

# Evaluating a model of delivering specialist palliative care services in rural New Zealand

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## ABSTRACT

**INTRODUCTION:** Various methods of delivering specialist palliative care to rural areas have been discussed in the literature, but published evaluations of these models are sparse. This study surveyed the stakeholders of a rural specialist palliative care service (SPCS) to help identify potential gaps and inform planning regarding the future vision.

**METHODS:** A survey was sent to all relevant stakeholders across the West Coast of New Zealand, including staff in primary care, aged residential care and the hospital. It focused on understanding the local model of palliative care, the quality of the current service and perceived gaps.

**RESULTS:** Thirty-three per cent of the surveys were returned, from a cross-section of health-care providers. The medical respondents rated the quality of the service higher than nursing and allied health participants. All of the groups reported feeling the specialist palliative care team (SPCT) was under-resourced. Additional educational opportunities were considered essential.

**DISCUSSION:** Stakeholders found the service easy to access, but improvements in communication, educational opportunities and forward planning were identified as being needed. This information helps the West Coast SPCT plan its future direction and develop a higher-quality service that meets the needs of all stakeholders.

**KEYWORDS:** Palliative care; service delivery; rural; evaluation

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## Introduction

The World Health Organization states that access to palliative care is essential for all.<sup>1</sup> It is defined as a way of caring that focuses on quality of life, encompassing family (whānau) and the patient. Globally, palliative care services have improved, particularly in urban and academic centres. However, significant challenges remain in providing high-quality specialist palliative care to rural regions. Barriers include geography, recruitment and retention of staff, unclear referral pathways to specialist services, fragmented health and social care services, challenges in

providing education to dispersed health professionals and living in the community where you work.<sup>2–6</sup> With respect to primary health-care providers such as general practitioners and community nurses, studies found they provide high-quality palliative care. However, primary health-care providers report feeling unsupported and overwhelmed in relation to caring for deteriorating palliative care patients.<sup>3,7,8</sup>

The literature outlines strategies for growing capacity and capability around the provision of quality palliative care in non-urban communities. Kelley, for example, describes a model of

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## WHAT GAP THIS FILLS

**What is already known:** There are significant challenges to providing specialist palliative care service to rural and remote communities. The key is working with local health-care providers to provide support, advice and education so they can deliver quality end-of-life care.

**What this study adds:** Evaluation of specialist palliative care services to rural communities is sparse. Identification of areas of need such as education, improved awareness of current services, better communication between health professionals and patients could potentially inform similar services in rural areas.

developing rural palliative care in Canada that had four distinct phases.<sup>2</sup> Initially, as a precursor to establishing a palliative care service, certain attributes are required, such as existing resources and infrastructure and the desire to improve care to dying patients. Next, a catalyst to stimulate the change is required, such as a difficult death or targeted government funding. Key people in the rural community then work collectively as a team towards a vision for better palliative care. In the final phase, the model describes growth and activities beginning to emerge, such as education, public awareness and changing clinical practice. Several studies highlight the importance of capacity development at the local level in developing and establishing health services, such as palliative care, in rural areas.<sup>2,9,10</sup>

Sachs *et al.* examined a rural palliative care service with the aim of describing a potentially successful model. They suggest that the minimum requirement for an effective team is two full-time clinical nurse specialists, with administration support and linkages with allied health. They also recommend formation of networks with other palliative care nurses in neighbouring districts. The outcomes should include equity of community nursing and access to primary care, inclusion of palliative care in all local hospitals and beds available specifically for palliative patients, and a community-based service.<sup>11</sup>

The West Coast of New Zealand is the most sparsely populated area of the country, spanning 600 km in length. For several years, three clinical

nurse specialists (2.4 full-time equivalents) have been employed by the West Coast District Health Board (WCDHB) to deliver specialist palliative care to this region. Approximately 7 years ago, a neighbouring DHB, Canterbury, was given extra government funding to support their specialist palliative care physician to visit the West Coast for 2 days, six times a year. This physician works with the local specialist nurses. In addition, the palliative care physician assesses patients at home or on the ward, provides education and assists with service development.

