyone from whom you would like to ask forgiveness? - Are you at peace? Session 3: Heritage and legacy - What are your most valuable lessons learned? - What would you like to share with future generations? - If you could choose one thing to pass on as your legacy what would that be? - What things would you like to accomplish?

nurse.[20,29,30,35] Hall et al.[22,36,42] only referred to the facilitator as a therapist, and Hack et al.[21] did not mention any details on the facilitator but used transcripts from Chochinov et al.[35] All studies except two[21,26] highlighted that their facilitator had undergone formal dignity therapy training but did not specify what this entails. A clinical psychologist facilitated the life review[31] and short-term life review[32,33] interviews. Finally, a nurse or a non-physician clinician facilitated the outlook intervention.[24,25,40]

Theoretical framework of narrative interventions

The interventions were all relatively brief psychotherapy based on reminiscence theory in which patients re-evaluate past experiences with the intention of resolving and integrating past conflicts, bringing new significance and meaning to their life[44] and empirical work on either dignity or end-of-life experience.[45] The framework underlying dignity therapy and legacy building was the model of dignity,[45,46] which focuses on dignity-conserving tasks such as settling relationships, sharing words of love and preparing legacies of memory and shared values. The framework for outlook[40] was based on social gerontology and health psychology self-disclosure literature. This outlook model has tasks very similar to the dignity model although they name them development tasks: sense of completion in relationships with family, expressions of regret and forgiveness, acceptance of gratitude and appreciation and sense of meaning of one's life. Underlying life review[31] and short-term life review[32,33] is the work on psychoexistential suffering as pain caused by extinction of being and meaning of self through losing relationships with others, losing autonomy or losing a future. All interventions have the sense of meaning as a core concept. Furthermore, all interventions share the underlying assumption that these tasks can be facilitated through the personal narrative with components of life review, forgiveness and legacy and positively affect the outcomes of quality of life, psychosocial and existential distress.

Content of personal narratives

Six studies explored what the patients found most important to address in their narrative, contributing evidence on dignity therapy,[20,21,26] life review[27] and outlook.[24,25] In general, the content of the narratives for these interventions is very similar. They all include life stories of upbringing, accomplishments, defining events, lessons learned, regrets, legacy and advice to loved ones. The most prominent theme of the narratives presented was family. Family was the underlying context behind the patients' narratives under which everything else seemed to be organized.[20–22,24–27] In the study in the United States,[20] the narratives included a role for God that was not explicit in studies from other countries.

Outcome of personal narratives

All studies used personal narrative interventions to address psychosocial and existential distress. The outcome of spiritual well-being was most commonly measured by using the Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale (FACIT-SP)[28,32,33,35] and anxiety with the Hospital Anxiety and Depression Scale (HADS).[32,33,35–38] Life review chose Skalen zur Erfassung von Lebens qualität bei Tumorkranken – Modified version (SELT-M).[31] Furthermore, the dignity therapy studies often included the Patient Dignity Inventory (PDI)[46] because they focused on dignity-related stress. Positive outcomes have been reported for dignity therapy,[29,35,36,38,39,41] life review[31] and short-term life rerview[33] as well as outlook,[40] with qualitative evidence supporting clinical application for patients nearing death as a means of enhancing their life. However, statistical significance in improving the ability to mitigate distress has not yet been proven. The pilot RCTs and the RCTs could not be blinded because of the nature of the narrative intervention and the setting. Furthermore, all RCTs except one[35] were quite small and might be insufficiently powered. One major challenge mentioned across the interventions was baseline distress. Many participants do not score high on baseline distress, creating difficulty in detecting positive change. Nevertheless, patients experiencing high levels of distress might have been more likely to decline participation.

Although all interventions shared the underlying belief of the personal narrative as having a function in affecting the individual's sense of meaning, only studies on dignity therapy explored this belief. A large qualitative study[21] conducted on 50 transcripts from dignity therapy participants found that the dignity therapy narrative serves several functions, both for self and for others. The function of 'self' included personal ethics, contentment, regret, turning point, role identification, life meaning, insight and resignation. The function of 'others' included affirmation, wishes, gratitude, disappointment, instructions, being remembered, clarification and reconciliation. Similarly, Hall et al.[22,42] explored the patients' perception of benefits within the underlying frame of dignity therapy and found support for the function of generativity, continuity of self, maintenance of pride, hopefulness and care tenor. The control group, however, also experienced similar benefits from participating in the study.[22] Vuksanovic et al.[27] compared dignity therapy with life review and found that the legacy component in dignity therapy facilitated resilience, hope and enduring sense of legacy, but perhaps at the expense of deeper exploration of interpersonal regrets, unfinished business and concerns about the aftermath.

Acceptability and feasibility of narrative interventions

The acceptability of narrative interventions was positive and consistent. Studies of dignity therapy stated that participants found the intervention satisfying or highly satisfying and helpful or very helpful and that it heightened their sense of dignity (Table 2). Vuksanovic et al.[27] reported high satisfaction from both life review and dignity therapy, and in addition, 93% of family members reported that dignity therapy was helpful. Houmann et al.[23] reported that professionals in Denmark had both positive and negative views on dignity therapy. They were mainly concerned about dignity therapy being too existentially confrontational, but the patients in Denmark had no such concerns, and they were more concerned about unacceptable self-praise. For legacy building, Bernat et al.[28] reported high satisfaction with both intervention and the final legacy project, but 80% of the participants who used the web portal reported dissatisfaction.

Some studies[20,22,24,35] mentioned the risk of personal narratives of being emotionally challenging, and a few elaborated on this either by saying that they would refer the patient to the appropriate service if necessary[24] or that none of the participants needed further counselling.[20] However, neither patients nor family reported serious harm from the narrative intervention.

The positive trend of acceptability was not present for feasibility since the interventions share several challenges. Primarily, recruitment and dropout were problems. A study of outlook[40] took 18 months to find 209 eligible patients; 127 refused to participate and only 42 completed all data points. Dignity therapy,[29] life review and short-term life review[31,33] had similar results. The legacy building intervention[28] participants had difficulty in using the web portal. In general, the declining health of the participants was described as the cause of recruitment and retention problems, as would be expected in studies of people with a progressive life-threatening illness.

Discussion

This section briefly discusses the main findings in accordance with the analytical themes, including the implications for clinical practice and further research. Furthermore, we discuss the strengths and limitations of the study.

Main findings, implications for practice and further research

Our study found that the narrative interventions were relatively brief psychotherapy sessions with the objective of relieving psychosocial and existential suffering and improving the quality of life. Telling your personal narrative is argued to be therapeutic since it facilitates meaning, purpose and continuity of self by re-evaluating significant life events. This argument was strengthened by the studies using qualitative methods[21,22,27,42] to analyze the outcome of the personal narratives.

To facilitate this story, all interventions used a semistructured interview guide designed to help the patients tell their experienced life story, reflect on their situation and find meaning. A systematic approach seems necessary when borrowing a concept from socio-narratology and psychotherapy to use in this specific setting of a hospital. The procedures of the narrative interventions were similar but not identical. The main differences were whether the personal narrative was edited into a legacy document or album or whether it was left as a story told. The interventions that edited legacy documents in cooperation with the participants found high satisfaction among both patients and loved ones. Nevertheless, the study that examined both dignity therapy and life review found that this restricted the focus to a positive narrative, leaving no room to discuss or reflect on unhappy memories.

The facilitator was the most prominent resource person mentioned across the studies, and we found that various health professionals with training could facilitate the interviews. A surprising finding, however, was the lack of financial considerations and details on how much time conducting these narrative interventions takes – even more so if a legacy document is produced. This aspect seems almost completely neglected but is important in clinical practice.[21]

Most studies did not have an explicit theoretical framework, and the various interventions had not consensus on the underlying theoretical framework. Each intervention was based on its own empirical data and model or theoretical outset, such as the model of dignity, social gerontology, health psychology and psychoexistential suffering as pain caused by a loss of meaning and self. Furthermore, the qualitative studies reported findings on an empirical level and lack discussion about narrative theory to broaden understanding of the meaning of using narrative interventions in a palliative hospital setting. Gucciardi et al.[47] found similar limitations in the theoretical foundation for the interventions in their scoping review on designing and facilitating storytelling interventions. A theoretical framework underpinning narrative interventions could provide greater understanding of the mechanisms of change in psychosocial and existential well-being,[48,49] and further research could address this gap in knowledge.

The dignity therapy, life review and outlook interventions[20,21,24–27] analyzed the content of the narratives and found that family was the most prominent theme, including stories of upbringing, accomplishments, defining events, lessons learned, regrets, legacy and advice to loved ones. However, the general choice of analysis approach in the qualitative design and the semistructured interview manual may have left little room for inductive themes in any of the studies.

The outcomes of the personal narratives were analyzed either through quantitative outcome measures focusing on distress, anxiety or depression or by deductive qualitative analytical methods. In general, the studies that aimed to show effect lacked power, and determining statistical significance seemed difficult. A systematic review of quantitative evaluation of therapeutic life review found similar results.[8] Showing statistical significance for positive outcomes such as meaning or quality of life by gathering information on negative outcome measures such as distress and depression poses several challenges. First, participants do not score high on baseline distress, which creates difficulty in detecting positive change. Nevertheless, patients experiencing high levels of distress might have been more likely to decline participation. Second, distress might not be defined identically for the patients and researchers. However, this does not mean that narrative intervention does not work: rather that it works at a meaningful level for the participants that may not be measured or calculated using quantitative methods.[50] To our surprise, the studies neglect the possibility that the narrative intervention might inflict harm on either the patient or family. We recommend that this should be considered more in future studies.

The study shows that the recurring sessions and longitude of the narrative intervention are key factors in feasibility and acceptability – another important clinical consideration. This was also evident in the systematic review by Keall et al.,[8] which found that shorter interventions resulted in lower attrition rates and better results. Such interventions as the short-term life review[32,33] and dignity therapy with legacy building through a web portal[28] addressed this issue by adjusting interviews and sessions. Bernat et al.[28] chose to conduct a short interview and leave the legacy part to be finished through a web portal, but 80% of the participants were dissatisfied with this option. This could indicate that the personal contact and possibility to tell one's story are more important than simply documenting it in a Word format. Findings in the outlook intervention strengthen this view.[24] Participants were offered the audio recordings, but only four accepted. We recommend that facilitators adapt to the logistics of both the setting and individual and integrate the use of personal narratives in the current treatment plan. Furthermore, we might recommend focusing less on the legacy document in clinical practice and more on facilitating the personal narrative as a means of finding meaning, hope and continuity of self.

Finally, taking the specific culture into consideration is important in using an intervention based on personal narratives. This is evident in the studies in the United States, where God plays a role in the narratives, and in the studies in Denmark, where patients object to the concept of self-praise.

Strengths and limitations

To our knowledge, this is the first study that systematically synthesized knowledge on using personal narratives in a hospital palliative care setting. The study was based on qualitative, quantitative and mixed-methods research designs, and we assessed the research quality using the CASP. We are aware that, based on the hierarchy of evidence, the case studies are of low quality. However, the purpose was to review all kinds of peer-reviewed, published studies on the subject – including the methods of documentation. We believe that this is a strength, since it presents a broader picture of evidence on personal narratives used in palliative care interventions at hospitals. The review, however, does have limitations. First, even though the search strategy was discussed with a research librarian and initially tested in PubMed for search terms, index words and text words, the concept of personal narratives is wide, and we may have missed some relevant studies. In particular, the search terms might not have been sensitive enough to catch all unique variations of personal narratives. We did, however, try to minimize this by manually searching the references from the included studies. We included only one additional study from this manual searching.

Furthermore, the strength argument of synthesizing evidence from different methodological designs also proved to be challenging regarding analysis. Comparing the interventions and including a discussion on how similarities and differences could lead to different outcomes could have been interesting. Unfortunately, we did not feel able to do this based on the included articles.

Conclusion

This study is based on current evidence on the potential of using personal narratives in palliative care to relieve psychosocial and existential problems and adds to this knowledge by providing a synthesis of the literature on using personal narratives in hospital-based palliative care interventions.

Based on this literature review, we conclude that personal narratives in hospital-based palliative care are and can be managed in a hospital setting to relieve psychosocial and existential suffering. The personal narrative interventions at the hospital have their roots in both socio-narratology and a psychotherapeutic theoretical understanding. However, different interventions have been developed. Each uses its own procedure manual to guide, structure and facilitate the personal narrative to the specific purpose of boosting a sense of meaning and enhancing the quality of life.

The use of personal narratives in palliative care is acceptable for both patients and loved ones and serves several functions, both for self and for others. However, the literature shows that both the specific setting of a hospital and the physical and emotional problems that present itself when living with a life-threatening disease can be a challenge. The intervention must be flexible enough to adjust to the practices of the setting and to the patient's life.

Although the evidence from this review is from a hospital setting, the scope is limited beyond a specialized palliative care setting. This leaves a research gap focusing on using personal narratives in general palliative care.

Acknowledgements

We thank research librarian Eva-Marie Helsted Ravn from the Danish Knowledge Centre for Rehabilitation and Palliative Care (REHPA) for guidance on the search strategy.

Author contributions

All authors discussed the study objective and design and revised the manuscript for intellectual content. S.G.R. conceived and designed the project, performed the initial and concurrent data search, coordinated the retrieval of data, assessed their eligibility, analyzed and interpreted the data and drafted and revised the manuscript. M.M. contributed substantially to retrieving and assessing the eligibility of data. H.B. contributed to retrieving and assessing the eligibility of data. M.N.S. contributed to retrieving and assessing the eligibility of data. H.T. contributed to designing, analyzing and substantially revising the intellectual content of the manuscript. All authors read and approved the final version of the manuscript.

Availability of data and materials

The manuscript contains the data supporting our findings.

Declaration of conflicting interests

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

Ethical approval

This systematic review does not require formal ethics approval. However, 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 Næstved, Slagelse and Ringsted Hospitals.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was funded under a larger PhD grant from the Næstved, Slagelse and Ringsted Hospitals' Research Fund.

ORCID iD

Stine Gundtoft Roikjær https://orcid.org/0000-0002-5851-7577

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Paper II

Når hjertet svigter – patientperspektiver og basal palliativ indsats på hospitalet

Roikjær SG

Omsorg, Nordisk tidsskrift for palliative medisin 2020 sep;3:40-45

Stine Gundtoft Roikjær

Når hjertet svigter – patientperspektiver og basal palliativ indsats på hospitalet

hjertesvigt, lidelse, palliation, patient perspektiv, sygdom
heart failure, illness and disease, palliative care, patient perspective.

Stine Gundtoft Roikjær
MScPH, er ph.d.-studerende ved Klinisk Insitut på Syddansk Universitet. Stine er ansat på kardiologisk afdeling ved Næstved, Slagelse og Ringsted Sygehuse samt Videncenter for rehabilitering og palliation, REHPA. Desuden er Stine tilknyttet forskningsenheden PROgrez på Næstved, Slagelse og Ringsted sygehuse, https://orcid.org/0000-0002-5851-7577.
E-mail: sgro@regionsjaelland.dk, stine.gundtoft.roikjaer@rsyd.dk.

