

Coordination of palliative care in community settings

Summary report

This resource may also be made available on request in the following formats:



 **0131 314 5300**

 **nhs.healthscotland-alternativeformats@nhs.net**

This briefing should be cited as: Riches E, Rennick L and Reid G.
Coordination of palliative care in community settings: summary report.
Edinburgh: NHS Health Scotland; 2018.

For further information about this publication please contact:
Emma Riches, Public Health Intelligence Adviser, Evidence for Action
Email: emma.riches@nhs.net

Published by NHS Health Scotland

1 South Gyle Crescent
Edinburgh EH12 9EB

© NHS Health Scotland 2018

All rights reserved. Material contained in this publication may not be reproduced in whole or part without prior permission of NHS Health Scotland (or other copyright owners). While every effort is made to ensure that the information given here is accurate, no legal responsibility is accepted for any errors, omissions or misleading statements.

NHS Health Scotland is a WHO Collaborating Centre for Health Promotion and Public Health Development.

Introduction

Supporting people with terminal illness or life-limiting conditions to stay at home or in a homely setting challenges healthcare providers to find new ways to coordinate effective end-of-life and palliative care in the community.

Aim

NHS Health Scotland was asked by the Living Well in the Community team within Healthcare Improvement Scotland to undertake a rapid evidence review of the components of palliative care models. A rapid review is a streamlined approach to synthesising evidence in a timely manner. It usually has a focused question and the sources of research used can be limited. The review was done to inform the design of change ideas being devised by six test sites across Scotland to support improvement in identification and care coordination of palliative and end-of-life care in the community.

Context of this work

The Scottish Government's national strategy for palliative and end-of-life care for 2016–2021 has a commitment to support the establishment of a Scottish Research Forum in Palliative and End of Life Care to strengthen research and coordinate knowledge exchange across Scotland. Scottish researchers are at the forefront of palliative care research internationally. The forum was formed in 2016 and some members of this forum undertook a systematic scoping review to identify all Scottish palliative care research published over a ten-year period (2006–2015). Some of the studies identified in that review included areas such as identifying people who should receive palliative care (and tools to assist practitioners to do this), future or anticipatory care planning, the role of informal carers, and educational interventions, which have some connections with this review although we also looked at literature outside of Scotland. If you are interested in Scottish specific research you can find the review of Scottish palliative care research [here](#).

The evidence from this rapid review will inform local practice in test sites located in six health and social care partnerships across Scotland that are looking to adopt or adapt change models. As such, the audience for this summary report is predominantly service managers who are at the forefront of the redesign of community-based palliative and end-of-life care. However, the findings may be of interest to a wider audience and could potentially be used alongside other sources of data, and particularly the growing and detailed person-based dataset, drawn from routine records, which are brought together [here](#).

What we did

We looked for published evidence, assessed the quality of the evidence and distilled the main findings on:

- early palliative care
- initiatives where palliative care was provided in the home
- a multidisciplinary approach to palliative care.

These three themes were considered to be of interest in examining approaches to palliative care coordination.

For all three themes, we looked for published studies in community settings, which could include a patient's home, nursing homes, and hospices. For some of the three themes we extended the literature search to other settings, such as acute hospital settings. This was because there was limited published evidence on palliative care in community settings, which was particularly the case for early palliative care.

Palliative care is not uniformly defined across the literature. In this report, we have accepted a broad definition of palliative care and included terms such as life-long illnesses, life-limiting conditions, and advanced terminal illness as well as end-of-life care. We recognise that much of the work that is done to support people with life-limiting conditions is not labelled as palliative care but is consistent with the ethos of palliative care.

For further information on this piece of work an evidence review report is available on request. This work was conducted as part of the Public Health Evidence Network (PHEN) work programme and was carried out jointly by NHS Health Scotland, Healthcare Improvement Scotland and What Works Scotland.

What we found

Early palliative care

Evidence from the published literature shows some support for including palliative care interventions early in the course of a life-limiting illness.

