

What are best practice service models in rural areas for the delivery of end of life and palliative care?

Objectives

To provide specific, innovative examples of best practice service models for end of life and palliative care services (cancer and non-cancer) in rural areas applicable to the UK.

In addition, to:

- Explore potential of new technology (tele-rehabilitation, tele-health, tele-medicine) in enhancing access to and the sustainability of rural services.
- Identify the barriers to success.
- Identify key themes of successful end of life/palliative care services from the perspective of patients, families and their carers.

Review Methods

A systematic search was conducted across a wide-ranging set of databases: Ovid Medline, including In-Process & Other Non-Indexed Citations, Ovid Embase, OVID HMIC, Ovid PsycINFO and Ebsco CINAHL.

The preliminary search strategy was developed on Ovid Medline using both text words and Medical subject headings from January 2005 to November 2015 restricted to English language and studies undertaken in UK, USA, Canada, Australia and New Zealand. The search strategy was modified according to the indexing systems of the other databases. (Search strategies available upon request).

To identify additional papers, we searched Rural Remote Health Journal, Google and checked reference lists of published reviews.

Study selection was carried out first by title and abstract by two reviewers of the results retrieved from the search. Full text papers were assessed independently using a pre-designed eligibility form according to inclusion criteria. Quality assessment was carried out by two reviewers independently on the eligible studies, using appropriate quality assessment checklists.

Any discrepancies between the two reviewers were resolved by consensus or by recourse to a third reviewer. Study data was extracted by one reviewer and checked by another using a pre-established data extraction form.

Context

In 2014 Welsh Government set out to explore options for the provision of high quality and sustainable health care in mid Wales. The Mid Wales Healthcare Collaborative Board (MWHCB) was subsequently developed to shape the rural mid Wales commissioning intentions of Powys Teaching Health Board, Hywel Dda Local Health Board and Betsi Cadwaladr Local Health Board, as described in the Mid Wales Healthcare Study. The Board is held accountable for its work by the Minister for Health and Social Services.

Palliative and End of Life Care was identified by the MWHCB as one of the eight Innovation Sub Groups developed to deliver the programme of work as described in the Mid Wales Healthcare Study.

The findings from the rapid review will be used by the End of Life / Palliative Care Sub Group to inform recommendations for service improvements / service change for end of life / palliative care services in rural mid Wales.

Key Findings

There are no robust randomised studies comparing service models in rural settings. Published studies have used mixed methods approaches to either prospectively evaluate outcomes for patient cohorts or assess impact from a provider perspective. One randomised controlled trial of a tele-health service intervention failed to reach target recruitment. Although evidence for a definitive service model is lacking, particular elements of care provision consistently emerge across studies as important to rural settings:

- Sustainability is most likely in remote/rural settings where the model is developed from within the existing care provider community. Services led by general practice/community nurse teams providing the majority of care, with access to specialist advice and information are preferred. Stand alone outreach services are unlikely to be sustainable (1, 2, 3, 4).
- Shared care models across social and healthcare networks are required to overcome tensions in rural settings between efficiency—in terms of human resource and equipment costs—and timely access (1, 3).
- Rural resourcefulness and capacity for self management are seen as particular positives for rural care provision (3).
- Detailing academic and skills training for primary care providers is a core service domain. Knowledge and skills deficits for general practitioners and community nurses are consistently defined in the literature as significant barriers to appropriate access to palliative services and threats to quality palliative care provision (1, 2, 3, 4).
- Ineffective communication during transition between care settings and between primary care and specialist palliative care services is consistently seen as a threat to the quality and safety of patient care. Improving timely access in rural community settings to complex patient information, and specialist palliative care advice, is central to sustainable and high quality care models.
- Where care coordinator roles have been introduced, often as advanced nurse practitioners, lack of role clarity and perceptions of role duplication with primary care may limit effectiveness. A focus on clinical information linkage, education and skills training and capacity building are important coordination functions in rural settings (1, 2, 4).
- The role of tele-health in supporting palliative and end of life care provision in rural settings remains to be defined. Hebert's randomised study of video phone consultations to replace some conventional palliative care home visits failed to recruit sufficiently to answer questions of effectiveness. Phillips study of out of hours telephone advice suggested benefit to caregivers in reducing isolation and receiving advice. However the impact on resource use in rural settings is not clear. Kuziemsky's position paper on information technology for rural palliative care settings suggests that both social and technological contextual factors need to be articulated and addressed prior to system design rather than enforcing existing technology – i.e. a 'bottom up' approach (5, 6, 7).