Den palliative indsats på hospitaler er hovedsageligt defineret ved de specialiserede tilbud, men der er et øget fokus på at udvikle kompetencer og tilbud i den basale indsats. Et dansk ph.d.-studie har som formål at udvikle, afprøve og evaluere en basal palliativ indsats på hospitaler til patienter med hjertesvigt. Første skridt var at undersøge, hvordan livet med hjertesvigt opleves, samt hvilke behov for lindring hjertesvigtspatienter giver udtryk for. Artiklen omhandler interviews med seks patienter.

Palliative care in Danish hospitals is primarily accessible in a specialized context. However, there is an increased focus on developing competencies and intervention in a general context. A Danish PhD study aims to develop, test and evaluate a general palliative care intervention for patients with heart failure. The first step was to investigate how life with heart failure is experienced as well as what needs for care, patients are expressing. This article focuses on interviews with six patients.

Hjertesvigt og palliation

Diagnosen

Medicinsk defineres hjertesvigt som et livstruende og fremadskridende syndrom, og diagnosen bestemmes udelukkende ud fra symptombillede, som eksempelvis væskeophobning, åndenød og hjerterytmeforstyrrelser, samt en scanning af hjertet – en såkaldt EKKO. Baggrunden for hjertesvigt kan eksempelvis være dårlig blodtilførsel til hjertet, et øget tryk fra lungekredsløbet eller en medfødt hjertefejl. Det er ikke altid muligt at finde den bagvedliggende årsag, og det er sjældent muligt at give patienter med hjertesvigt en sikker prognose. Sværhedsgraden af symptomer er styrende for den behandling, patienten bliver tilbudt, og dermed også den tilknytning, han/hun får til hospitalsvæsenet. Desuden har patienten, der lider af hjertesvigt, ofte andre sygdomme, som også har betydning for deres hverdag og livskvalitet. Statistisk set er 5-års dødeligheden mellem 46 og 60 % (1, 2).

Hverdagslivet

Sundhedsvidenskabelig forskning viser, at hjertesvigtspatienten generelt oplever en reduktion i livskvalitet med usikkerhed, angst, depression og smerte og har svært ved at vænne sig til et liv med hjertesvigt (3-6). At leve med hjertesvigt er selvfølgelig en subjektiv oplevelse, og hvert forløb er forskelligt. Dog ligner de hinanden i den forstand, at der er gode tider, hvor sygdommen er »under kontrol«, og tilbagefald med forværring af både symptomer og prognose (7). Hvordan dette opleves, har blandt andre Brännström og kollegaer undersøgt i et fænomenologisk interview studie (8), hvor de fulgte en mand (og hans ægtefælle) med hjertesvigt over 4,5 år. De sammenligner livet med hjertesvigt med en rutsjebanetur, man ikke kan komme ud af, og fandt, at dette liv handler om at integrere det uforudsigelige ind i hverdagslivet med både lidelse og gode tider. I nedturene lever man i en situation med lidelse, kamp, død og en følelse af skyld. I opturene forsøger man at holde styr på sin sygdom og at tilpasse sit hverdagsliv til dagsformen (8). De fandt også, at den støtte, patienten fik gennem et palliativt team, fungerede som en slags sikkerhedssele og gav en følelse af tryghed på grund af en vedvarende opmærksomhed (8).

Palliativ indsats

En palliativ indsats kan spille en vigtig rolle i lindring af hjertesvigtpatientens problemer og anbefales som en integreret del af behandlingen, men udviklingen på området er stadig mangelfuld (7-9). I de nationale anbefalinger fra 2017 slår sundhedsstyrelsen endnu engang fast, at palliation er for alle mennesker med livstruende sygdom (10). I praksis er der dog stadig ulige adgang til en palliativ indsats, som hovedsalig er rettet mod kræftpatienter (11).

I forbindelse med det nævnte ph.d.-projekt var formålet med dette delstudie at undersøge, hvordan livet med hjertesvigt opleves af patienter – herunder deres møde med hospitalet.

Metode

Den overordnede metodologi for ph.d.-projektet er baseret på kvalitative metoder med hermeneutisk videnskabsforståelse som rammen. Det samlede projekt er opdelt i tre faser: 1) Gennem litteraturstudie og interview undersøgte vi viden om og behov for en palliativ indsats til patienter med hjertesvigt; 2) gennem workshop baseret på fortællinger og dialog udviklede og afprøvedes en palliativ indsats i en hospitalskontekst; 3) gennem observation og interviews evalueres på nuværende tidspunkt omtalte palliative indsats.

Artiklen omhandler interviews fra projektets fase 1 med seks patienter med hjertesvigt. Patienterne har været indlagt minimum to gange under diagnosen hjertesvigt på et lokalt sygehus. Interviews blev lydoptaget og transskriberet efterfulgt af kodning af data samt en tematisk analyse.

Temaer blev diskuteret med forskerkollegaer og forståelsen åbnet yderligere med Arthur Kleinmans begreber om *illness*; forstået som patientens oplevelse af sygdom (lidelse) indlejret i sit levede liv og situationelle kontekst, og *disease*; forstået som den professionelle biomedicinske kategorisering af sygdom (12). Derudover anvendes Arthur Franks teori om sygdomsfortællingen som en støtte til blandt andet at forstå en ny livssituation (13).

Patienternes perspektiv

Oplevelser af hjertesvigt

Patienterne beskriver deres oplevelse af at være hjertesyg ud fra den akutte situation, kropslige oplevelser, fysiske og psykiske begrænsninger i deres hverdag, sociale ændringer og tanker om både fortid, nutid og fremtid. Det er gennemgående, at de alle har svært ved helt at forholde sig til sygdommen hjertesvigt i medicinsk forstand. Det er ligeledes gennemgående, at de fleste har flere sygdomme at takle. Patienterne nævner epilepsi, sukkersyge, stomi og blodpropper i hjernen, som også bliver en del af deres samlede oplevelse af at være syg.

»At beskrive sygdom gennem diagnoser og symptomer er en medicinsk tankegang.«

Analysen viste tydeligt det hverdagslivsorienterede patientperspektiv, Kleinman beskriver som illness (12). Patientens oplevelse af sygdom er indlejret i hans eller hendes levede liv og livsverden, og han/hun har svært ved at fortælle, præcis hvad der forbindes med diagnosen. Dette ses meget bogstaveligt, når patienten end ikke kan relatere til diagnosen *hjertesvigt*:

> Hjertesvigt? Er det dét, jeg har – det ved jeg da ikke rigtigt, om det er.
>
> p1

I stedet fortæller de med sorg om en følelse af at blive isoleret fra venner, oplevelser og det liv, de før levede, og stiller spørgsmålstegn ved, hvorfor det netop har ramt dem. At beskrive sygdom gennem diagnoser og symptomer er en medicinsk tankegang, der ikke nødvendigvis harmonerer med patientens oplevelse af hverdagens problemer.

Denne forskel mellem oplevelsen af illness og diagnosticeringen af disease synes at skabe en konflikt især for den kroniske patient, som jo netop ikke kureres, men skal leve med sin sygdom (12). Patientens usikkerhed på sygdommen hjertesvigt kan måske i nogen grad tilskrives denne konflikt. Patienter fortæller om det chok, de får ved anden indlæggelse, hvor det pludselig går op for dem, at hjertesvigt ikke »bare« er et enkelt akut tilfælde, men er noget, de skal leve med resten af deres liv. Flere har ved første akutte indlæggelse og behandling fået den opfattelse, at de nu var helbredt, for lægen fortalte jo, at væsken omkring lungerne og presset på hjertet var fjernet. Desuden får de medicin, der »passer på« og »styrker« hjertet.

Én af de store udfordringer, som patienten med hjertesvigt har, er at leve et liv, som den ene dag opleves symptomfrit, men som dagen efter kan være præget af forværring, indlæggelse og udsigt til endnu en lang kamp mod bedring. En sisyfosopgave, så at sige:

> Jeg kunne det hele, da jeg blev indlagt – nu kan jeg ikke engang gå alene uden rollator. Så det bliver op ad bakken én gang til. Og den modgang – det vil jeg sige – den er sværest at holde til.
>
> p1

Disse perioder med forværring har ikke kun fysisk betydning for patienten, men i høj grad en hverdagslig og eksistentiel betydning, men denne betydning synes ikke at blive adresseret i hospitalsregi. En patient fortæller eksempelvis, at hun har været nødsaget til at gå til psykolog for at bearbejde sin angst for tilbagefald.

Oplevelser af uudtalte problemer

Patienterne beskriver, hvordan fokus på hospitalet er på medicinsk behandling, men flere kæmper som sagt med eksistentielle problemer. En patient fortæller, hvordan hun i frustration over tabet af det liv, hun kendte, råbte ad sin læge:

> … for pokker, giv mig dog mit gamle liv tilbage, giv mig mit liv tilbage.

Patienten stiller her skarpt på livet og nævner end ikke sygdommen. Når hospitalspersonalet arbejder ud fra et diseaseperspektiv, vælger de derimod at stille skarpt på de problemer, der kan identificeres i en biomedicinsk tankegang, eksempelvis væske på lungerne. Med denne tilgang er der stor behandlingssucces, da væske på lungerne meget specifikt kan behandles med diuretika. Det betyder dog samtidig, at patienten efterlades med uudtalte problemer og muligvis også udækkede behov (12).

Arthur Frank beskriver, hvordan sygdom altid kalder på en fortælling (13). En fortælling, der blandt andet har som formål at skabe mening med og i den syges liv og situation. Fortællingen er altså vigtig for patientens forståelse af lidelse. Men lige nu er der ikke rum til dette på hospitalet. En patient fortæller, hvordan hun føler sig helt alene og bange som aldrig før. Jeg spørger, om hun har talt med nogen på hospitalet om dette, men det afviser hun:

> Det kan de jo ikke bruge til noget, normalt, kan de det? – Men det er jo heller ikke rigtigt, at man skal komme og snakke om det jo – altså det føles da ikke sådan i hvert fald.
>
> p2

Patienten forsøger at tilpasse sin fortælling i ambulatoriebesøget til det, hun tror, sygeplejersken kan *bruge til noget*. Frank taler om en medicinsk kolonisering, hvor patientens fortælling må tilpasse sig (i hvert fald midlertidigt) til en medicinsk faktuel »sandhed«. (13) Problemer, der ikke kan oversættes til tegn på sygdom, får ingen opmærksomhed. Denne overgivelse eller tilpasning kan være nødvendig, men er også problematisk. Kleinman hævder, at når den sundhedsprofessionelle forsøger at oversætte illness til disease, så mister man noget betydningsfuldt i oplevelsen af livet med kronisk sygdom (12, s. 6).

»Problemer, der ikke kan oversættes til tegn på sygdom, får ingen opmærksomhed.«

Alle patienter beskriver oplevelser fra deres møder med sundhedsprofessionelle. De patienter, der har været akut behandlet for en blodprop i hjertet, beskriver med stor respekt, hvordan reddere, læger og sygeplejersker udstrålede ro og kompetence i en fuldstændig kaotisk situation. Flere fortæller dog også, at selve indlæggelsen på det lokale sygehus efterfølgende var en helt anden forvirrende oplevelse. I den kaotiske situation, hvor patienten oplever isolerede hjertesmerter og bliver mødt med en biomedicinsk sygdomstilgang, der behandler på netop disse, går alt op i en højere enhed. Når patienterne derimod senere i forløbet oplever kaos i *livet med* hjertesvigt, mangler de støtte.

Da jeg spørger den samme patient fra før, om hun mener, at det havde været rart at have et forløb, hvor man også kunne få lov til at snakke om andre ting end kun de medicinske problemer, svarer hun uden tøven:

> Ja, det tror jeg! … Det tror jeg nok det kunne. Det kan godt være, at man får øjnene op for noget andet.

Hvem denne *man* er, fik jeg ikke spurgt ind til, men hvis vi ser det gennem Arthur Franks teoretiske briller, så er *man* i denne sammenhæng både patient og professionel. Frank beskriver, at den personlige vinkel i at fortælle om sygdom er, at det giver mulighed for at reflektere over oplevelsen med at være syg og at skabe ny mening. Samtidig har det også et socialt aspekt, da man jo fortæller det til *nogen*. Et mere sociologisk aspekt er, at en fortælling ikke skabes udelukkende af fortælleren selv, men både præger og præges af det samfund, som fortælleren lever i (13). At give plads til den personlige fortælling er således også at åbne op for en bredere forståelse af livet med sygdom end den, der beskrives med diagnoser og symptomer.

Behov for en basal palliativ indsats på hospitaler

I Danmark er hjertesvigtpatientens forløb præget af afbrudte medicinske forløb i hospitalsregi, og når symptomerne er under kontrol, følges hun hos egen læge, typisk med en konsultation hvert halve år. Så det er måske ikke så mærkeligt, at patienter forbinder diagnosen hjertesvigt med akutte events og har svært ved at begribe sin situation. Dette er da også set i andre studier (14, 15).

Problemet er, at den dominerende indsats på hospitaler lige nu planlægges ud fra et disease-perspektiv med fokus på sygdommens symptomer, diagnose og medicinske behandling. Ved ikke at være nysgerrig på patientens illness-perspektiv kan patienten miste muligheden for at sætte sygdommen ind i sin egen forståelse: Hvorfor den er opstået, hvordan hun kan håndtere den, eller hvad den vil betyde for hendes liv (12). Patienter efterlades således med udækkede psykosociale og eksistentielle behov samt en følelse af at være alene. Derudover overser patienter muligvis nye symptomer, fordi de ikke forbinder deres hverdagsproblemer med hjertesvigt.

Modsat fandt Brännström og kollegaer, at patienten og hans kone var meget opmærksomme på at genkende symptomer på forværring (8). De forklarer deres fund med, at patienten var i et palliativt hjemmeforløb. De fandt, at den kontinuerlige opmærksomhed på patienten og hans situation bidrog positivt til hans forståelse af sygdommen og de udfordringer, der var og ville komme (8).

Ved at introducere en basal palliativ indsats allerede i hospitalsindsatsen og således forene illness- (lidelses-) og disease- (sygdoms-) perspektivet, skabes der mulighed for en gensidigt dybere forståelse af betydningen af livet med hjertesvigt. Denne forståelse fremmer endvidere indsatsen med at lindre patientens problemer, uanset om de er af fysisk, psykisk, social eller eksistentiel art. For at genoptage sisyfossammenligningen, kan en basal palliativ indsats måske både lette patientens samlede lidelse og følelsen af endnu en gang håbløst at kæmpe sig op ad bjerget.

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Paper III

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

Roikjær SG, Timm HU and Simonÿ CP

Scand J Caring Sci. 2021 Mar 3. doi: 10.1111/scs.12978. Epub ahead of print. PMID: 33656179.

