Integrating Palliative Care and Heart Failure: the PalliatHeartSynthesis realist synthesis

Tracey McConnell,[1,2*] Carolyn Blair,[1] Geoff Wong,[3]
Claire Duddy,[3] Clare Howie,[1] Loreena Hill[1]
and Joanne Reid[1]

[1]School of Nursing and Midwifery, Queen's University Belfast, Belfast, UK
[2]Marie Curie Hospice, Belfast, UK
[3]Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK

[*]Corresponding author t.mcconnell@qub.ac.uk

Published September 2024
DOI: 10.3310/FTRG5628

Scientific summary

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Health and Social Care Delivery Research 2024; Vol. 12: No. 34
DOI: 10.3310/FTRG5628

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Background

Cardiovascular disease is the most common cause of death worldwide and the most frequent cause of hospitalisation among individuals aged > 65 years. In 2012, heart failure (HF) was estimated to account for £22.5B of health expenditure globally; between 2012 and 2030 it is estimated that total costs will increase by 127%. Integrating palliative care (PC) with routine management of HF has been shown to significantly reduce healthcare costs overall compared to usual care (without PC) and significantly reduces the number of hospital visits and duration of inpatient stays. There is evidence of improved patient and informal caregiver outcomes when PC is integrated in HF management. Integrated palliative and HF care aims to achieve continuity of care by integrating administrative, organisational, and clinical services that make up the patients care network. However, two decades have passed since the first publication on the benefits of PC for patients with HF. The scarcity of effective integration of PC into HF management can be explained by a number of factors, including uncertainty around the HF disease trajectory and complexities of communicating this uncertainty to the patient and family members. The 2021 European Society of Cardiology (ESC) Guidelines for the diagnosis and treatment of acute and chronic HF highlighted the need for studies to determine specific options for PC within the treatment of HF. Although we have some promising examples of integrated PC and HF interventions, there is heterogeneity in terms of countries, healthcare settings, delivery and intervention components. Hence, this review is vital for identifying what works best, for whom and in what circumstances.

Aim and objectives

To understand how integrated PC and HF interventions work in different healthcare settings for example inpatient/outpatient, and for which groups of people, so we can recommend strategies to maximise the potential for widespread implementation, reduce healthcare costs, and improve quality of life (QoL) for patients and informal carers.

1. To conduct a realist synthesis (RS) to build an understanding of which integrated PC and HF interventions work best together, in which contexts and for which patients who have HF and informal carers.
2. To co-produce implications with an expert stakeholder group, to maximise potential for widespread implementation through a user guide for healthcare providers and user-friendly summaries for patients and the public.

Review questions

1. What are the mechanisms by which integrated PC and HF interventions work to produce their intended outcomes?
2. What are the contexts which determine whether integrated PC and HF interventions produce their intended or unintended outcomes?
3. In what settings are integrated PC and HF interventions likely to be effective?

Methods

To understand and make sense of the complexity of integrating PC in HF management, we used a RS approach to examine what works for whom, in what circumstances, how and why. RS is a theory-driven approach for understanding existing diverse sources of evidence relating to complex interventions. It is theory driven because it uses evidence to iteratively develop and test structurally coherent explanations (i.e. theories) of complex interventions. The methodology followed Pawson's five iterative stages for RS: (1) locating existing theories; (2) searching for evidence; (3) selecting documents; (4) extracting and organising data; and (5) synthesising the evidence and drawing conclusions. The review ran for 22 months, from September 2021 to June 2023.

Data sources

Searches of bibliographic databases were conducted in November 2021 using the following databases: EMBASE, MEDLINE, PsycInfo, AMED (via Ovid), HMIC (via Ovid) and CINAHL (via EBSCO*host*). Further relevant documents were identified via alerts and through our stakeholder group.

Study selection

The initial inclusion and exclusion criteria for the review were deliberately broad as we aimed to identify all relevant quantitative, qualitative, mixed-methods and non-empirical documents relating to HF and PC. We applied the following inclusion criteria:

- Document types – All documents focused on PC for patients who have HF
- Study design – All study designs. Non-empirical data (e.g. from opinion/commentary pieces) which help direct/shape theory development
- Types of settings – All documents about inpatient or outpatient or home-based care settings
- Types of participants – All adult patients (18 years and over)
- Types of intervention – Any combination of PC strategies for the management of patients with HF
- Outcome measures – All integrated PC- and HF-related outcome measures

Following the presentation of the preliminary initial programme theory to our stakeholder group, stakeholders focused on healthcare professionals' perspectives for implementation of integrated PC in HF management. This iterative process of identifying the most pertinent explanatory theory allowed us to narrow the scope of the synthesis to focus on healthcare professionals' perspectives on integrated PC into HF management.