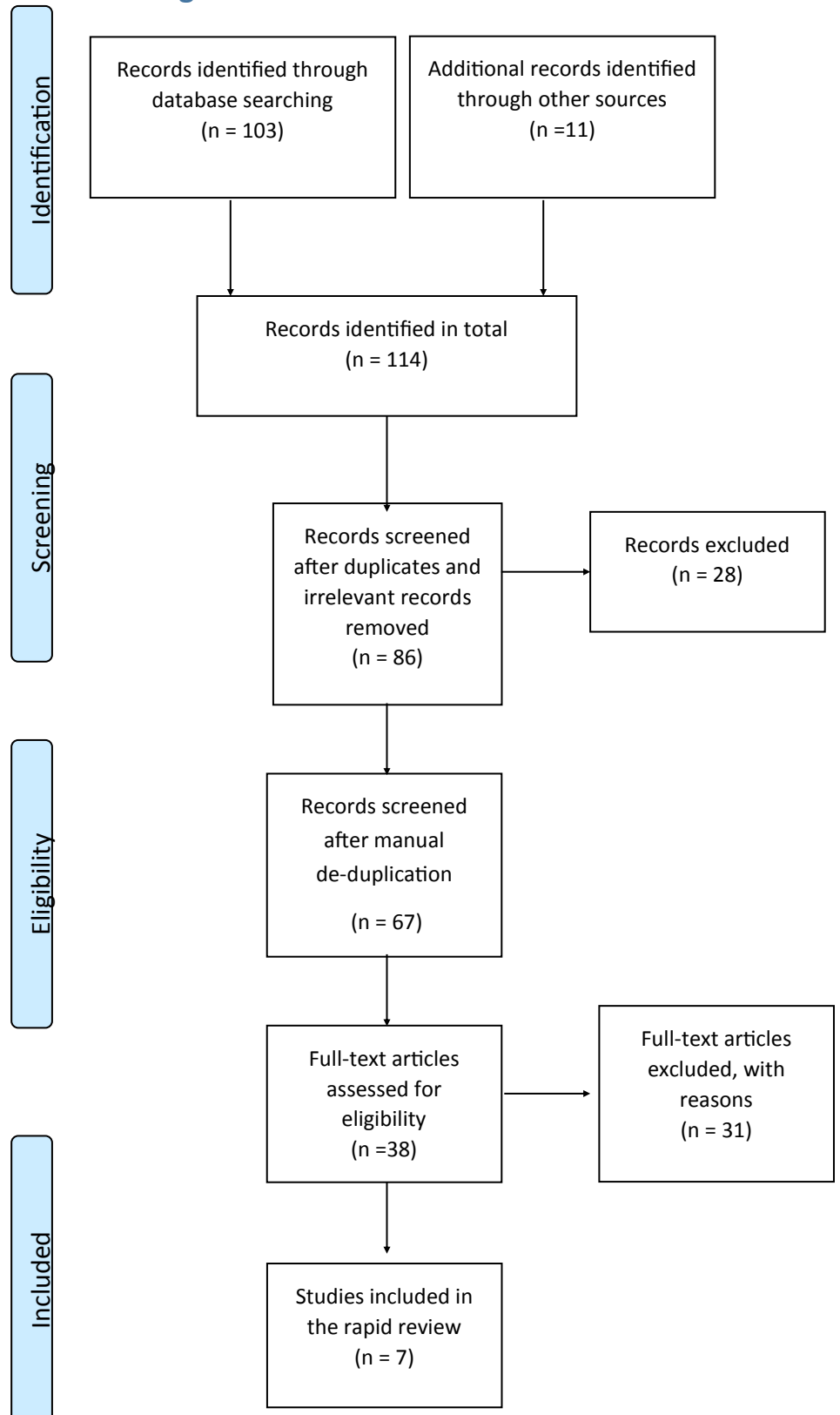
Policy Implications:

- Sustainable palliative care modelling in rural communities requires an integrated approach across health and social care networks to provide flexibility of, and timely access to, human resource and equipment.
- Provisions of nursing and respite care in the home setting poses a particular challenge in the rural context.
- Where the primary care team/district nurse unit is seen as a multisource provider, the impact of role strain needs to be addressed.
- The role of health information technologies in supporting palliative and end of life care provision needs further evaluation and should be considered in the broader context of the social, geographical and technological challenges of the specific rural community.