Received: 23 June 2020 | Accepted: 7 February 2021

DOI: 10.1111/scs.12978

Scandinavian Journal of Caring Sciences

EMPIRICAL STUDIES

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

Stine Gundtoft Roikjær[1,2,3] | **Helle Timm**[1,3] | **Charlotte Simonÿ**[4,5]

[1]Department of Clinical Research, University of Southern Denmark, Odense C, Denmark

[2]Medicine 2, Department of Cardiology, Næstved, Slagelse and Ringsted Hospitals, Region Zealand, Denmark

[3]REHPA, the Knowledge Centre for Rehabilitation and Palliative Care, Nyborg, Denmark

[4]Department of Regional Health Research, University of Southern Denmark, Odense, Denmark

[5]Department of Research, Næstved, Slagelse and Ringsted Hospitals, Region Zealand, Denmark

Correspondence
Stine Gundtoft Roikjær, Department of Clinical Research, University of Southern Denmark, Odense C, Denmark.
Email: sgro@regionsjaelland.dk

Funding information
Næstved, Slagelse, Ringsted Hospital Research Fund

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 organisational 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 organisation 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

BACKGROUND

Heart failure and standardised 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 standardised 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 standardised plan describes the HF treatment, the information for the patient and the organisation of HF from the first encounter with the health system to the rehabilitation phase. The plan does not mention palliative care (PC).

Palliative care

Palliative care 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.

Palliative care can be organised into general and specialised care. General palliative care is delivered by health professionals in a setting that does not have PC as the main task. Specialised palliative care is delivered by health professionals in a specialised 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.

TABLE 1 Characteristics of the stages of progressive heart disease, recommended palliative care and clinical indicators for each stage

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 hospitalisations 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 individualised 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

Translated from (16 pg4).

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) integrate the intervention and (4) 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 realise 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 realised 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 operationalising 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.

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” (37 pg4) It is the embodied patient perspective. Disease is the “problem from the practitioner's perspective” (37 pg5): a professional biomedical perspective originating from a natural paradigm (36).

PARTICIPANTS

Based on recommendations in PC and HF (14,37), a group of ten professionals were invited to participate in a workshop. The strategy was purposeful sampling (38), 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 organisational priorities.

SETTING

Based on the standardised 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 15–20 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.

TABLE 2 Participant data.

Participants	Nurse 1	Nurse 2	Nurse 3	Nurse 4	Physician	Hospital Chaplain	Physio-therapist
Sex	♀	♀	♀	♀	♂	♀	♀
Age	60 s	40 s	40 s	60 s	50 s	60 s	40 s
Field	♥	♥	♥	🕊	♥	†	♥

♥, cardiology; 🕊, palliative care; †, theology.

DATA COLLECTION AND ANALYSIS

Data for the analysis consisted of field notes 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 field notes. A thematic analysis focused on meaning was then undertaken involving the following elements: familiarisation with the data, coding and generation of themes (39). 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.

TABLE 3 Example of derived themes.

Quotes	Central theme	General theme
"We try to educate patients to take care of their disease" (nurse 1). "Our main focus is to optimize medical treatment" (nurse 2). "In physiotherapy we try to guide them [patients] in exercises aimed at their problems" (physiotherapist).	A dominant perspective in a hospital setting	Recognition of differing perspective
"Sometimes I feel like they only attend to please me" (physiotherapist). "I just don't understand why they don't react. It's like the alarm doesn't ring" (nurse 1).	Frustration of noncompliance	
"You are first and foremost **a person** with an illness - you are not the disease" (chaplain). "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" (chaplain). "People die as they have lived" (PC nurse).	The patient perspective	
"You have to go through your own recognition, and this happens through your emotions" (chaplain). "A poem reads: at birth you cry and those around you smile. Live your life so that when you die you smile and those around you cry" (nurse 1).	Reframing	Building bridges between perspectives
"We cannot solve everyone's problems" (PC nurse). "HF is more than clinical symptoms, and we need to argue that treatment does not end just because the medical treatment does" (physician).	Adjusting objective	
"I find it difficult to talk about death when treatment is just beginning" (nurse 1). "There must be a call to a life that is still worth living" (chaplain).	Setting	Planning action for general palliative care in heart failure treatment
"We need lessons in communication" (nurse 1). "I am unsure how to actually start the conversation" (nurse 2). "The conversation has to be dialogue based" (PC nurse).	Competences	
"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).	Organisation	

Recognition of differing perspectives

This general theme revealed a need to recognise 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 optimised 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 recognises 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 (37 pg6). 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 recognise 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 recognised 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 reintroduced into the cardiac setting" (nurse 1).

The field notes show a dialogue going back and forth between the importance of getting the patient to recognise 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 professionalisation 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 emphasises 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 summarise, 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 organisation 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 organisation. 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 organisation's willingness to prioritise 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 organisational 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 are foreseen as a challenge by the group. Interpreting Kleinman, this challenge occurs as medical students are encouraged to prioritise disease before illness as part of the process of professionalisation (37 pg254).

Scholars from philosophy (40), sociology (41) and medicine (42) have argued for the inclusion of the patient perspective in health care for decades. An accepted approach is through patient narratives (41). This has been tried by Artioli et al. (43) 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 (43). The authors argue, citing Charon (44), 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 (44 pg14).

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 (45), Bergenholtz and colleagues explored the wishes of patients and their relatives with regard 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 (45). 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 whether 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 specialised PC literature recommendations (30,37,46). These recommendations are likely founded on a need for different specialised 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 (47). 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 (47).

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 organisational 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 (15,48). However, in practice there has been little change (49). 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 recognise 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 (50).

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.

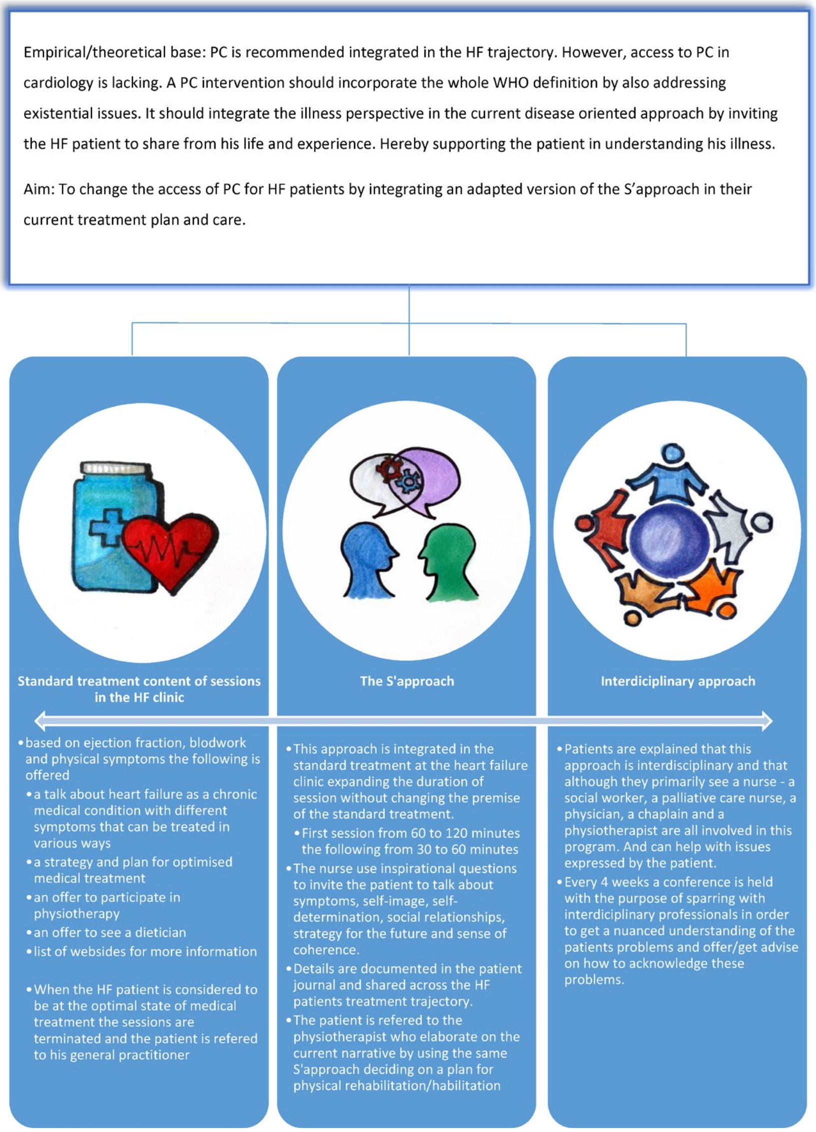
An element of this participatory method is that the group members act as representatives for the larger organisation. This puts great responsibility on each member to push change forward, which requires both authority and courage. We had hoped to involve a head nurse from cardiology, but unfortunately, 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 recognised 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 (51). This is also true for the current study. However, the dialogue method can be transferred to another setting, enabling a similar process for change.



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.

Aim: 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.

Standard treatment content of sessions in the HF clinic

- based on ejection fraction, blodwork and physical symptoms the following is offered
  - a talk about heart failure as a chronic medical condition with different symptoms that can be treated in various ways
  - a strategy and plan for optimised medical treatment
  - an offer to participate in physiotherapy
  - an offer to see a dietician
  - list of websides for more information

  - When the HF patient is considered to be at the optimal state of medical treatment the sessions are terminated and the patient is refered to his general practitioner

The S'approach

- This approach is integrated in the standard treatment at the heart failure clinic expanding the duration of session without changing the premise of the standard treatment.
  - First session from 60 to 120 minutes the following from 30 to 60 minutes
- The nurse use inspirational questions to invite the patient to talk about symptoms, self-image, self-determination, social relationships, strategy for the future and sense of coherence.
- Details are documented in the patient journal and shared across the HF patients treatment trajectory.
- The patient is refered to the physiotherapist who elaborate on the current narrative by using the same S'approach deciding on a plan for physical rehabilitation/habilitation

Interdiciplinary approach

- Patients are explained that this approach is interdisciplinary and that although they primarily see a nurse - a social worker, a palliative care nurse, a physician, a chaplain and a physiotherapist are all involved in this program. And can help with issues expressed by the patient.
- Every 4 weeks a conference is held with the purpose of sparring with interdiciplinary professionals in order to get a nuanced understanding of the patients problems and offer/get advise on how to acknowledge these problems.

FIGURE 1 Integrated general palliative care for heart failure patients (Roikjær 2019).

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 organisational 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).

ACKNOWLEDGEMENTS

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 Simonÿ contributed substantially to designing, analysing and revising the intellectual content of the manuscript. All authors read and approved the final version of the manuscript.

ETHICAL APPROVAL

The ethical considerations in this project are based on the International Council of Nurses ethical guidelines (52). 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. The Næstved, Slagelse, Ringsted Hospital Research Fund provided funding for this study. 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.

ORCID

Stine Gundtoft Roikjær https://orcid.org/0000-0002-5851-7577

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How to cite this article: Roikjær SG, Timm H, Simonÿ C. First steps to integrate general palliative care into a cardiac hospital setting – using dialogue-based workshops. *Scand J Caring Sci*. 2021;00:1–12. https://doi.org/10.1111/scs.12978

APPENDIX A

Rationale and content of workshop

Purpose
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 regard 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.
Participants
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.
Structure
The structure and time for these workshops were discussed with other researcher 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 session 2 weeks apart lasting 5 hours. The venue was a conference room at the hospital making it easily accessible for the participant.
Preparations
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 advance heart disease, (2) been on a study trip to Hospice Djursland and experienced the S' approach in a clinical setting and (3) 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 an 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

Paper IV

Qualitative study to explore what patients with heart failure find significant during integrated palliative care sessions in a Danish clinic

Roikjær SG, Simonÿ CP and Timm HU

BMJ Open. 2020 Dec 31;10(12):e043955. doi: 10.1136/bmjopen-2020-043955. PMID: 33384400; PMCID: PMC7780519.

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Qualitative study to explore what patients with heart failure find significant during integrated palliative care sessions in a Danish clinic

Stine Gundtoft Roikjær [1,2,3] Charlotte Paaske Simonÿ,[4,5] Helle Ussing Timm[1,3]

To cite: Roikjær SG, Simonÿ CP, Timm HU. Qualitative study to explore what patients with heart failure find significant during integrated palliative care sessions in a Danish clinic. *BMJ Open* 2020;**10**:e043955. doi:10.1136/bmjopen-2020-043955

► Prepublication history for this paper is available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2020-043955).

Received 19 August 2020
Revised 11 December 2020
Accepted 18 December 2020

[1]Institute of Clinical Research, University of Southern Denmark, Odense, Denmark
[2]Medicine 2 Cardiology, Næstved, Slagelse and Ringsted Hospitals, Region Zealand, Denmark
[3]REHPA, Knowledge Center for Rehabilitation and Palliative Care, Nyborg, Denmark
[4]Institute for Public Health, University of Aarhus, Aarhus, Denmark
[5]Department of Research, Næstved, Slagelse and Ringsted Hospitals, Region Zealand, Denmark

Correspondence to
Dr Stine Gundtoft Roikjær;
stine.roikjaer@gmail.com

ABSTRACT

Objective In the field of palliative care (PC) as it is integrated into heart failure (HF) treatment, it is essential to explore the patient experience and build on this knowledge for the further development of PC practice and policy. Based on an intervention study, this paper explores what patients with HF find significant in integrated sessions using a narrative S' approach.

Design We conducted a semistructured interview study with a qualitative analysis focused on meaning making. The study follows the guidelines of Consolidated Criteria for Reporting Qualitative Research.

Participants and setting The inclusion criteria for the PC intervention were (1) a new diagnosis of HF, (2) follow-up treatment at this local Danish HF clinic and (3) informed consent to participate in the integrated PC intervention. The only exclusion criterion was if the patient was already engaged in a PC programme. 20 patients agreed to participate in the intervention, and 12 of these completed the S' approach sessions and participated in this interview study.

Results Overall, the analysis showed that the integrated S' approach sessions were successful in joining an embodied patient perspective with a medical perspective. The thematic analysis resulted in three themes supporting the overall findings: sessions bring comfort, telling your story provides a sense of meaningfulness, and integrating perspectives of HF into everyday life.

Conclusion The method using the S' approach in integrated PC and HF sessions was significant in various ways. First, patients experienced a calm and safe atmosphere and perceived that the nurse was truly interested in them. Second, the integrated sessions based on the S' approach were able to bring comfort to lived physical, psychosocial and existential issues. Last, it allowed patients to combine their embodied understanding of HF with a medical perspective, thereby finding meaning in the sense of how everything is connected.

Strengths and limitations of this study

- Qualitative interviews provided insight into the essential patient experience.
- Our recruitment strategy had to be altered due to lack of inclusion.
- Patients in this interview study were all ethnic Danes and predominantly male.
- Limitations of generalisability are common to qualitative research methodologies.

INTRODUCTION

There is a broad clinical consensus that palliative care (PC) should be an essential part of the treatment and care of patients with heart failure (HF).[1,2] Nevertheless, there is a gap in our knowledge regarding integrated PC in HF treatment from diagnosis onwards. Specifically, the current research literature lacks insight into the significance of integrated PC for patients with HF.