Data extraction

Initial coding of the documents used both inductive (codes emerging through data analysis) and deductive methods (codes determined prior to analysis through initial programme theory and stakeholder discussions). The coding framework resulted from the analysis of the richest documents, which were documents with the most potential to inform the programme theory; within this review, these were mostly qualitative research papers. Examples of initial codes identified were 'biomedical culture within cardiology' and 'terminology – understanding what PC is and is not'. We concurrently worked to identify 'guiding principles' and features underpinning the interventions, and relevant implications discussed mostly in policy documents, reviews and commentaries. The framework generated was applied to the remainder of the documents and refined as the analysis progressed. For example, we identified relevant contexts when mechanisms were likely to be 'triggered', such as a shared

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understanding (across patient, informal caregiver and healthcare professionals) that PC in HF management positively contributes to optimised QoL. Such contexts and mechanism became 'codes'.

Analysis and synthesis

The analysis was driven by a realist logic. We sought to interpret and explain mechanisms, such as shared vision and provision of joint PC and HF education, in which integrated PC in HF management would occur (or not). We used the coding of the included documents within NVivo (QSR International, Warrington, UK) to draw relationships between contexts, mechanisms and outcomes, and to further develop our initial programme theory.

In summarising, the evidence synthesis process was achieved using the below analytic processes:

- Juxtaposition of data sources: data reported in different documents were compared and contrasted.
- Reconciling 'contradictory' or disconfirming data: when outcomes differed in seemingly comparable circumstances, further investigation was undertaken to find explanations for why different outcomes happened. This involved looking closer at what made up the context for different kinds of 'problems', to understand how mechanisms triggered could explain different outcomes.
- Consolidation of sources of evidence: when findings from different documents had similarities, a judgement was made as to whether these similarities could adequately form patterns to inform the development of context–mechanism–outcome configurations (CMOcs) and programme theory, or whether there were nuances that required highlighting, and for what purpose.

The aim of the analysis was to reach theoretical saturation, that sufficient information had been captured to portray and explain the processes leading to the implementation of integrated PC in HF management and the mechanisms that can aid this implementation.

Consistency checks

Consistency checks were carried out by a second reviewer Tracey McConnell (TM) on a 10% random sample of the screening (title, abstract and full text) and the coding process for the main search. Minimal inconsistencies were identified and, when identified, were resolved through discussion.

Stakeholder group

Our patient and public involvement (PPI) group members were involved throughout the planning and execution of this project. They sat on our stakeholder group made up of 32 stakeholder participants including specialist HF nurses, cardiology and PC consultants, people who had HF, an informal caregiver, and researchers.

During the review, we asked PPI stakeholder group members:

- to help us develop our initial programme theory;
- for their advice and feedback on our programme theory as it evolved;
- to consider our findings and implications from their varied perspectives;
- to provide input and support into our dissemination strategy; and
- to review and contribute to our materials, to ensure they met the needs of patients and the wider public.

Results (research findings)

A total of 1768 documents were identified, of which 1076 met the inclusion criteria for further screening. Based on programme theory and discussions with stakeholders, it was decided to refine the inclusion criteria further to align with the focus of the review leading to 130 documents being included. Our realist analysis developed and refined 6 overarching context–mechanism–outcome configurations with 30 sub CMOcs. We used the capability, opportunity, motivation, behaviour (COM-B) model to help identify intervention strategies needed to produce desired behaviours and avoid undesired behaviours. Although the COM-B model relates to individual behaviour change, it also considers team and organisational behaviour. For example, an individual's capacity to carry out a specific behaviour also depends on the organisational culture they work within, and the opportunities afforded to them within their team and organisation.

Capacity

According to the 'capacity' component of the COM-B model, individuals must believe they have the required knowledge and skills to carry out a behaviour. Unsurprisingly, education was a key intervention strategy for providing key individuals with the required knowledge and skills to overcome many of the key blockages identified in the literature, from a biomedical culture (CMOc 1–1.1), to misunderstandings around terminology which equate PC with end-of-life care only (CMOc 1.2–1.5), complexities of the HF illness trajectory (CMOc 1.6–1.7), to the challenges of integrating PC in the context of patients with HF who have life-prolonging devices (CMOc 1.8–1.8b). The realist analysis and synthesis of the literature helped uncover what 'types' of educational strategies are required to achieve integration of PC into HF management. These included shared education and experiential learning within and between disciplines across all care settings (CMOc 2.1), communication skills training (CMOc 2.8), public health approach/messaging (CMOc 2.9), evidence-based examples of good practice (CMOc 3) and guidelines embedded in undergraduate (UG) and postgraduate education (CMOc 6).

Opportunity

The opportunity component of the COM-B model proposes that individuals must have the required physical (time and resources) opportunities for behaviour change to occur. Therefore, providing evidence-based educational strategies is not enough to create behaviour change without due attention to the required opportunities. The literature and stakeholders stressed the importance of protected time for education and choice of educational setting (e.g. online, face to face or hybrid) (CMOc 2.7). The importance of having guidelines was highlighted by the review findings. This also showed that despite the availability of guidelines there is still a lack of clarity within HF management around who is responsible for initiating PC conversations, when this should happen, and how often. Therefore, guidelines for integrating PC and HF should be visible, easily accessible and their use prioritised, with clarity on expectations and roles, so patients receive the right care, from the right people, at the right time (CMOc 6).