Clinical Implications:

- Sustainability of the service model requires a focus on primary/community care led delivery. Academic and skills training becomes a central pillar of sustainability and effectiveness. The nature of direct specialist palliative care access and patient review will be determined by the degree of remoteness and existing community skill base.
- Communication between care settings, and during transitions of care between settings, remains a significant challenge. Future coordinating functions may wish to incorporate an information linkage role for individual patient information sharing across services.
- The role of health information technologies remains to be clearly defined. A 'bottom up' approach in the early design phase is recommended, addressing social and technological challenges in the broader context of the rural community.
- Areas for further study include defining core elements of effective communications strategies; the role definitions of palliative care coordinators; the specific role of tele-health applications in Welsh rural settings.

Flow Diagram:



PRISMA Flow Diagram: The flow diagram depicts the flow of information through the different phases of the rapid review.

Summary Table—Page 1

Buikstra 2006 (2)	Study Setting—Rural catchment area of Southern Queensland regional city of Toowoomba, Australia.
Summary of the Study	<p>The Support, Education, Assessment and Monitoring (SEAM) palliative care service: a pilot service, developed using a participatory action research approach, using an integrated service model to provide palliative care to a rural population.</p> <p>Qualitative design using semi-structured interviews and content analysis approach.</p> <p>Participants included the SEAM nurse, four GPs, one pharmacist, three health service managers and 11 registered nurses from various health-care settings.</p>
Appraisal summary	<p>The operational detail and activity volume of the service are not well described.</p> <p>Reporting of the study methodology is of moderate quality. The lack of patient and/or carer perspective was a significant study weakness.</p> <p>Key findings include:</p> <ul style="list-style-type: none"> • Lack of role clarity hindered service effectiveness; several existing community teams were unable to identify the added value of the service and perceived it as duplicating provision; • Insufficient prior engagement with existing services to map needs and inadequate service promotion were significant contributors to failure; • The service was not sustainable, failing to provide a significant volume of direct patient/family care because of poor uptake by existing GP/community teams; • Where the service was utilised, key positive functions were highlighted as: clinical information provision and service liaison; education and skills consolidation for community teams; network and capacity building, rather than direct care provision.
Goodridge 2010 (3)	Study Setting—Two predominantly rural health regions in south western Saskatchewan, Canada.
Summary of the Study	<p>Provision of palliative and end of life care in two rural settings by community (district) nurses and GPs. Qualitative design using focus groups and individual interviews, using interpretative descriptive analysis. Study participants were forty-four registered or licenced practical nurses who had provided palliative and end of life care in the last year.</p>
Appraisal summary	<p>The study did not interrogate a specific model of palliative care provision but retrospectively assessed community nurse experiences of providing palliative care in two rural settings. Methodological quality was good but lack of patient and carer perspective was a significant limitation. Three main themes with associated sub themes:</p> <ul style="list-style-type: none"> • Effectiveness and safety with minor themes of <ul style="list-style-type: none"> - knowledge and skills including lack of interest of colleagues; - lack of palliative care training; - Ineffective communication during transition between care settings; - lack of physical resource to provide home care. • Patient centered care: consistent sense of this being a real positive in rural settings because of longstanding relationships with patients and families • Efficiency and timeliness with minor themes of: <ul style="list-style-type: none"> - lack of human resource and equipment; - tension between efficiency in rural settings and timeliness of access to equipment.
Howell 2011 (1)	Study Setting—Rural area in Ontario, Canada.
Summary of the Study	<p>A pilot shared care intervention programme providing palliative care in a rural setting. The intervention involved integration of an advanced practice nurse (APN) and palliative medicine physician within local health and social care services; the APN acted as clinical care coordinator with direct patient assessment. The intervention focused on: early patient identification; structured assessment; coordination of home care service delivery; education and skills training. Prospective pilot cohort study of 95 patients. Patients with any advanced progressive disease expected to die within 6 months, and who had symptom or supportive care needs, were eligible. Primary outcomes were changes from baseline to death, or study end, in symptom severity and emotional distress (patient and family separately), and a secondary outcome of the concordance between patient preferences and place of death.</p>
Appraisal summary	<p>The study reporting is of good quality for the design and outcomes described. As a pilot study, a sample size for statistical significance was not calculated. The study was therefore not powered to detect a difference although appropriate univariate and multivariate analysis techniques, including handling of missing data, were used. Key findings:</p> <ul style="list-style-type: none"> • A trend in improvement of symptoms in the first 14 days was noted. • Assessment of concordance between preference and actual place of death was possible for 60 patients with 64% achieving their stated preference for home death. • The study was unable to identify demographic or disease characteristic differences between those who did and did not achieve their preference. <p>Limitations of the paper include a lack of description of how the service was designed and how key service elements were identified, and a lack of interrogation of the structure of the care interventions themselves and why they might have been successful. It is difficult therefore to determine which core domains of the intervention are likely to be effective in a larger study or in other settings.</p>