The patient perspective in healthcare is a foundation for a democratic and patient-centred care approach.[3,4] Hence, knowledge of the patient experience is essential for the further development of meaningful and integrated PC in HF treatment. This article describes the experiences of patients participating in a PC intervention with a narrative approach.

The scope of HF

HF affects over 37 000 000 people worldwide, making it a serious global health problem in need of widespread concern and attention.[5] Cardiology is a highly evidence-based medical area focused on saving lives by solving structural or biomedical problems of the heart. Advances in technology and pharmaceuticals have had a positive effect on cardiovascular death.[6] Nevertheless, with regard to chronic HF, the main option is slowing the progression of the illness and treating the accompanying symptoms.

Living with HF has been described as a roller coaster you cannot get off[7] or as a Sisyphean struggle.[8] Both descriptions capture the experience of an unreliable illness that fluctuates from periods of deterioration with life-threatening events to better times where symptoms are under control. In addition, studies have shown that patients with HF have difficulty understanding their condition, possibly increasing the risk of acute events.[9 10]

Different perspectives on PC and HF

PC is defined as using a holistic approach to increase quality of life for people suffering from life-threatening illnesses by relieving problems of a physical, psychosocial and existential nature.[11] Embedded in the philosophy of PC is an acknowledgement of the essential embodied patient perspective.[12]

The medical anthropologist and MD Arthur Kleinman has argued for the importance of patient perspective within his theory on illness and disease. He contends that the embodied illness perspective is essential in the holistic treatment and care of patients with chronic diagnoses.[4] The illness perspective holds the key to a comprehensive understanding of living with HF, as it is the ‘principal difficulties that symptoms and disability create in our life’ (p4).[4] The nature of illness as an embodied and subjective experience requires a narrative and explorative approach. Conversely, a medical professional’s disease perspective may be based on a biomedical view of a problem formed by years of medical training.[4] Hence, to provide holistic PC, a method that incorporates several different perspectives is needed.

Ideally, PC should be implemented alongside standard treatment of HF. However, the current research literature[1 2 6] focuses on medical and technological strategies in the advanced stages of HF. More research on the existential aspects of HF is needed.

Exploring the patient experience

In recent decades, healthcare and research have developed a more democratic and patient-centred focus, recognising the importance of the patient’s perspective.[3 13] Although the reasons might seem obvious to our reader, we will try to articulate a few.

In general, health research seeks to add value and quality to health interventions.[14] Incorporating evidence of real-life experiences into both research and healthcare is seen as an essential part of improving patient outcomes and ensuring positive experiences of healthcare.[14] This is supported by a recent systematic review[15] indicating a positive association between patient experience, clinical effectiveness and patient safety.

In the new field of general PC as it is integrated with HF treatment, it is essential to explore the patient experience and build on this knowledge in the further development of practice and policy. Narrative inquiry can provide insight into how a subject experiences an intervention. In addition, narratives can be used as an intervention itself.

The narrative S’ approach

Narratives in research or practice are not new. Sociologist Arthur Frank argued that illness always calls for a story,[16] and a narrative can provide a meaningful understanding of experiences, events or ideas. Interventions using personal narratives have shown promise with existential distress in PC.[17–19] However, it is not easy to apply the resource-intensive reminiscence-based narrative in the fast-moving hospital setting.[17–19]

The S’ approach[20] was developed by Ternestedt and her team to operationalise PC in a clinical setting by exploring needs and resources in the dimensions of symptom control, self-image, self-determination, social relationships, strategy for the future and sense of coherence.[20 21] Based on the idea of narratives as a method to provide meaningful patterns, the S’ approach aims to integrate patient and professional perspectives in PC.[21] However, the literature lacks research on the S’ approach in general hospital PC and in HF treatment.

METHODS

Aim

This study explored what patients with HF found significant in integrated PC and HF sessions using a narrative approach.

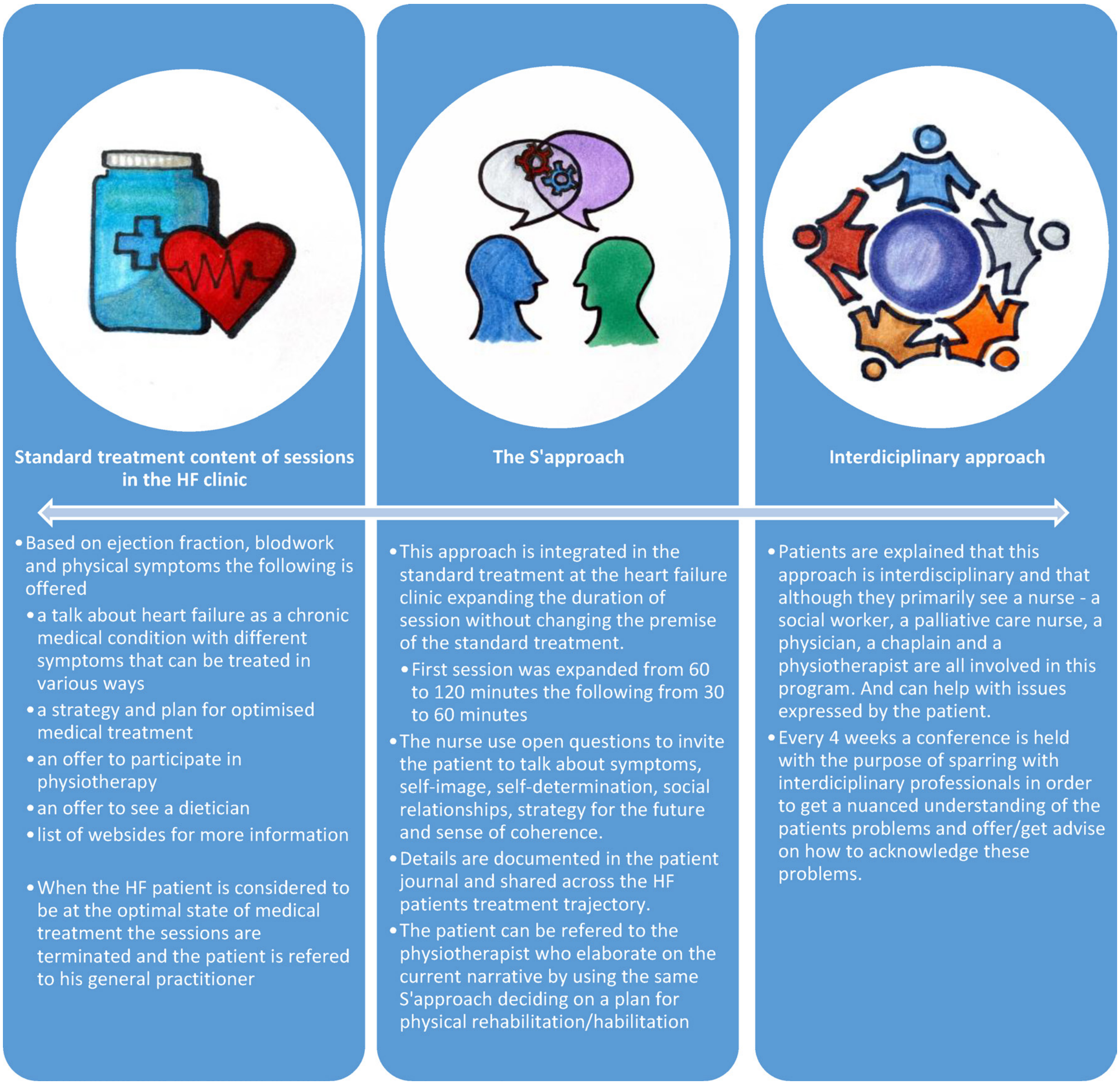
A PC intervention for HF

On the basis of current research[17] exploring the need for[8] and lack of knowledge of PC in a general hospital setting, an intervention was designed and implemented alongside the standard treatment provided by a general outpatient HF clinic at a hospital in Denmark.

The principal ideas for this PC intervention were (1) to operationalise the WHO definition of PC, (2) to integrate patient and professional perspectives using dialogue and personal narratives and (3) to integrate the PC intervention into the standard treatment and care of patients with HF to enable large-scale implementation.

These ideas were converted into the following actions: educating the interdisciplinary team in PC as well as HF through a seminar. The seminar presented current knowledge on PC for patients with HF, examples of the organisation of PC in HF treatment in Denmark and a panel discussion on clinical cases. Furthermore, the intervention nurses were trained in communication with a narrative S’ approach. Through workshops, the interdisciplinary project group adjusted the inspirational S’ questions to focus less on end of life and more on life with a life-threatening illness.

The intervention nurses were responsible for exploring the patient perspective using the adjusted S’ approach. They invited the patients to share experiences, worries or thoughts from their life supported by a guide with inspirational questions. The narrative approach was integrated into the standard HF sessions, and the nurses documented the narrative under *S* categories in the patient’s file, making it accessible to the interdisciplinary team. Every 4 weeks, an interdisciplinary conference was held. During the conference, the nurses presented possible PC needs based on the S’ words and received recommendations from the other members on how to manage a need.



Standard treatment content of sessions in the HF clinic

- Based on ejection fraction, blodwork and physical symptoms the following is offered
  - a talk about heart failure as a chronic medical condition with different symptoms that can be treated in various ways
  - a strategy and plan for optimised medical treatment
  - an offer to participate in physiotherapy
  - an offer to see a dietician
  - list of websides for more information

  - When the HF patient is considered to be at the optimal state of medical treatment the sessions are terminated and the patient is refered to his general practitioner

The S'approach

- This approach is integrated in the standard treatment at the heart failure clinic expanding the duration of session without changing the premise of the standard treatment.
  - First session was expanded from 60 to 120 minutes the following from 30 to 60 minutes
- The nurse use open questions to invite the patient to talk about symptoms, self-image, self-determination, social relationships, strategy for the future and sense of coherence.
- Details are documented in the patient journal and shared across the HF patients treatment trajectory.
- The patient can be refered to the physiotherapist who elaborate on the current narrative by using the same S'approach deciding on a plan for physical rehabilitation/habilitation

Interdiciplinary approach

- Patients are explained that this approach is interdisciplinary and that although they primarily see a nurse - a social worker, a palliative care nurse, a physician, a chaplain and a physiotherapist are all involved in this program. And can help with issues expressed by the patient.
- Every 4 weeks a conference is held with the purpose of sparring with interdiciplinary professionals in order to get a nuanced understanding of the patients problems and offer/get advise on how to acknowledge these problems.

Figure 1 Integrated heart failure (HF) and palliative care (PC) intervention.

The mean number of sessions with the nurse was 8, with a range from 3 to 13. Figure 1 illustrates the integrated intervention.

Patient and public involvement

As this is a qualitative interview study, patients played an essential part as informants. In addition, this study is part of a larger PhD study aimed at changing clinical practice. During this process, patients and professionals from cardiology and PC were involved at different stages: (1) we conducted semistructured interviews with patients with HF to inform needs for a PC intervention; (2) we conducted workshops with professionals to develop integrated PC and HF sessions using a narrative approach.

Study design

We chose a qualitative interview study design to explore subjective experience of patients with HF of sessions using the S' approach (hereafter, these are referred to as ‘sessions’). The study follows the Consolidated Criteria for Reporting Qualitative Research guidelines.[22]

Participants

The inclusion criteria for the PC intervention were (1) a new diagnosis of HF, (2) follow-up treatment at this local Danish HF clinic and (3) informed consent to participate in the integrated PC intervention. The only exclusion criterion was if the patient had already followed a PC offer due to other illnesses. The inclusion period was March–August 2019, and the aim was to include between 20 and 25 participants. As patients were referred to the HF clinic, the first author approached them by phone or in person, inviting them to join the integrated PC intervention. Patients all received information about the study in writing and were encouraged to discuss it with family, professionals or the first author before deciding to participate. In all, 22 patients were approached, 20 agreed to participate in the PC intervention and 12 of these completed the sessions and participated in this interview study (see figure 2).

Data collection

To gain an understanding of the lived experiences of participating in the sessions, the first author planned

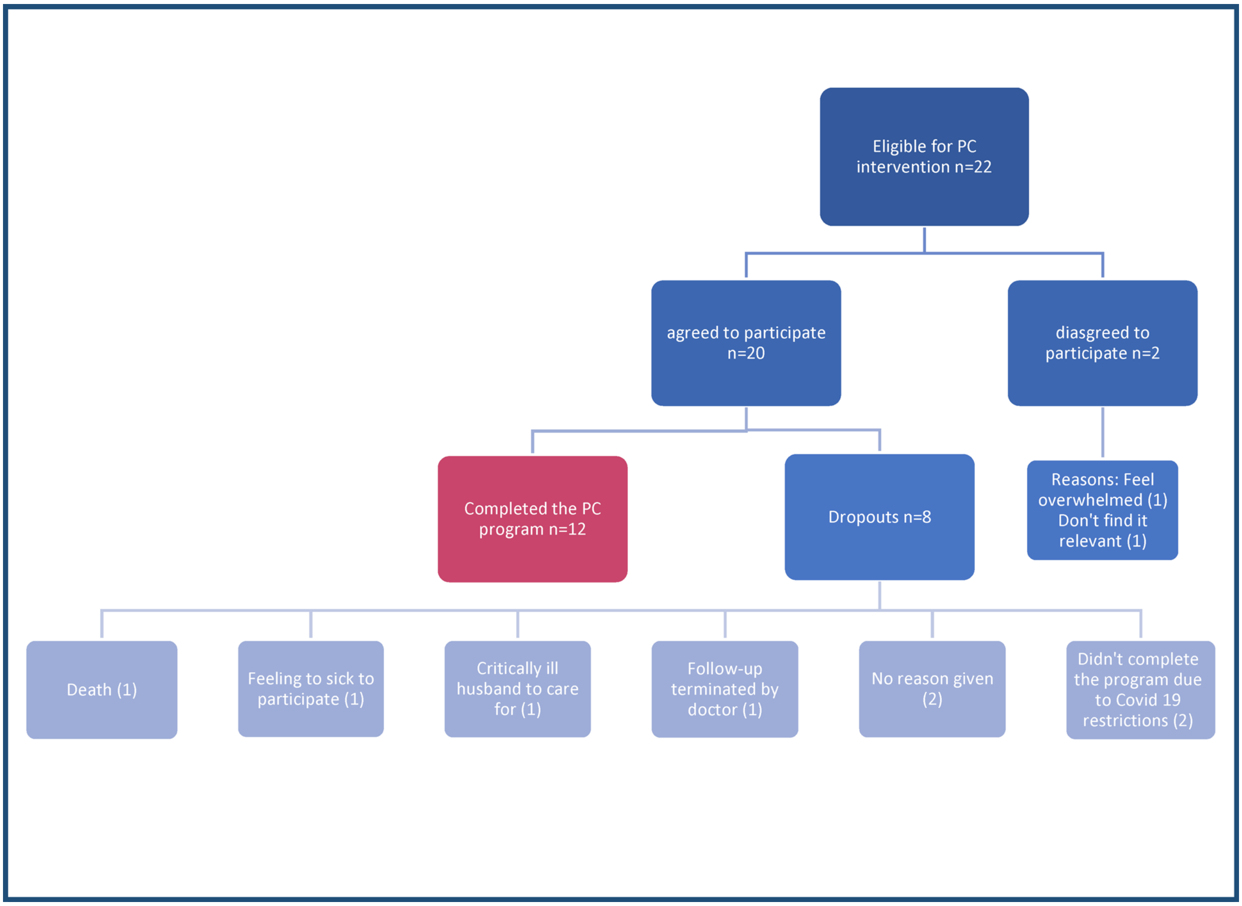


Figure 2 Flow chart of participants. PC, palliative care.

and performed individual semistructured interviews with the patients as they concluded the sessions. Participant observations were conducted by the first author during earlier sessions; hence, a relationship had already been established with the patients. Only the interview data will be presented in this analysis.