Motivation

According to the COM-B model, motivation is a core component necessary for behaviour change, meaning that the behaviour must be more desirable and important than other competing priorities. CMOc 3 identified the importance of increased awareness and seeing benefits of PC in HF management (CMOc 3) as key intervention strategies. Stakeholders noted that evidence may win minds, but we also need to convince hearts, and so emphasised the importance of winning both hearts and minds. The synthesis of the international evidence also supported the importance of conveying the emotive and

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intellectual need for integrating PC and HF via credible champions, seeing direct patient benefit, and evidence-based education (CMOc 3.1).

Conclusions and implications

Ongoing refinement of the programme theory at each stakeholder meeting allowed us to co-produce implications. These implications outline the required steps to ensure the core components and determinants of behaviour are in place so that all key players have the capacity, opportunity and motivation to integrate PC into HF management.

- Integrated PC and HF services must be prioritised by senior decision-makers in the health and care system.
- Services must be adequately funded to ensure that staff are able to develop and run fully integrated PC and HF services.
- Service design should start with an assessment of the availability of PC and HF services in their locality (e.g. 'postcode lottery' issues) and find solutions.
- Services integrating PC into HF management must be provided which are reflective of the diversity of the whole population within the local healthcare context.
- Develop service delivery models that provide continuity of care for patients with HF including:
  - reconfigured services to promote a multidisciplinary team (MDT) working between specialties and settings (including primary care)
  - processes to monitor and address gaps in provision and caseloads
  - processes to show the benefits (e.g. reduction in the need for inpatient care and cost-savings) of integrated PC and HF
  - resources for all settings (e.g. primary and secondary care) and all audiences involved (e.g. patients, carers and clinicians) with clear and consistent messages about PC and HF. For example, develop a patient information leaflet, co-designed by PPI and engagement, to highlight what integrated PC in HF management is and when this might be suitable

- Develop guidelines for MDT meetings to identify who, when and how each of the below key decisions and action will be completed for each patient with HF:
  - who is responsible for introducing PC to the patient and informal caregiver(s)?
  - who will assess PC needs and how often (e.g. at every healthcare professional contact)?
  - agreeing care plan (needs to be individualised to each patient)
  - executing care plan
  - reassessing care plan
  - ensuring needs and care plans are communicated across settings and specialties
  - ongoing evaluation including patient reported outcome measures, to enable refinement and benchmarking of guidelines/care pathway.

- Evaluate current PC education in UG and post-registration medical, nursing, allied health and social care (HSC) professional curriculum to identify deficits in the PC curriculum around caring for those with HF.
- Effective communications skills training is required across all levels of the curriculum in nursing, medicine and allied HSC professional education to ensure all have the means to communicate the value of PC and HF and provide ongoing care.
- Facilitate joint decision-making: Set up and run MDT meetings for those involved in PC and HF that enable members to develop trusting relationships, work collaboratively and learn from each other.
- Create active engagement by demonstrating the value of integrated PC in HF, for example, through the sharing of examples of good practice, for example through visits and placements.
- Develop effective patient PC education for individuals diagnosed with HF.

- Equip and enable all people involved with PC and HF (e.g. patients, consultants, nurses, informal carers) to champion the value and need for integrated PC and HF.
- Address public (mis)understanding of PC and HF through public health campaigns focused on raising awareness of PC as a holistic, wrap around care plan for improving QoL for those with HF.

Study registration

This study is registered as PROSPERO CRD42021240185.

Funding

This award was funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme (NIHR award ref: NIHR131800) and is published in full in *Health and Social Care Delivery Research*; Vol. 12, No. 34. See the NIHR Funding and Awards website for further award information.

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Health and Social Care Delivery Research

ISSN 2755-0079 (Online)

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This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

This journal was previously published as *Health Services and Delivery Research* (Volumes 1–9); ISSN 2050-4349 (print), ISSN 2050-4357 (online)

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This article

The research reported here is the product of an HSDR Rapid Service Evaluation Team, contracted to undertake real time evaluations of innovations and development in health and care services, which will generate evidence of national relevance. Other evaluations by the HSDR Rapid Service Evaluation Teams are available in the HSDR journal.

The research reported in this issue of the journal was funded by the HSDR programme or one of its preceding programmes as award number NIHR131800. The contractual start date was in September 2021. The draft manuscript began editorial review in June 2023 and was accepted for publication in March 2024. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HSDR editors and production house have tried to ensure the accuracy of the authors' manuscript and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this article.

This article presents independent research funded by the National Institute for Health and Care Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the HSDR programme or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, the HSDR programme or the Department of Health and Social Care.

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