The evidence that early palliative care could be considered for both patients with cancer and patients with other chronic life-limiting conditions comes mainly from two reviews of randomised trials and two recent trials not included in these reviews. These reviews and the included trials and recent trials were all generally well conducted and the evidence is therefore considered to be robust. It was not clear from the evidence what was meant by 'early' palliative care.

Most of the published studies on early palliative care were undertaken in North America and investigated patients with cancer, particularly with a specific type of cancer or at advanced stages of disease. This means that the evidence might not be applicable to UK settings. The definition of 'early' palliative care varied across the published literature and therefore the optimal timing and setting to introduce palliative care was not clear. Overall, the evidence for early palliative care interventions varied in terms of population, setting, intervention or approach to early palliative care and outcomes that were measured, which meant it was difficult to draw comparisons between studies.

Some evidence from one review highlighted some key barriers to an early integrated approach to palliative care among cancer and non-cancer patients in a hospital setting. Among patients with cancer, these were:

- poor staff communication with patients and their families about their prognosis
- not embedding palliative care into healthcare systems.

Among patients with chronic conditions such as chronic heart failure and chronic obstructive pulmonary disorder, key barriers included:

- difficulty in identifying a specific point at which the patient is identified for a palliative approach
- the unpredictable prognosis and illness trajectory
- perception of their disease as not life-threatening
- poor patient understanding of their disease prognosis
- poor communication skills among healthcare professionals
- lack of cooperation between different healthcare specialists.

A number of studies, including the reviews, trials within the reviews and two recent trials, found that early palliative care achieves a wide range of outcomes. One recent review found that in most trials, an early simultaneous approach to palliative care (palliative care plus standard care of the disease) had a positive impact on overall survival, quality of care, cost reduction and patient and carer's satisfaction. However some of the outcomes, such as an improvement in quality of life and symptom control, were not seen across all trials. This might be because the studies did not find these outcomes, but equally it might be due to the studies not measuring these outcomes. Inconsistency in results, in terms of the outcomes they found, was seen in another review, but it variably demonstrated benefits of an integrated early palliative care to patient and carer's wellbeing and to health care utilisation. Some of the benefits included:

- improvements in symptoms such as depression
- improvement in patient quality of life
- reduced aggressive care – for example unnecessary interventions or medications at the end of life
- increased advance or anticipatory care planning
- improved carer's burden
- better maintenance of carer's quality of life
- increased patient and family satisfaction
- reductions in the medical cost of care.

There was limited cost evidence for early specialist palliative care.

Home-based palliative care initiatives

Published evidence suggests that there is some support for home-based palliative care initiatives in the community.

A home-based initiative is a way of providing health and/or social care in a patient's home, community hospice or a nursing home.

Two robust systematic reviews of randomised and controlled trials provided some support for home-based approaches to palliative care in cancer and non-cancer populations. They concluded that home-based approaches can reduce symptom burden.

However the reviews were inconclusive as to whether home-based approaches:

- are value for money
- can reduce patient admissions to hospital
- improve patient satisfaction
- improve patient and carer quality of life.

The published evidence showed wide variation in approaches to home-based palliative care in community settings.

The published evidence suggested that most home-based initiatives were tailored packages of palliative care designed to meet the needs of the populations they supported.

Home-based palliative care initiatives usually involved one or more interventions, but they differed in their composition, format and duration. There was also heterogeneity in the healthcare professionals engaged in coordinating palliative care, the patient population they were designed for, the setting, healthcare system and country in which the initiatives took place, and in the patient and healthcare outcomes that were measured. These differences meant it was difficult to draw comparisons between studies.

Most initiatives identified in this review took place in the patient's home rather than any other setting. Home-based initiatives sought to:

- prevent admission to hospital
- continue care after a patient's discharge from hospital
- allow smooth transition between care settings
- allow the patient to be supported and cared for at home.

Our review identified one area of home-based palliative care for which there was some robust evidence, and three areas for which there is a growing body of evidence:



Case conferencing

There is evidence from one well-conducted systematic review that case conferencing is a feasible approach in coordinating palliative care in patients with advanced dementia living in nursing homes. In this population and setting, case conferencing enhanced the management of patient medication, and improved symptom management and care outcomes.