The key question, 'please tell me your experiences with the sessions at the HF clinic', guided the interview. If necessary, the first author followed up with, 'can you say a bit more about that?' or 'what did that mean to you?'

To create a calm and engaged atmosphere as well as a sense of neutrality, most interviews were conducted at the participants' homes. Some participants preferred to have their spouse present. However, due to logistics, three patients preferred that the interview took place at the HF clinic in conjunction with their last follow-up visit. The interviews had a mean duration of 61 min and were audio recorded and transcribed ad verbatim. By the 10th interview, data saturation consistent with our aim, sampling plan and inclusion criteria had occurred.[23]

Demographic data for the patients participating in the study are presented in table 1.

Data analysis and interpretation

The first author used the software programme NVivo V.12 Pro for coding and managing data, with the following steps as described by Green: (1) organising the data, (2) familiarising ourselves with the data, (3) coding the data

Table 1 Participant demographic data

Participant	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Sex	F	M	F	M	M	M	M	F	F	M	M	M
Age	60s	50s	80s	70s	60s	50s	70s	70s	80s	40s	70s	70s
Married/partner	Yes	No	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Other diagnoses	MI	VAB, AF	NST, COL	BPH	NST	SCA	ASHD	NP	ASHD, RI		CHD	AF, HT
Sessions	10	13	7	7	5	3	8	13	10	7	6	6

AF, atrial fibrillation; ASHD, arteriosclerotic heart disease; BPH, benign prostatic hyperplasia; CHD, coronary heart disease; COL, chronic obstructive lung disease; HT, hypertension; MI, mitral insufficiency; NP, nephropathy; NST, non-ST-elevation acute myocardial infarction; RI, renal insufficiency; SCA, sudden cardiac arrest; VAB, bicuspid aortic valve.

and (4) creating the themes.[24] The qualitative thematic analysis, informed by Kvale and Brinkmann, focused on meaning making.[25] It was derived through a continuous hermeneutic process of going back and forth between parts and the whole in discussion with the coauthors.[25] The analysis was further interpreted using theory and additional research from the field.

RESULTS

Overall, the analysis showed that the integrated S' approach sessions were successful in joining patient and professional perspectives. This approach was meaningful for the patient in terms of integrating illness into everyday life.

For many patients, their HF diagnosis manifested as physical symptoms, anxiety and worries in their everyday life. The sessions with a narrative approach provided an inviting, calm and safe atmosphere to express worries and share stories. This in turn led to a sense of coherence and meaningful understanding of HF and thereby provided comfort. Those who did not experience problems still appreciated the personal focus and atmosphere but were not able to express the significance of participating. The thematic analysis resulted in three themes that support the overall findings: sessions bring comfort, telling your story provides a sense of meaningfulness and integrating perspectives of heart failure into everyday life.

We present these themes supported by quotes from patients.

Sessions bring comfort

The patients perceived the integrated HF and PC sessions using the S' approach as a response to their problems. Most expressed that regardless of their nature, their problems were always welcomed and recognised.

Many patients highlighted issues of anxiety as a reaction to their diagnosis of HF. One described feeling a state of panic:

> Well, I was panicking. Just as soon as I had fallen asleep, I woke up. I couldn't breath—and this had nothing to do with my illness. It was fear—pure and simple. P8

This anxiety kept the patient from socialising. She would turn down every invitation and stay home watching her newly planted beautiful flowers. Flowers, she told me during an earlier conversation, that she imagined would adorn her grave. She continued the interview by clarifying how the sessions relieved her from that state of panic, and the nurse helped her get a grip on reality and fear:

> She (the nurse) made me feel in good hands. Well, just that fact, and the fact that she had everything under control, and me knowing that everything was as it should be and not as horrific as I thought. Because I thought I was about to die. P8

Another patient specifically articulated a transition between chaos before a session and a sense of calm after a session:

> I am always completely relaxed after seeing Helen (fictive name for the nurse). Before I get there, I am in a state of oh oh (swirls her head around making frantic gestures with her arms). P9

An example of a response to an existential problem was the story told by P11. He described how his father died from a heart attack when he was only 56 years old. He speaks of the incident as '*tragic*' and '*hectic*'. As the following quote shows, he was very angry with his mother and blamed her for his father's death:

> My father had died and my mother had found another… I didn't visit her for 12 years—I didn't. P11

He had talked to the nurse about this, and in addition to listening, she advised him to talk to the hospital chaplain because she suspected that this could be connected to his current anxiety. At first, he had declined, but after giving it some thought, he had a talk with the chaplain. I asked him what that meant to him talking to the nurse and the chaplain. He responded with a quote that conveyed a sense of comfort as well as togetherness:

> I was sad—I really was. However, it feels good to talk. Had I been alone I think this problem would have become even bigger. P11

In terms of practical problems, the patients shared how the nurses offered constructive advice. One patient (P11) mentioned that he had trouble remembering taking his pills in the evening due to sporting activities. The nurse advised him simply to set an alarm on his phone, and now he remembers the pills.

It seems, however, that not all problems can be resolved as a patient with chronic insomnia pointed out.

> I have spoken with her (the nurse) about it, but unfortunately, I am none the wiser. P7

He wished that the programme had involved some joint interdisciplinary sessions to tackle this problem. However, he continued:

> You can discuss how to organise this, but I have been in the hands of competent people, and that has brought me comfort. P7

Even if the patients did not experience psychosocial, existential or practical problems, all expressed great satisfaction with the sessions. Many stated that this should be offered to everyone, regardless of diagnosis. They especially highlighted the atmosphere and attentiveness projected during the sessions:

> There you feel that you are the only one in the world they are concerned about. P5

In summary, the analysis shows how patients felt cared about, which enabled them to share their personal experiences, thoughts or worries. The nurses appeared willing to address any issue, and patients perceived them as competent and concerned. The patients articulated how they felt a sense of comfort after sessions.

Telling your story provides a sense of meaningfulness

The S' approach builds on dialogue and narratives, and this was appreciated by patients:

> It is a nice feeling—especially as a patient—that you know that someone wants to hear what you have to say. P9

The interview data showed how patients interpreted this as genuine interest from the professionals. Many spoke of this as a new experience compared with other times they or loved ones had needed support during illness as the following quote supports:

> I will say—I felt someone took care of me. It was different when I came home after having the blood clot—no one took care of me then. P11

The patients described telling stories of difficulties coping with, for example, the loss of a father, a complicated relationship in the family, or more obvious illness-related stories of prior illnesses, hospitalisations and fear of dying.

The opportunity to share and tell stories brought about a sense of meaningfulness and coherence for most patients. One patient (P7) described that the approach took into account that he is a whole person and not only the part with illness. Another reason was that by sharing from his everyday life (P11), the nurse was able to obtain a more nuanced picture of his problems and was, therefore, better able to support him. Complementary, another reported that he himself had benefited from an improved understanding of the whole situation:

> It is significantly meaningful, both in regards to medicine and that stuff but also in how one understands… how should I put it… the whole thing. P4

The following example further supports how this approach was seemingly meaningful and brought a sense of how everything is connected to the patients: one patient (P5) explained during the interview that he quite quickly felt physically back in shape. Nevertheless, he had trouble concentrating and felt easily overwhelmed, which resulted in a bad mood. He had taken this up during sessions, believing that the pills were the reason for his mental state. The nurse listened to his troubles and agreed to adjust some of the medication. However, she had asked him to talk more about his situation at home. Encouraged by the nurse's invitation, this made him share the story of his daughter who was going through an awful divorce, which affected the whole family. He worried about her and the granddaughter. The daughter, on the other hand, was worried that she had caused the hospitalisation of her father. During the interview, he related how as he told his story to the nurse, he came to realise that this might indeed be a factor in his mental state and expressed gratitude that the sessions allowed for such reflections.

Another example of feeling a sense of coherence is one of inheritance and reminiscence. A patient told me stories of how she had inherited personal items from her grandparents, and now she had passed them on to her children and grandchildren.

> you know what; I will give it to you now. I have no room for it, and this way I can enjoy seeing you use it. P9

She expressed how this in part was brought on by the sessions and the stories she shared with her nurse.

These examples show how telling stories from lived life can help recognise the bigger picture, thereby creating a sense of meaning and coherence. However, not all patients exploited this opportunity to share stories and narratives. One explained that she would rather talk to loved ones if she experienced feeling sad or anxiety and denied a need to do so. She stated that it was a personality trait:

> I'm not really one for company or talk. P3

Another explained that he had no reason to share:

> Well, I don't feel we have any problems—or that I have. And the things you mention about sharing different things, I just don't think there is a reason to. P12

Both of these patients perceived their life to be no different now from before the diagnosis, as they had no problems of either a physical or an existential nature. However, when I asked one of the patients if she found the nurses questions provocative, she denied this. I sensed that the nurse was sensitive to the patient's perspective and refrained from pushing for a story. Forcing these patients to share stories from their everyday life would have been meaningless to them.

Integrating perspectives of HF into everyday life

Some patients expressed a need to comprehend the physiology in terms of their diagnosis and their experienced symptoms. Others had a need to understand the connection between their blood tests and treatment or if there was anything they could do in their everyday lives to improve their outcomes. Most conveyed a need to know what the HF diagnosis would mean for their everyday life and future.

These needs share an underlying wish to join a personal and embodied understanding of HF with a medical perspective.

Discussions of the severity of HF and considerations of death were included in the sessions. The patients shared that they welcomed the talk of death and dying:

> Well, it is the one thing you can be certain of in this life. P4

This patient found death to be a natural part of life and elaborated on how he and his family had always spoken openly about their wishes in terms of death. However, he went on to express what I interpret as a difference between preparing for death and being prepared to die:

> it's like… You can never be prepared 100%. P4

Another patient (P11) told me that due to the sessions, he had written his will. He had been visiting churches in his parish, as he wanted to hear the priest's sermons and choose a burial site. In addition, another spoke about how he had gone over legal documents, ensuring that everything was up to date in case of his death. He believed that this was just as important as deciding on the funeral:

> It brings me comfort that my family is financially secure in case I die—to know that my bereaved are comfortable and won't need that struggle on top of everything else. P6

I asked him what it meant for him to be able to talk these things over with the nurse, and he elaborated on finding a balance between fear of dying due to the seriousness of the illness and letting go:

> I give it less and less attention—I mean it has to get some consideration—you can never let it go completely. It is present but it must not dominate (life). P6

All patients let me understand that death was probably not in their imminent future, as they felt better after treatment and the sessions. This sense of *feeling better* was not restricted to physical well-being but just as significantly a psychological well-being. One patient put it this way:

> If the kids asked how I was, I cried excessively and instantly. Now when they ask, I tell them that I am brilliant and they are so happy. P8

She went on to tell me that the sessions had given her hope and a way to integrate her worries of HF within her everyday life:

> It's like Winnie the Pooh is saying 'the rest of the days you have to live' and that is so true. P8

As a whole, these examples show that sessions supported the patients in combining their embodied understanding of HF with a medical perspective. Therefore, the sessions helped patients integrate different perspectives of HF in their everyday life. The patients considered death a threat avoided for now due to the treatment. However, they recognised the severity of the illness and felt supported in balancing worries with hope and living life.

DISCUSSION

PC is a holistic approach focusing on relieving physical, psychosocial and existential problems.[11] Based on the analysis, we found overall satisfaction with the integrated PC sessions using an S' approach. The patients described a calm and inviting atmosphere with time for them to share stories from their life. They felt a genuine concern from the nurse and understood the sessions as a response to their problems, regardless of their nature. Furthermore, we found that most patients in our sample felt that the sessions provided relief for their problems.

This is supported in an RCT study on the effects of the S' approach as integrated PC.[26] Brännström and Boman found that integrated care relieved physical, physiological, social and spiritual problems. Furthermore, it reduced the number of hospitalisations and the number of days spent in the hospital.[26] However, that study differed from our current study in several ways. In addition to the obvious differences in methodology, the patients in the RCT study were suffering from advanced HF, and the intervention was home based. To our knowledge, our study is the first to involve participants in an intervention at the time of diagnosis.

PC is often mistakenly seen as exclusively an end-of-life intervention delivered only by specialists. However, as our study shows, patients were able to convey and relieve problems of varying natures even though they were in the early stages of their illness and in a general HF clinic. The early onset of problems as well as the variety of needs over the course of the illness has been found in similar studies,[27 28] which strengthens the argument for integrated PC. However, our study found that not everyone experiences psychosocial or existential problems in the early stages of HF. Screening for psychosocial and existential problems as triggers for PC could be helpful in the organisation of PC for patients with HF.

The outcomes related to the comfort that the patients described have also been reported before. A phenomenological study[29] with the aim of describing comfort and discomfort experienced by inpatients at a PC unit concluded that PC units created a space of comfort where the patient could find a suitable therapeutic response to their needs.[29] Based on our findings, we would argue that the key to comfort is not whether the setting is general or specialised, but rather that there is a holistic approach embedded in the philosophy of PC that acknowledges all problems presented by patients. Nevertheless, not all problems could be solved during the sessions.

Several studies have shown that patients find it hard to comprehend the nature of HF.[8–10] The PC sessions using the S' approach that integrates patient and professional perspectives on illness and disease proved valuable to the patients in terms of understanding HF. Kleimann has argued that illness perspectives are formed from how patients understand and talk about symptoms, how the disease is viewed in our culture and, most importantly, the patient's individual life world.[4] Our analysis shows that when patients experience a nurse acknowledging their life stories, it facilitates internal reflection. This supports patients in achieving a sense of how everything is connected, which again enables a nuanced understanding of HF. This outcome could mean a decrease in unnecessary acute events, as Brännström and Boman found.[26]

The current organisation in HF clinics does not prioritise acknowledgement of such stories. At present, the main purpose is to adjust medical treatment to clinical symptoms and known effects. Our study showed that providing time and creating a safe atmosphere to share stories and incorporate the patient perspective had a significantly meaningful impact on patients. However, to change current practices and policies, there might be a need to strengthen arguments through cost–benefit analyses and clinical trials.