Summary Table—Page 2

Pesut 2015 (4)	Study Setting - Two rural communities in British Colombia, Canada.
Summary of the Study	A feasibility study implementing a rural palliative supportive service, whereby a Nurse coordinator makes a bi-weekly visit. A total of 23 participants and 10 FCGs have been recruited to the service.
Appraisal summary	<p>The study reporting is of good quality. The development of the service and its key components are well described. Reporting of feasibility focuses on service recruitment including reasons for non-uptake, structured assessments and data capture, engagement with communities. The paper describes in detail the community based research approach used including a 21 member community advisory committee, and its benefits and challenges. Key findings:</p> <ul style="list-style-type: none"> • Community involvement at earliest stage of service design identified unique rural contexts which shaped the nature of the intervention and its acceptability. • Focused GP engagement and education facilitated recruitment at an earlier stage of the palliative phase. • Supporting self-management and symptom control were key components of clinical encounters. • Structured patient and caregiver assessments facilitated care planning and systematic assessment of service quality. <p>Limitations of the paper include a lack of data on improvement in patient outcomes and cost effectiveness which will be reported for the</p>
Hebert 2006 (6)	Study Setting - Four health authority areas in rural Alberta, Canada.
Summary of the Study	Palliative care videophone visits with a reduced number of conventional home visits compared with usual number of conventional home visits. A randomised, controlled, parallel study design. Outcomes: differences in symptom burden, quality of life and level of care; cost effectiveness of service delivery. Survey and semi structured telephone interviews. Participants were recruited from 11 rural communities in four Health Authorities in Alberta. The four participating health regions expected a total of 10 new patients per month. A planned recruitment of 200 patients over the two years, however only 44 patients participated.
Appraisal summary	<p>The study reporting is of modest quality. The study failed due to lack of recruitment. The sample size was calculated to detect a small to moderate effect on symptom management, with a planned recruitment of 200 participants over 12-18 months. Only 44 were randomised (19 to usual care, 25 to the video visit arm). There was no significant difference between the groups for symptom measures and the sample size was too small to estimate cost effectiveness.</p> <p>A change in service provision with more emphasis on outpatient care and late referral to community care services were highlighted as barriers to recruitment rather than refusal to anticipate, although eligibility and consent rates were not given. Interestingly clients generally indicated a higher level of readiness to use the videophone technology than the home care nurses.</p>
Phillips 2008 (7)	Study Setting - Rural community setting in New South Wales, Australia.
Summary of the Study	An evaluation of a centralized after-hours telephone support service provided by generalist nurses. A mixed-method evaluation, including semi structured interviews. A total of 357 patients were registered as part of the Mid North Coast Rural Palliative Care Program. 35 (10%) patients and/or their families accessed the service.
Appraisal summary	<p>Reporting quality was moderate, methodology reporting lacked detail on the qualitative analysis and cost effective analysis. Key findings:</p> <ul style="list-style-type: none"> • Ten per cent of registered patients/carers used the service over the 20 month evaluation period. • 80% of calls were from caregivers and most were between 6pm and midnight. • Majority of issues resolved by phone; only 6% of calls resulted in emergency room referral. • Adherence with call protocols was high: 98%. • Key skills of the registered nurses were considered to be their wide generalist skill base and comprehensive knowledge of primary care resulting in practical problem solving and lateral thinking to address issues. • Caregivers described positive impact in reducing the sense of isolation and affirming their competency as carers particularly in medicines management and care when dying. <p>Limitations include the small sample size, lack of comparison of outcomes with patients/carers who did not use the service and lack of understanding of why the majority did not access the service. The cost effectiveness of the service was not well defended because of lack of data and better description of the procedural manuals and specific skill sets of importance would help assessment of the generalizability of the service.</p>
Kuziemsky 2012 (5)	Study Setting- Hospice palliative care delivery in rural setting, Canada.
Summary of the Study	A needs assessment for health information technology (HIT) to support hospice palliative care (HPC) delivery in rural settings. The design consisted of a roundtable discussion using nominal group technique and content analysis. A total of 41 participants, a mix of clinicians (doctors and nurses), researchers and policy makers in both health and health informatics.
Appraisal summary	<ul style="list-style-type: none"> • 20 unique issues related to using HIT in a rural HPC setting were identified. • Central theme of patient centeredness. • Supporting themes of Management, Technological, Political, Human and Spiritual Health Systems