Education has been a major focus of the role, across settings of care and disciplines, from carers in aged residential care to other specialists. Various initiatives have evolved during this time, such as telehealth for patients, weekly regional complex case meetings, fortnightly interdisciplinary discussions led by clinical nurse specialists and clinical pathways available to all stakeholders. Due to the myriad of initiatives implemented over time, it became clear that evaluation of the current service was necessary to clarify what was working well and identify potential gaps to enable an informed redesign of the service to take place if required.

This study evaluates a specialist palliative care service based on the perceptions of other healthcare providers and clinicians in a rural and remote area of New Zealand. The primary aim is to inform future service improvements. It must be recognised, however, that the next piece of work must include capturing the patient and family (whānau) voice. Together, this will give the most accurate picture going forward for specialist palliative care on the West Coast of New Zealand.

## Methods

### Study design and recruitment

The study is a cross-sectional descriptive study that used a survey technique. It was conducted from the beginning of December 2015 until the end of January 2016.

The survey was disseminated to a wide range of stakeholders across the West Coast via the local Primary Health Organisation (PHO) by the

Health Navigator co-ordinator. This included medical practices, acute hospital teams, private pharmacies, rurally based nurses, allied health, Māori health providers, aged residential care and the Cancer Society. Respondents were given 6 weeks to complete the questionnaire and return it to the research co-ordinator. The University of Otago Human Ethics Committee approved the study (D15/365), and the return of the survey represented participants' consent.

### Survey

A survey based on a New Zealand Ministry of Health document titled 'Measuring What Matters', which outlines quality outcomes for palliative care services, was developed by the first author (A. Landers).<sup>12</sup> The survey was tested for face validity with a specialist palliative care colleague and the quality co-ordinator, who was employed by the WCDHB.

The final instrument had an initial set of questions collecting demographic data and information about the roles participants had within the West Coast DHB or their place of work. It also asked about contact with palliative care patients and the specialist palliative care service (SPCS).

The second section of the survey focused on the care provided by the SPCT, including accessibility, communication from the SPCT and any perceived gaps in the service already provided. The eight questions utilised a Likert rating method ('strongly disagree' to 'strongly agree'). There was also an option to provide free-text comments.

Section three of the survey investigated education, as this is a core component of the specialist service. Again, these questions employed Likert response options. Questions specifically asked about education given by SPCT and its quality, as well as gaps participants believed to be present in what was currently offered. The participants were asked to circle particular topics from a list that they would like to have education sessions on and what format would be the most suitable. There was also opportunity for respondents to write suggestions in a comments section.

The final section comprised one question asking the respondent to rate the quality of the SPCS on an 11-point Likert scale from zero to 10, with 10 representing excellence.

The survey was paper-based as it was unclear what computer access was available to all stakeholders. It was distributed to the various organisations through the West Coast DHB Quality Co-ordinator and collected by the Health Navigator Co-ordinator. One reminder was sent in person or by email to the service managers.

### Data analysis

The quantitative data was analysed using descriptive statistical methods to obtain percentages, averages, standard deviations and ranges. Analysis of the qualitative data involved conventional content analysis by authors AL and DD, which sought to identify salient and recurrent themes. Two cycles of coding were undertaken. The first cycle involved examining each comment line-by-line, looking for similarities and differences. The researchers discussed the content and began grouping them into initial themes. A second cycle of coding refined the data into a smaller number of themes. An independent review of the emerging themes was undertaken by a clinical nurse educator in palliative care who cross-referenced them with original ones.

## Results

### Respondent characteristics

Of the 447 surveys distributed, 147 were returned (33%). Most respondents were nurses (49.6%), with the next largest group being 'other' (23.8%). The 'other' group may have included management, carers and reception staff. There were ~10% of both allied health and medical practitioners and just under 7% identified as pharmacists.

Respondents represented varying places of work in the region. The most common places of work were the inpatient setting and primary care, making up almost half of the participants. Aged residential care staff and the community teams also featured strongly. The remaining respondents came from the private sector and 'other'

groups. Fifteen of the 147 (10%) who completed surveys indicated they had more than one area of work; for example, participants may have indicated that they work in both primary care and the community. There was a spread of respondents across the various settings, with most coming from primary and community care (38%) and 25% based within in-patient care.