Limitations

To obtain a representative sample, the strategy was to invite patients as they were referred to the HF clinic. This strategy failed as patients in the hospital ward were not detected. We had to change our strategy and manually go through referral lists. This is a clear limitation, as patients eligible for participation were not invited.

Another limitation in this interview study is that participants were all ethnic Danes and predominantly male. This is a problem, as a recent cohort study[30] showed a higher incidence of heart diseases among non-Western immigrants than among Danish-born patients. To achieve a more nuanced picture of the significance of integrated PC in HF treatment, further research could target these non-Western immigrant populations.

CONCLUSION

The method using the S' approach in integrated PC and HF sessions was shown to be significant in various ways. First, it allowed the patients to feel and experience a calm and safe atmosphere with a nurse who was truly interested in them. Second, integrated sessions based on the S' approach brought comfort to participants experiencing lived physical, psychosocial and existential issues. Last, it allowed patients to combine their embodied understanding of HF with a medical perspective, thereby finding meaning in the sense of how everything is connected. These findings are in agreement with the aim of PC and provide a 'real-life' argument for an integrated approach to PC in HF treatment.

These findings might reflect a common sense interpretation to the reader. However, the discussion of the findings in the context of a theoretical framework and with additional research provides a more general reflection. This reflection is vital for future integrated PC.

Ethical approval and consent to participate

The Committee on Health Research Ethics for Region Zealand, Denmark (REG-108–2017), covering Næstved, Slagelse and Ringsted Hospitals, approved this study. Further ethical considerations for this project were based on both the International Council of Nurses ethical guidelines[31] and the Helsinki Declaration.[32] The patients were made aware that this study was part of a PhD study.

Twitter Stine Gundtoft Roikjær @RoikjR

Acknowledgements The authors would like to thank the patients for sharing their experience with this PC intervention. Furthermore, they are thankful that the HF clinic found the study to be worthy of investing their time and resources.

Contributors All authors were involved in designing the study to meet the objective. SGR executed the study, collected data, coded, analysed and interpreted the data as well as drafted and revised the manuscript. CPS contributed by revising the intellectual content of the manuscript. HUT contributed in both analysis and in revising the intellectual content of the manuscript.

Funding This study was funded under a larger PhD grant from the Næstved, Slagelse and Ringsted Hospitals' Research Fund. Grant number is not applicable.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication All participants stated their consent for publication as part of their consent to participate.

Data availability statement Data are available upon reasonable request. The qualitative dataset generated and analysed during this study are available from the first author but restrictions apply to the availability of these data.

Author note SGR is a PhD student, has an MSc in public health and is also a registered nurse with cardiac experience. At the time of this study, she was a PhD student. CS is the head of research at Næstved, Slagelse and Ringsted hospitals. HT is a professor in palliative care and at that time employed at REHPA, the Knowledge Center for Rehabilitation and Palliative Care.

ORCID iD

Stine Gundtoft Roikjær http://orcid.org/0000-0002-5851-7577

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Appendix A: Information to Patient Participants

Information til deltagere ved projekt om lindring til mennesker med hjertesvigt 2019

Lindring til mennesker med nedsat pumpefunktion, også kaldet hjertesvigt, med fokus på deres behov og ønsker.
Du inviteres hermed til at deltage i et projekt med henblik på at udvikle sygehusets indsats for mennesker med diagnosen 'hjertesvigt'. Projektets fulde titel er *Basal Palliation til Mennesket med Hjertesvigt Baseret på Deres egne Fortællinger.* Nedenfor kan du læse mere om, hvad projektet drejer sig om.

Hvem er jeg/forskeren?
Mit navn er Stine, jeg er forsker og har en fortid som sygeplejerske ved hjerteafdelingen på Slagelse Sygehus. Jeg er interesseret i patienters oplevelser med sygdom og i at sikre de bedst mulige forløb for patienter.

Hvad er formålet med projektet?
Formålet med forskningsprojektet er at afprøve en lindrende (palliativ) indsats, hvor den enkelte patients egen historie om sit liv og sin sygdom fylder mere i det samlede tilbud til mennesker med nedsat pumpefunktion. I den forbindelse har vi brug for patienter, der har lyst til at afprøve indsatsen og vurdere den bagefter.

Skal du deltage?
Du bestemmer naturligvis selv om du vil være med – og hvis du siger nej, påvirker det ikke dit videre behandlingsforløb! Hvis du vælger at deltage, vil jeg bede dig om at underskrive en samtykkeerklæring. Denne er du fri til at annullere på et hvilket som helst tidspunkt, også uden at det får nogen betydning for dit videre forløb.

Hvad indebærer projektet?
Som et supplement til den almindelige opfølgning på ambulatoriet vil din første samtale i ambulatoriet blive udvidet, så vi kan høre mere om din oplevelse af at få konstateret nedsat pumpefunktion. Du vil på forhånd modtage et brev med nogle spørgsmål, så du kan forberede dig lidt på, hvad du mener er vigtigst at få fortalt. Samtalen skal bruges til at finde ud af, hvordan personalet bedst kan hjælpe dig i dit forløb. Du vil primært møde en højt specialiserede ambulatorie sygeplejerske, men der er tilknyttet både kardiolog, fysioterapeut, præst og konsulenter til dit forløb.

Hvad bliver resultaterne af projektet brugt til?
Projektet skal bruges til at udvikle den fremtidige indsats for mennesker med en hjertesvigtsdiagnose, så indsatsen virker mest muligt relevant og dækkende for dig og andre mennesker med hjertesvigt.

Vil dine oplysninger blive behandlet fortroligt?
Ja. Alle oplysninger vil blive behandlet strengt fortroligt som lovgivningen foreskriver. Når resultaterne formidles er du anonymiseret, så du ikke genkendes af udenforstående.

Hvem har vurderet og godkendt undersøgelsen?
Denne undersøgelse er vurderet af Videnskabsetisk Komité, og godkendt af Datatilsynet, Syddansk Universitet samt Sygehusene Næstved, Slagelse og Ringsted i Region Sjælland.

Kontaktoplysninger
Hvis du har spørgsmål vedrørende projektet er min e-mail adresse sgro@regionsjaelland.dk og mit telefonnummer +45 29704949

Med venlig hilsen
Stine Gundtoft Roikjær, sygeplejerske, MscPH, Ph.d. studerende

Appendix B: Informed Consent Form

Informeret samtykke formular

Projektets titel: Basal palliation til mennesket med hjertesvigt baseret på deres fortællinger

Navn på undersøgeren: Stine Gundtoft Roikjær

Skriv dine initialer i boksen

1. Jeg bekræfter at have læst og forstået informationsarket for ovennævnte projekt. Jeg har haft lejlighed til at overveje oplysningerne, stille spørgsmål og har fået projektet grundigt forklaret.	
2. Jeg forstår at min deltagelse er frivillig og at jeg kan trække mig på hvilket som helst tidspunkt, uden at give nogen begrundelse, uden at min behandling eller juridiske rettigheder påvirkes.	
3. Jeg forstår og giver tilladelse til at forsker og sundhedspersonale tilknyttet projektet tilgår min journal i forbindelse med indhentning af data og informationer til projektet.	
4. Jeg forstår at relevante dele af informationer og data indsamlet i løbet af projektet kan ses af ansvarlige enkeltpersoner fra Syddansk Universitet, fra tilsynsmyndigheder eller fra dette hospital. Jeg giver disse personer tilladelse til at se mine data og informationer.	
5. Jeg accepterer at deltage i ovennævnte projekt	
6. Jeg accepterer anvendelsen af audio, interview og citater i afhandling eller publikationer på baggrund af dette projekt.	

Deltagers navn og CPR nr — Underskrift — Dato

Navn på den person der indhenter samtykket — Underskrift — Dato

Stine Gundtoft Roikjær

Undersøger — Underskrift — Dato

Appendix C: Obtained Approval

REGION SJÆLLAND
DATA OG UDVIKLINGSSTØTTE
- vi er til for dig

Stine Gundtoft Roikjær
Næstved, Slagelse og Ringsted Sygehuse
Medicin2 - Kardiologisk og Endokrinologisk Afdeling
Ingemannsvej 30
4200 Slagelse

Dato: 24.03.2020

Sagsnummer: 20-000021/108-2017
Initialer: jebra

Data & udviklingsstøtte
Alléen 15
4180 Sorø
E-mail: datatilsyn@regionsjaelland.dk

www.regionsjaelland.dk/forskning

Godkendelse af projekt, REG-108-2017:
"Patientperspektiver på livet med hjertesvigt og betydningen af den tidligere palliativ indsats ".

Ovennævnte projekt er anmeldt internt i Region Sjælland som offentligt sundhedsvidenskabeligt forskningsprojekt og indgår hermed i regionens interne fortegnelse.

Det fremgår af anmeldelsen, at du er ansvarlig for projektet, herunder ansvarlig for de personoplysninger, som projektet beskriver. Behandlingen af oplysningerne i projektet er påbegyndt den 01.07.2017 og forventes nu at ophøre den 01.02.2021.

Øvrige medarbejdere i Region Sjælland med adgang til data:

1. *Speciale ansvarlig overlæge Henrik Ryde.*
2. *Kardiologisk speciale Sygeplejerske Karen Birgit Bruun, Begge fra Medicin2 kardiologisk ambulatorie ved NSR sygehuse, Ingemannsvej 30, 4200 Slagelse*
3. *Adjunkt, Ph.d. Charlotte Simonÿ, Afdelingen for fysioterapi og ergoterapi ved NSR Sygehuse. Ingemannsvej 32, 4200 Slagelse*

Der er anmeldt behandling af følgende kategorier af data i projektet:
Kategori af registrerede personer: *28 patienter diagnosticeret med hjertesvigt der behandles på Slagelse sygehus fra juni 2017-sept 2020*

Kategorier af data: *Almindelige personoplysninger og følsomme personoplysninger i form af helbredsoplysninger.*

Konkrete data: *cpr.nr. navn, adresse, tlf.nr, diagnoser, EKKO, HADS score, EORTC score, men det vigtigste er information om oplevelse af livet med hjertesvigt, herunder også behandlingen.*

Lokation for behandling af data: *Slagelse sygehus, Afdelingen for fysioterapi og ergoterapi Fælledvej 2C, 4200 Slagelse*
Hjemmearbejdsplads: Kongebrovej 53, 4180 Sorø.

Opbevaring af data: *Data opbevares i både elektronisk form, på sikret Region Sjælland computer via Sharepoint Teamsite og på krypteret USB sticks, samt i papirform. Både USB sticks og evt. papir opbevares i aflåst skab med nøgle i aflåst forskningsrum, afd. for fysioterapi,*
Fælledvej 2, 4200 Slagelse.
Ved brug af hjemmearbejdsplads tilgås projektets data på PC'er udlevet af Region Sjælland. Ved transport af krypteret USB sticks og Regionens bærbare PC er disse under konstant opsyn og opbevaret i taske med lås. I tilfælde af data på papir på hjemmearbejdspladsen opbevares det i pengeskab med lås.

Der er til projektet indgået følgende databehandleraftaler:

Kim Bjørke, KLS Transskription, Kronborggade 10, København N.
Perioden 23.03.2020 – 01.07.2020.

TILLADELSE

Region Sjælland meddeler hermed tilladelse til projektets gennemførelse efter intern anmeldelse i regionen og indførelse på regionens interne fortegnelse i henhold til artikel 30 i Europa-Parlamentets og Rådets forordning (EU)2016/679 af 27. april 2016 (GDPR).

Det skal i forlængelse heraf nævnes, at behandlingen af personoplysninger under projektets gennemførelse skal foregå i overensstemmelse med de gældende databeskyttelsesregler, reglerne efter sundhedslovgivningen samt efter de vilkår, som fremgår nedenfor.

Internt i Region Sjælland har projektet beholdt godkendelsesnummeret **REG-108-2017.**

Region Sjælland fastsætter i forbindelse med godkendelsen følgende vilkår:

Generelle vilkår

Tilladelsen gælder indtil: Den 01.02.2021.

Ved tilladelsens udløb skal du særligt være opmærksom på følgende:

Hvis du ikke inden denne dato har fået tilladelsen forlænget, skal personoplysningerne være slettet, anonymiseret, tilintetgjort eller overført til arkiv, jf. nedenstående vilkår vedrørende projektets afslutning, pkt. 22-24.

Region Sjælland gør samtidig opmærksom på, at al behandling (herunder også opbevaring) af personoplysninger efter tilladelsens udløb vil være en overtrædelse af de gældende persondatabeskyttelsesregler, jf. GDPR artikel 5, stk. 1, litra e.

1. *Professor, overlæge, Ismail Gögenur* er ansvarlig for overholdelsen af de fastsatte vilkår.

2. Oplysningerne må kun anvendes til brug for projektets gennemførelse, herunder det/de formål, som projektet beskriver.

3. Behandling af personoplysninger må kun foretages af den projektansvarlige eller på foranledning af den projektansvarlige. Region Sjælland er dataansvarlig og al behandling af data sker således på regionens vegne, jf. GDPR artikel 32, stk. 4.

4. Enhver, der foretager behandling af projektets oplysninger, skal være bekendt med de fastsatte vilkår. Det er den projektansvarliges ansvar at oplyse om de i godkendelsen fastsatte vilkår.

5. Hvis en behandling af personoplysninger skal foretages på vegne af den dataansvarlige (Region Sjælland), skal der udelukkende benyttes databehandlere, der kan stille de fornødne garantier for, at de vil gennemføre de passende tekniske og organisatoriske foranstaltninger på en sådan måde, at behandlingen opfylder de krav, som regionen opstiller samt kravene efter databeskyttelsesforordningen, og databehandleren skal sikre beskyttelse af den registreredes rettigheder. En databehandlers behandling skal være reguleret af en kontrakt (databehandleraftale), der er bindende for databehandleren i forhold til Region Sjælland, og som fastsætter genstanden for og varigheden af behandlingen, behandlingens karakter og formål, typen af personoplysninger og kategorierne af registrerede samt øvrige forpligtelser og rettigheder.

6. Behandling af oplysninger skal tilrettelægges således, at oplysningerne ikke hændeligt eller ulovligt tilintetgøres, fortabes eller forringes. Der skal endvidere foretages den fornødne kontrol for at sikre, at der ikke behandles urigtige eller vildledende oplysninger. Urigtige eller vildledende oplysninger eller oplysninger, som er behandlet i strid med loven eller disse vilkår, skal berigtiges eller slettes, jf. GDPR artikel 32. En vurdering skal også foretages af lokaler og andre faciliteter, der benyttes til opbevaring og behandling af projekts data.

7. Oplysninger må ikke opbevares på en måde, der giver mulighed for at identificere de registrerede i et længere tidsrum end det, der er nødvendigt af hensyn til projektets gennemførelse jf. jf. GDPR artikel 5, stk. 1, litra e.

8. En eventuel offentliggørelse af undersøgelsens resultater må ikke ske på en sådan måde, at det er muligt at identificere enkeltpersoner.