Included Studies:

Papers were included if they reported rural models of service delivery that are generalisable to the rural mid Wales Community, as stated by the requester.

1. Howell D, Howell D, Marshall D, Brazil K, Taniguchi A, Howard M, et al. A shared care model pilot for palliative home care in a rural area: impact on symptoms, distress, and place of death. *Journal of Pain & Symptom Management* 2011 Jul;42(1):60-75.
2. Buikstra E, Pearce S, Hegney D, Fallon T. SEAM – Improving the quality of palliative care in regional Toowoomba, Australia: Lessons Learned. *Rural and Remote Health* 2006;6:415-424
3. Goodridge D, Duggleby W. Using a quality framework to assess rural palliative care. *J Palliat Care*. 2010 Autumn;26(3):141-50.
4. Pesut B, Pesut B. Feasibility of a rural palliative supportive service. *Rural & Remote Health* 2015: 15(2):3116-Jun.
5. Kuziemyk C, Jewers H, Appleby B, Foshay N, Maccaull W, Miller K, Macdonald M. Information technology and hospice palliative care: social, cultural, ethical and technical implications in a rural setting. *Informatics for Health and Social Care* 2012 Jan; 37(1):37-50
6. Hebert MA, Hebert MA. Potential and readiness for video-visits in rural palliative homecare: Results of a multi-method study in Canada. *Journal of Telemedicine and Telecare* 2006;.12(Suppl 3).43-45
7. Phillips JL, Davidson PM, Newton PJ, Digiacomio, Phillips JL. Supporting patients and their caregivers after-hours at the end of life: the role of telephone support. *Journal of Pain & Symptom Management* 2008 Jul;36(1):11-21

Excluded Studies:

A number of studies have been excluded due to various reasons including the following: No focus on innovative service models in rural areas, papers look at experiences and views of palliative care in rural areas, palliative care without suggestions on how to improve the service and descriptions of approaches to palliative care provision. For full list of excluded studies please contact PaCERSWCRC@cardiff.ac.uk

Additional materials available upon request:

- Critical appraisal / data extraction forms
- Search strategies
- List of excluded studies

Disclaimer: Palliative Care Evidence Review Service (PaCERS) is an information service for those involved in planning and providing palliative care in Wales. Rapid reviews are based on a limited literature search and are not comprehensive, systematic reviews. This review is current as of the date of the literature search specified in the Review Methods section. PaCERS makes no representation that the literature search captured every publication that was or could be applicable to the subject matter of the report. The aim is to provide an overview of the best available evidence on a specified topic using our documented methodological framework within the agreed timeframe.

This report should be cited as follows: Palliative Care Evidence Review Service. A rapid review: What are best practice service models in rural areas for the delivery of end of life and palliative care? Cardiff: Palliative Care Evidence Review Service (PaCERS); 2016 February.

Permission Requests: All inquiries regarding permission to reproduce any content of this review should be directed to PaCERSWCRC@cardiff.ac.uk