Hospice at home

A hospice at home model was a common type of home-based initiative identified in 11 studies of varying design and quality. Evidence from randomised trials suggested that home hospice initiatives can reduce symptom burden among populations with chronic disease compared with usual care, but there were inconsistent results about the impact of these care models on patient quality of life. There is some evidence from observational and randomised studies to suggest that home palliative care initiatives are associated with reduced hospitalisations, and may potentially bring about cost savings.



Nurse or general practitioner-led initiatives

Home-based palliative care initiatives that were led by a nurse or general practitioner were seen in six studies. Evidence from randomised and non-randomised studies suggested that these types of initiatives may lead to improved management of symptoms and patient satisfaction but there was inconsistency in the results for healthcare utilisation. Several of these initiatives were designed to coordinate palliative care for patients located in rural areas.



Technology

There is support for the use of technology in coordinating palliative care at home, particularly among rural populations to overcome geographical distances in coordinating palliative care. Telephone advice and support featured in a number of studies but personal alarms and video conferencing were also used.

A multidisciplinary approach to palliative care

There were mixed results for the effectiveness of multidisciplinary working in palliative care.

There was no single definition of multidisciplinary or interdisciplinary palliative care. The approach has been identified as working together, working in partnership or working as a team with people from different disciplines and/or professions ultimately for the benefit of the patient. It can also mean integrated working or collaborative working.

Evidence for the effectiveness of a multidisciplinary approach to palliative care came from 12 studies of varying design and quality.

One of the systematic reviews did not find any evidence of the effectiveness of a structured interdisciplinary collaboration among hospice teams in home care settings with regard to patient satisfaction and hospital re-admissions. Another systematic review, which evaluated multicomponent interventions in end-of-life care, reported moderate evidence in support of multidisciplinary teams. This review had some quality issues with how it was undertaken. However, a number of the other studies (including a trial, systematic review and qualitative studies) did find that multidisciplinary palliative care can improve outcomes for the patient, carers and healthcare providers. These benefits varied across the studies. Potential benefits could include:

- improvements in symptom management
- advance care planning
- care coordination and care continuation
- patient's quality of life
- reduction in carer's burden
- reduced hospital admissions or use of medical services.

One systematic review, which had some methodological weaknesses, also reported that partnership working benefited health and social care staff in terms of empowering generalists in the area of palliative care and improved decision-making.

There was very little cost evidence on multidisciplinary approaches. Where there was evidence on costs it was not clear if it was the intervention or the multidisciplinary approach which was cost effective.

Based on the published evidence, we noted some common themes on multidisciplinary approaches to palliative care. These included:

- There was variation in the membership of multidisciplinary teams involved in palliative care interventions and was likely to be specific to the intervention. Multidisciplinary teams

may want to include a doctor and a nurse as part of the team, one of which should be trained in palliative care, allied health professionals (such as occupational therapists), social workers, care assistants, counsellors, chaplains, and volunteers as well as the patient and their family.

- There was variation in the services a multidisciplinary team can offer but these are likely to be related to the intervention being evaluated. These could include symptom management, psychological support or counselling, disease education or support, advance care planning, medical care and care coordination.
- The main barriers to effective multidisciplinary working included ambiguity over role, conflict between team members, communication problems and issues over leadership. These barriers can be addressed by improved communication, clear roles and responsibilities, having a key worker, culture of trust within the team, good coordination between staff, and providing learning and education on palliative care and collaborative working. A systematic review and qualitative study highlighted how communication could be improved through the use of electronic medical records, teleconferencing or secure e-messaging to share information.

Implications for practice

The findings from our evidence review contribute to the evidence base on coordination of palliative care in the community.

Service planners and healthcare professionals should consider initiating palliative care promptly after identifying someone is eligible for palliative care. Home-based palliative care initiatives could be considered when planning local models of palliative care. Case conferencing may be of value in some populations and settings, and further evaluation of home-based approaches involving hospice at home, nurse-led initiatives and the use of technology should be supported. Evidence for multidisciplinary working is currently inconsistent.

The limited cost evidence for the three components of palliative care we looked at does not mean that interventions in these areas do not offer value for money but rather health economics data in palliative care research are increasingly required.