9. Regler og vilkår, der fastsættes efter anden lovgivning, skal overholdes.

Elektroniske oplysninger – krav til sikkerhed

10. Der skal foretages en vurdering af, hvilke foranstaltninger der skal træffes for at sikre et tilstrækkeligt sikkerhedsniveau. Foranstaltningerne der skal afvejes i forhold til de eventuelle risici for et forskningsprojekt. Dette betyder, at persondata altid skal pseudonymiseres eller krypteres, hvis det er muligt i forhold til forskningsprojektets opfyldelse. En krypteringsnøgle, kodenøgle m.v. skal opbevares forsvarligt og adskilt fra personoplysningerne. Kun de personer, der er beskæftiget med forskningsprojektet, må have adgang til data og disse må ikke kunne se mere data end nødvendigt set i forhold til deres rolle i projektet. Alle medarbejdere, der kan tilgå data skal have et personligt login og deres aktivitet med personoplysninger skal logges. Loggen skal vise oplysninger om tidspunkt, bruger, type af anvendelse og angivelse af den person, de anvendte oplysninger vedrører og de anvendte søgekriterier. Hvis dette ikke er teknisk muligt, kontaktes Regions Sjællands IT-helpdesk for nærmere vejledning. Ovenstående skal ikke ses som en udtømmende liste for

de tekniske foranstaltninger, der skal træffes for at beskytte data. Det er projektansvarliges ansvar at træffe de tekniske foranstaltninger der skal til for at beskytte data.

11. Adgangen til projektdata, herunder personoplysningerne, må kun finde sted ved benyttelse af et fortroligt password. Password skal udskiftes mindst hver tredje måned, og når forholdene tilsiger det.

12. Ved overførsel af personhenførbare oplysninger via internet eller andet eksternt netværk skal der træffes de fornødne sikkerhedsforanstaltninger mod, at oplysningerne kommer til uvedkommendes kendskab. Oplysningerne skal som minimum være forsvarligt krypteret under hele transmissionen. Ved anvendelse af interne net skal det sikres, at uvedkommende ikke kan få adgang til oplysningerne. Se yderligere i IT's Informationssikkerhedsfolder (kræver adgang til Region Sjællands Intranet): http://intra.regionsjaelland.dk/regionshus/praktisk/it-service/it%20sikkerhed/Documents/Informationssikkerhedsfolder.pdf

13. Udtagelige lagringsmedier, sikkerhedskopier af data m.v. skal opbevares forsvarligt aflåst bag 2 gange lås og således, at uvedkommende ikke kan få adgang til oplysningerne.

Manuelle oplysninger – krav til sikkerhed

14. Manuelt projektmateriale, udskrifter, fejl- og kontrollister, m.v., der direkte eller indirekte kan henføres til bestemte personer, skal opbevares forsvarligt aflåst og på en sådan måde, at uvedkommende ikke kan gøre sig bekendt med indholdet.

Oplysningspligt over for den registrerede

15. Hvis der skal indsamles oplysninger hos den registrerede (ved interview, spørgeskema, klinisk eller paraklinisk undersøgelse, behandling, observation m.v.) skal der uddeles/fremsendes nærmere information om projektet. Dette skal foregå efter GDPR artikel 13. Den registrerede skal heri oplyses om den projektansvarliges navn, formålet med projektet og med den behandling, som personoplysningerne skal bruges til, at der foreligger et retsgrundlag for behandlingen – ofte et samtykke, at det er frivilligt at deltage, og at et samtykke til deltagelse til enhver tid kan trækkes tilbage, samt oplysninger om den dataansvarlige og den projektansvarlige, kontaktoplysninger på databeskyttelsesrådgiveren (DPO'en), eventuelle modtagere eller kategorier af modtagere af personoplysningerne, hvor det er relevant, at den dataansvarlige agter at overføre personoplysninger til et tredjeland eller en international organisation (se nærmere i artikel 13)

16. Den registrerede skal endvidere oplyses om, at projektet er anmeldt til Region Sjælland efter EU's databeskyttelsesforordning, samt at Region Sjælland har fastsat nærmere vilkår for projektet til beskyttelse af den registreredes privatliv jf. GDPR og Databeskyttelsesloven.

Indsigtsret

17. Den registrerede har krav på indsigt i de oplysninger, der behandles om den pågældende, hvis den registrerede anmoder herom.

Videregivelse

18. Personhenførbare oplysninger må ikke senere behandles til andre formål end i statistisk eller videnskabeligt øjemed, jf. databeskyttelsesloven § 10, stk. 2. Oplysninger anvendt i forskning der videregives til tredjemand kræver forudgående tilladelse fra tilsynsmyndigheden, når videregivelsen 1) sker til behandling uden for databeskyttelsesforordningens

territoriale anvendelsesområde, jf. GDPR artikel 3, 2) vedrører biologisk materiale eller 3) sker med henblik på offentliggørelse i et anerkendt videnskabeligt tidsskrift el.lign., jf. databeskyttelsesloven § 10, stk. 3.

Region Sjælland skal for god ordens skyld også gøre opmærksom på, at der i Sundhedslovens § 46 findes særlige regler om videregivelse fra patientjournaler til forskning, herunder regler om godkendelse fra Videnskabsetisk Komité og Styrelsen for Patientsikkerhed. Yderligere findes der regler i Sundhedslovens § 42 d om indhentning af oplysninger der kan anvendes til forskning, både med og uden patientens samtykke.

19. Videregivelse må kun ske efter forudgående tilladelse fra Region Sjælland. Bemærk, at Region Sjælland kan stille nærmere vilkår for videregivelsen samt for modtagerens behandling af oplysningerne. Videregivelse til udlandet uden for GDPR's territoriale område eller videregivelse af biologisk materiale kan alene ske efter godkendelse fra Datatilsynet.

Ændringer i projektet

20. Ændringer i projektet skal anmeldes til Region Sjælland (som ændring af eksisterende anmeldelse).

21. *Ændring af tidspunktet for projektets afslutning skal altid anmeldes.*

Ved projektets afslutning

22. *Senest ved projektets afslutning skal oplysningerne slettes, anonymiseres eller tilintetgøres, således at det efterfølgende ikke er muligt at identificere enkeltpersoner, der indgår i undersøgelsen. Den projektansvarlige skal ved projektets afslutning over for Region Sjælland bekræfte, at oplysningerne er slettet, anonymiseret eller tilintetgjort ved projektets afslutning.*

23. Alternativt kan oplysningerne overføres til videre opbevaring i Statens Arkiver (herunder Dansk Dataarkiv) efter arkivlovens regler. Region Sjælland skal som dataansvarlig informeres, hvis data ønskes flyttet til Dansk Dataarkiv. Region Sjælland skal godkende overførsel af data til arkiv.

24. Sletning af oplysninger fra elektroniske medier skal ske på en sådan måde, at oplysningerne ikke kan genetableres, jf. IT's retningslinjer herfor.

Ovenstående vilkår er gældende indtil videre. Region Sjælland forbeholder sig ret til senere at tage vilkårene op til revision, hvis der skulle vise sig behov for det.

Særlige vilkår

Opmærksomheden henledes specielt på, at Region Sjællands vilkår også skal iagttages ved behandling af oplysninger på de deltagende centre mv., jf. de generelle vilkår nr. 4.

Region Sjælland gør opmærksom på, at denne tilladelse alene er en tilladelse til at behandle personoplysninger i forbindelse med projektets gennemførelse. Tilladelsen indebærer således ikke en forpligtelse for myndigheder, virksomheder m.v. til at udlevere eventuelle oplysninger til dig til brug for projektet.

Databeskyttelsesloven kan læses/hentes på Datatilsynets hjemmeside under punktet "Lovgivning".

Advarsel – ved brug af Excel, PowerPoint m.v.
Den dataansvarlige skal til enhver tid sikre sig, at dokumenter og andre præsentationer, som publiceres eller på anden måde gøres tilgængelig for andre på internettet, usb-nøgle eller på andet elektronisk medie, ikke indeholder personoplysninger.

Der skal vises særlig agtpågivenhed i forbindelse med brug af grafiske præsentationer i Excel og PowerPoint, da de uforvarende kan indeholde indlejrede persondata i form af regneark, tabeller mv. Præsentationer, der gøres tilgængelig på internettet, bør derfor omformateres til Portable Digital Format (PDF), da dette fjerner eventuelle indlejrede Excel-tabeller.

Inspektion
I tilfælde af, at Region Sjælland som dataansvarlig ønsker at foretage en fysisk inspektion af de ovennævnte vilkår, forpligter den projektansvarlige sig til – med et rimeligt varsel – at stille tid og ressourcer til rådighed herfor.

Med venlig hilsen

Jeanne Britt Holm
Sekretær

Appendix D: Semi-structured Interview Guide Phase I

Denne guide er revideret efter de 3 første interviews da jeg oplevede at bruge ord som hjertesvigt og palliation eller lindrende behandling som ingen af deltagerne brugte. Ligeledes havde de tre deltagere svært ved a forstå spørgsmålet ’hvad er det vigtigste at vide om dig for at hjælpe dig bedst’ Jeg var derfor nødt til at ændre på mit ordforråd og spørge ind på en måde der bedre afspejlede deres forståelse at situationen.

Jeg er Ph.d. studerende ved Syddansk Universitet i gang med mit ph.d. projekt ’Patientperspektiver fra livet med hjertesvigt og betydningen af en tidlig palliativ indsats’. Formålet med dette forskningsprojekt er at udvikle, afprøve og evaluere en ny lindrende (palliativ) indsats til hjertesvigtspatienter. I den forbindelse har jeg et ønske om at forstå, hvordan du oplever livet med hjertesvigt.

Disse interviews er særligt vigtige da de præsenterer dit perspektiv som menneske med en hjertesvigtsdiagnose og vil danne baggrund for udviklingen af den lindrende behandling.

Jeg har valgt at definere nogle hovedspørgsmål som udgangspunkt for vores samtale, men disse er kun vejledende. Det er vigtigt for mig at du deler de ting du har lyst til og finder vigtige, glædelige eller eventuelt bekymrende i dit liv med hjerteproblemer. Jeg har sat ca. 60 minutter af til vores samtale, men dette er selvfølgelig fleksibelt.

- Hvad betyder din hjertesygdom for dig?
- Kan du beskrive eventuelle bekymringer eller følelser i forbindelse med dine hjerteproblemer?
- Hvordan vil du beskrive din hverdag? Har dine hjerteproblemer nogen betydning for din hverdag?
- Hvad har du brug for?
- Hvem hjælper dig?
- Hvad synes du er vigtigt at vi ved om dig for at hjælpe dig bedst i dit forløb på Slagelse eller Næstved sygehus?

Appendix E: Program for the Seminar

NÅR HJERTET SVIGTER
TEMADAG OM PALLIATION TIL HJERTEPATIENTEN

Den 4. september 2018 kl. 8.45-16.00, Psykiatrisygehus Slagelse, Fælledvej 6, 4200 Slagelse

PROGRAM

08.45 - 09.00	Kaffe, croissant og registrering
09.00 - 09.10	Velkomst ved oversygeplejerske Annette Lindholm, Medicin 2 NSR Sygehuse
	EVIDENSBASERET PALLIATION Ordstyrer: Heidi M. Bergenholtz, post.doc. og klinisk sygeplejespecialist ved Holbæk Sygehus og REHPA
09.10 - 09.30	**Evidens for palliation til hjertesvigtpatienten - Hvad ved vi på baggrund af systematisk litteraturgennemgang?** Ann-Dorthe Zwisler, klinisk professor, overlæge i kardiologi, centerleder ved REHPA, præsenterer resultater fra en systematisk litteraturgennemgang om evidensen for palliativ indsats til hjertepatienter
09.30 - 09.50	**Beslutningsstøtteredskab. Evidens og best practice – for hvem virker det?** Gitte E. Ingwersen, klinisk udviklingssygeplejerske, Kardiologisk Afd., Sjællands Universitetshospital. Resultater fra et udviklingsprojekt
09.50 - 10.10	**Pause**
	HELE PATIENTEN Ordstyrer: Stine G. Roikjær, ph.d. studerende ved Medicin 2 NSR Sygehuse og REHPA
10.10 - 10.50	**Hjertesygdom som eksistentielt vendepunkt** Bente H. Viuf, sygehuspræst ved Slagelse Sygehus, gennemgår betydningen af alvorlig livstruende sygdom for patienter og pårørende med fokus på eksistentielle overvejelser og vendepunkter
10.50 - 11.30	**S-Tilgangen fra Hospice Djursland** Annegrete Venborg, udviklingssygeplejerske ved Hospice Djursland, beretter om deres valg af tilgang til palliation
11.30 - 12.30	**Frokost**, sandwich
	ORGANISERING AF PALLIATION TIL HJERTEPATIENTEN Ordstyrer: Gitte E. Ingwersen
12.30 - 13.15	**Vejlemodellen** Vibeke Brogaard Hansen, ph.d., overlæge i kardiologi og Elin Fredsted Petersen, specialeansvarlig sygeplejerske, Hjertemedicinsk Afdeling, Vejle Sygehus, fortæller om deres erfaringer fra klinikken
13.15 - 14.00	**Erfaringer fra primærsektoren** Leif Sehested, speciallæge i Almen Medicin og praktiserende læge i Næstved, fortæller om den palliative indsats i primærsektoren
14.00 - 14.45	**Inaktivering af ICD-enheden** Jens Brock Johansen, overlæge ved Kardiologisk Afdeling, Odense Universitetshospital, fortæller om, hvordan man i praksis inaktiverer ICD-enheden, og hvad man særligt skal være opmærksom på i den terminale fase
14.45 - 15.15	**Pause**, kaffe og 'walk and talk' – del dine erfaringer med palliation
15.15 - 16.15	**PANELDISKUSSION OM CASES FRA HVERDAGEN** Facilitator: Helle Timm, professor, forskningsleder for Palliationsgruppen i REHPA Paneldeltagere: Annegrete Venborg, Bente H. Viuf, Jens Brock Johansen, Leif Sehested, Vibeke Brogaard og Knut Borch-Johnsen, lægefaglig vicedirektør, Holbæk Sygehus.
16.15 - 16.30	**Tak for i dag** ved Stine G. Roikjær

REHPA
Videncenter for Rehabilitering og Palliation

PROgrez

REGION SJÆLLAND
SLAGELSE SYGEHUS
– vi er til for dig

REGION SJÆLLAND
SJÆLLANDS UNIVERSITETSHOSPITAL
– vi er til for dig

Appendix F: EORTC QLQ-C15-PAL

DANISH

EORTC QLQ-C15-PAL

Vi er interesserede i at vide noget om dig og dit helbred. Vær venlig at besvare alle spørgsmålene selv ved at sætte en ring omkring det svar (tal), som passer bedst på dig. Der er ingen "rigtige" eller "forkerte" svar. De oplysninger, som du giver os, vil forblive strengt fortrolige.

Patientnummer |_|_|_|_|_|_|

Dato for udfyldelse af dette skema (dag, måned, år): |_|_|_|_|_|_|

	Slet ikke	Lidt	En del	Meget
1. Har du nogen vanskeligheder ved at gå en <u>kort</u> tur udendørs?	1	2	3	4
2. Er du nødt til at ligge i sengen eller at sidde i en stol om dagen?	1	2	3	4
3. Har du brug for hjælp til at spise, tage tøj på, vaske dig eller gå på toilettet?	1	2	3	4

I den forløbne uge:	Slet ikke	Lidt	En del	Meget
4. Havde du åndenød?	1	2	3	4
5. Har du haft smerter?	1	2	3	4
6. Har du haft besvær med at sove?	1	2	3	4
7. Har du følt dig svag?	1	2	3	4
8. Har du savnet appetit?	1	2	3	4
9. Har du haft kvalme?	1	2	3	4

<u>Vær venlig at fortsætte på næste side</u>

I den forløbne uge:	**Slet ikke**	**Lidt**	**En del**	**Meget**
10. Har du haft forstoppelse?	1	2	3	4
11. Var du træt?	1	2	3	4
12. Vanskeliggjorde smerter dine daglige gøremål?	1	2	3	4
13. Følte du dig anspændt?	1	2	3	4
14. Følte du dig deprimeret?	1	2	3	4

Ved det næste spørgsmål bedes du sætte en ring omkring det tal mellem 1 og 7, som passer bedst på dig

15. Hvordan vil du vurdere din samlede livskvalitet i den forløbne uge?

1	2	3	4	5	6	7
Meget dårlig						Særdeles god

16. Har du haft andre væsentlige symptomer eller problemer, som ikke er nævnt i spørgsmålene ovenfor?

☐ Nej
☐ Ja. Skriv venligst de vigtigste (op til tre), og angiv, I hvor høj grad, du har haft symptomerne eller problemerne i den sidste uge:

I hvor høj grad har du i den forløbne uge haft:	**Slet ikke**	**Lidt**	**En del**	**Meget**
Symptom/problem A: ______________________	1	2	3	4
Symptom/problem B: ______________________	1	2	3	4
Symptom/problem C: ______________________	1	2	3	4

Besvarede du spørgeskemaet:
☐ Uden hjælp fra personale *eller*
☐ Med hjælp fra personale?

Appendix G: Inspirational S' question Guide

Symptomlindring
Har du ondt eller føler du andet fysisk ubehag?
Påvirker symptomerne din følelse af livskvalitet
Er du tilfreds med den behandling du har fået?
Hvis ikke, hvad synes du kunne have været bedre?
Kan vi lindre dig på anden måde?
Er der noget du gerne vil, som du ikke kan?

Selvbillede
Hvad synes du det er vigtigt for os at vide om dig?
Hvordan har dit liv været, i familien, på arbejdet,
og hvad har gennem tiden været det bedste og vigtigste for dig?
Har du fritidsinteresser, du er gået op i?
Hvad har gjort dig glad og stolt i livet?
Hvad tænker du tilbage på med glæde og taknemmelighed?
Har du været god til at håndtere svære situationer i dit liv?
Hvordan har sygdommen påvirket dig, og hvordan henter du kræfter til at klare det lige nu ?
Hvordan kan vi bedst hjælpe dig med at være dig selv?

Selvbestemmelse
Hvad vil du nu gerne selv tage ansvar for?
Hvilke beslutninger kan og vil du medvirke i?
Hvem skal tage beslutning for dig hvis du ikke selv orker eller kan?
Er du sædvanligvis god til at tage initiativ?
Hvordan føles det at være afhængig af andres hjælp?
Hvordan kan vi som personale bedst støtte og styrke dig?

Sociale relationer
Hvem i din familie eller omgangskreds har helt særligt betydning for dig?
Hvem af dine nærtstående skal og må personalet give oplysninger til?
Er der nogen vi ikke må informere?
Føler du at dine pårørende er en ressource eller belastning?
Har du behov for ind imellem at være alene?
Er der noget vi kan hjælpe med, når det gælder dine nærmeste?

Strategier
Hvordan klarer du det at være uhelbredeligt syg?
Har du kunnet tale med dine nærmeste om det?
Er du bange for at dø, eller har mange spekulationer omkring det?
Vil du gerne tale med nogen om det?
Ønsker du besøg af en fagperson (f.eks præst)

Sammenhæng
Hvad giver dig mening og håb lige nu?
Er der noget du synes du gerne vil nå eller afslutte?
Er du et troende menneske, og måske medlem af Folkekirken eller et andet trossamfund?
Tænker du over om ”der er mere mellem himmel og jord” ?
Vil du gerne tale med nogen om det du tror og håber på? (f.eks. din egen sognepræst eller sygehuspræsten)

Appendix H: Letter to Patients

REGION SJÆLLAND
- vi er til for dig

Kære NAVN

Først en stor tak for at du, i forbindelse med din opfølgning på ambulatoriet for hjertesygdom, har takket ja til at deltage i forskningsprojektet: *Basal palliation til mennesket med hjertesvigt – baseret på deres fortællinger*.

Vi har sat ekstra tid af til samtale i dine besøg hos os da vi ønsker at høre om dig og dit liv for bedst muligt at kunne planlægge dit behandlingsforløb.

Vi vil gerne høre om det du mener er vigtigst at vi ved om dig. Måske har du lyst til at fortælle om særlige oplevelser i dit liv, om familien, om arbejde, om tro og håb, eller om tanker i forbindelse med opdagelse af din nedsatte pumpefunktion.

Vi har desuden vedlagt et skema som du bedes udfylde og medbringe ved vores første møde. Hvis du ikke har mulighed for at printe skemaet ud, kan du møde 15 minutter tidligere og udfylde det i venterummet. Spørg sekretæren.

Vi glæder os til at møde dig

Mvh

Personalet på ambulatoriet for hjertesygdom

Slagelse Sygehus

Appendix I: Evaluation Program for the Pilot

Delstudie med midtvejsevaluering af den nye palliative indsats på Slagelse sygehus.

Introduktion: Sundhedsstyrelsen anbefaler en palliativ indsats til mennesker med livstruende sygdom som eksempelvis hjertesvigt, men vores viden på området er begrænset (Sundhedsstyrelsen, 2017). Vi har derfor i et større PhD projekt valgt at udvikle, afprøve og evaluere en basal palliativ indsats på hjertesvigtsambulatoriet i Slagelse. Formålet med dette delstudie er at evaluere på denne indsats i starten af processen for eventuelt at kunne justere på detaljer inden en egentlig fuld implementering. Kvalitativ forskning er dynamisk og analyse starter samtidig med dataindsamling. Det har været naturligt og vigtigt for os at videreføre denne kvalitative tankegang ind i klinisk forskning og give patienter såvel som sundhedsprofessionelle en stemme både før under og efter implementering af den nye indsats.

Dette studie er delt op i to dele. Den første er en mini fokusgruppe med patienter der har afprøvet den nye indsats – den næste er ligeledes en fokusgruppe med en åben refleksion af disse oplevelser i gruppen af sundhedsprofessionelle.

Kvale og Brinkmann beskriver at fokusgruppens formål er at få flere synspunkter om et givent emne og er velegnet til at undersøge nye områder som eksempelvis sociale tiltag (Kvale and Brinkmann, 2014). Det er derfor en fornuftig metode i forbindelse med opstarts-evaluering af den nye palliative indsats for mennesker med hjertesvigt. Vores ønske er at få en nuanceret viden om indsatsen for eventuelt at kunne justere på formen inden den fulde implementering. Størrelsen af en fokusgruppe afhænger af formål og forskningsspørgsmål. Jo mere vedkommende spørgsmålet er for deltagere jo færre bør der være i gruppen. Vi har valgt mini fokusgruppen som metode i første del af studiet da vi ønsker en personlig beretning om patienters oplevelser af den nye palliative indsats, men med det sociale sammenspil og refleksion der sker i en gruppe.

Hovedpointer og udsagn fra patient-deltagere vil præsenteres for sundhedspersonale umiddelbart efter mini fokusgruppen med henblik på at reflektere over og diskutere deres oplevelser. Denne åbne demokratiske refleksion i fokusgruppen med sundhedspersonale vil anvendes til eventuelt at justere vores palliative indsats inden den tilbydes til en større gruppe patienter. Brown beskriver at når mennesker gennem dialog opnår en fælles forståelse omkring 'real-life issues' igangsætter det en handlekraft (Brown, 2001). Metoden er inspireret af dialog café designet (Brown, 2001), men justeret til fokus gruppe niveau på grund af etiske overvejelser omkring ulige forhold mellem få patienter og mange sundhedsprofessionelle.

1. del - Mini fokusgruppe om oplevelsen af den palliative indsats 9:00-11:00

Denne mini fokusgruppe er et evaluerende delstudie med det formål at undersøge patienters oplevelse af den nye indsats. Til stede er patienter og 2 forskere. Den ene faciliterer samtalen, den anden observerer og skriver feltnoter.

Ved fokusgrupper kræves en atmosfære der giver mulighed for at modstridende synspunkter kan komme til udtryk. Det er ikke et mål at nå til enighed. Intervieweren er ikke styrende, men udstikker de overordnede emner og faciliterer samspillet (Kvale and Brinkmann, 2014).

Vi har derfor valgt at starte dagen med morgenbrød for at skabe en afslappet og rar stemning. For at danne et overblik er fremgangsmåden præsenteret i nedenstående skema.

Introduktion og morgenbrød 9-9.30

- Dagen i dag er en foreløbig evaluering af forskningsprojektet *lindrende indsats til mennesker med hjertesvigt.*

Introduktionsrunde

- Alle præsenterer sig

Start på interview 9.30-11.00

Information

Interviewet i dag handler om

- Jeres opfattelse af den nye ambulatorie indsats med udvidede samtaler. Formålet er at I som eksperter på det at leve med hjertesvigt fortæller om hvordan I oplever den indsats I får for tiden.

Interviewet varer ca. 1 time, det bliver optaget men al information bliver behandlet fortroligt.

Hvad kommer der til at foregå i dag?

- Dette gruppeinterview er anderledes end det man normalt forbinder med et interview. Ud fra centrale spørgsmål gives der plads til at I diskuterer jeres oplevelser med den nye indsats I får tilbudt i hjerte ambulatoriet.
- Forestil jer at I sidder hjemme hos én af jer og fortæller hinanden om jeres erfaringer med forløbet.
- Det er helt i orden at være uenig. I har hver jeres egen oplevelse som jeg er meget interesseret i at forstå.
- Alle oplevelser er lige okay og lige vigtige og der er ingen rigtige eller forkerte svar.

Spørgsmål

1. Begynd gerne med at fortælle om oplevelser I har haft i dette forløb
2. Hvad har gjort særligt indtryk på jer?
3. Kan I give nogle eksempler på nogle af disse oplevelser?
4. Kunne I have ønske noget anderledes?

Afslutning på interview

Det er vigtigt at dialogen afsluttes ordentligt og at deltagere oplever at have bidraget med det de havde lyst til og brug for. Deltagerne takkes mange gange for deres indsats og får endnu engang at vide at deres oplevelser er vigtige for vores videre arbejde med at forbedre vores ambulatorie indsats til mennesket med hjertesvigt.

Inspiration til skemaer og opbygning er hentet fra (Brinkmann og Tanggard 2015 kap. 6)

Tematisering af mini-fokus gruppe 11:00-13:00

Hele seancen er optaget på lyd, men også dokumenteret via feltnoter. Disse noter og umiddelbare refleksioner diskuteres af de to tilstedeværende forskere med afsæt i Kvales analyse tilgang med identifikation og tematisering af meningsenheder (Kvale and Brinkmann, 2014). Fremkomne temaer med eksemplariske meningsenheder præsenteres for sundhedspersonalet med det formål at danne en umiddelbar bro mellem patienten og den sundhedsprofessionelle og samtidig tage etisk hensyn til den ulige magtfordeling mellem grupperne.

2. del – Åben refleksion ved fokus gruppe 13:00-15:00

Anden del af dette delstudie er en fokusgruppe med sundhedsprofessionelle; læge, sygeplejersker, fysioterapeuter.

Udover sundhedsprofessionelle er der ligeledes to forskere til stede; en der faciliterer samtalen og en observatør der nedskriver feltnoter.

Formålet er at få sundhedsprofessionelles til åbent at reflektere og diskutere patientens oplevelser til videre udvikling af den palliative indsats til mennesket med hjertesvigt.

Introduktion og plan for dagen

- Dagen i dag er en foreløbig evaluering af forskningsprojektet *lindrende indsats til mennesker med hjertesvigt.*
- Vi vil præsentere jer for umiddelbare oplevelser fra to patienter der har deltaget og ønsker at få en åben dialog og refleksion omkring disse oplevelser.
- I kører som udgangspunkt selv samtalen og alle synspunkter er okay. Det er ikke enighed vi er interesseret i, men jeres umiddelbare refleksioner og tanker.
- Jeres samtale bliver optaget og jeg tager samtidig feltnoter til videre analyse.

Inviterende spørgsmål

1. Begynd gerne med at fortælle om jeres umiddelbare tanker efter vores præsentation.
2. Hvad har optaget jer særligt?
3. Kan I give nogle eksempler?

Afslutning på fokusgruppen

Deltagere takkes for deres tid og lyst til at dele deres refleksioner og der tages afsked.

Analyse af data

Lydspor fra fokus grupperne transskriberes efter Bloor et al’s transskriberingsregler og analyseres med udgangspunkt i Kvales meningskondensering (Halkier, 2018). Denne analyse metode er valgt da vores fokus er på det tematiske indhold af fokusgruppeinterviewene og sekundært det kontekstuelle (Malterud, 2012).

Appendix J: Semi-structured Interview Guide Phase IV

Forskningsspørgsmål	Interview spørgsmål	Opfølgende ?
Baggrund	**Vil du kort fortælle din baggrundshistorie med hjertesvigt.**	Hvordan oplevede du at få diagnosen hjertesvigt. Hvilke tanker satte det i gang? Hvilken betydning havde det på familien?
Før ambulatorie forløb Motivation Forventninger	**Kan du sætte ord på hvorfor du valgte at deltage i dette studie?**	Hvilke forventninger havde du til forløbet? Hvilke overvejelser gjorde du dig i forhold til at deltage? Involverede du din familie i processen?
Ambulatorie forløbet Oplevelse af forløbet	**Fortæl mig om dine oplevelser i forløbet.** **Hvilken betydning har samtalerne haft for dit forløb? For din forståelse af din sygdom? For dit samarbejde med sygeplejersken? (Kan du give eksempler)**	Har forløbet levet op til dine forventninger? Hvordan oplevede du samtalerne med sygeplejersken? Havde du samtaler med andre, præst, fysioterapeut? Læge? Hvordan oplevede du disse? Oplevede du en balance mellem de ting i talte om? Havde du mulighed for at snakke om de ting du synes var vigtige? Udfyldte du spørgeskema undervejs? Hvad tænker du om dette? Har du involveret din familie i processen?
Afrunding	**Er der noget du gerne vil fortælle her til sidst?**	Noget du vil tilføje til det vi allerede har snakket om? Noget vi mangler?