Most participants were NZ European (79%), with almost 8% identifying as Māori. Approximately 6% indicated they were Asian. Seven surveys indicated dual ethnicities: Māori and NZ European.

### Respondent involvement with the SPCT

Five per cent of participants had no involvement in their working day with palliative care patients. Most (60%) often or very often had interaction with patients requiring palliative care. However, 46% reported they only occasionally had contact with specialist palliative care services, with the same number having more involvement (often or very often).

### Palliative care delivery

Eight questions focused on service delivery and understanding of the current specialist palliative care service. The results related to these are

reported in Table 1. The participants who identified as being medical tended to score the service higher than other groups, finding the SPCT easy to access and reporting that the model is working for their patients. In contrast, the allied health group did not feel the model was effective, although they scored the SPCT highly on access.

The aged residential care (ARC) subgroup was analysed separately as this is a priority area for the health system at both a governmental and local level. The ARC staff manage many patients with palliative care requirements and this is a growing area of need. The results from this group suggest ARC staff find the SPCT easy to access but feel staffing of the specialist team is an issue.

### Education

Almost universally, respondents agreed or strongly agreed that palliative care education was important. Many indicated they had never attended a education session. They were asked to comment on which topics they would like to see offered in their local area. The four most popular choices included advance care planning, pain and symptom management, communication and non-malignant palliative care. Workshops and lectures were the most commonly chosen method for the delivery of education, followed by online learning and whole day seminars.

Table 1. Survey responses from stakeholders about the West Coast District Health Board specialist palliative care service delivery

Survey questions	Medical n = 14	Allied Health n = 15	Nursing n = 72	Other n = 29	ARC n = 16
Q 2.1 There is good knowledge among health providers of services the SPC provide on the West Coast?	3.78 (0.58)	3.46 (0.92)	3.50 (0.98)	3.48 (0.78)	3.47 (0.81)
Q 2.2 It is easy to access the SPC team on the West Coast?	4.07 (0.73)	4.00 (0.65)	3.85 (0.93)	3.65 (0.72)	3.72 (0.80)
Q 2.3 I have a good understanding of what services the SPC provide on the West Coast	3.61 (0.87)	3.57 (1.16)	3.56 (1.08)	3.50 (0.69)	3.52 (0.81)
Q 2.4 There is good communication from the SPC service to you	3.71 (1.07)	3.50 (1.09)	3.85 (0.95)	3.68 (0.66)	3.84 (0.77)
Q 2.5 I feel there are gaps in what the SPC currently provides	3.23 (0.67)	3.00 (1.10)	3.06 (1.01)	2.89 (0.50)	3.10 (0.77)
Q 2.6 I feel there is adequate staffing of the SPC on the West Coast	2.71 (0.61)	2.57 (0.92)	2.89 (0.83)	2.86 (0.64)	3.00 (0.57)
Q 2.7 I feel the current model of SPC is working for me and my patients	3.71 (0.52)	3.06 (1.10)	3.65 (0.65)	3.31 (0.60)	3.63 (0.80)
Q 2.8 I feel the current SPC service delivery is culturally appropriate	3.79 (0.70)	3.46 (0.66)	3.84 (0.51)	3.37 (0.49)	3.57 (0.63)

1 = strongly disagree to 5 = strongly agree.

Results are presented as mean (standard deviation). ARC (aged residential care); SPC (specialist palliative care).

### Quality of service

The survey asked participants to rate the service as a whole on a scale of 0 to 10. The overall average for all respondents was 7.2, with ARC having a mean of 6.7 and doctors a mean of 7.5. Analysis of the qualitative data follows.

### Qualitative analysis

Four recurring inter-related themes emerged: knowledge of the service, resources, forward planning and communication. These four themes and representative examples are described in Table 2.

### Discussion

This study surveyed the stakeholders of a specialist palliative care service in a rural area of New Zealand. The results suggest respondents found the service easy to access, with reasonable communication to and from the team. Education was a significant gap, as has been described in other studies.<sup>13,14</sup> The preference from respondents in this study was for education to be delivered via lectures and workshops. The qualitative findings indicate work needs to occur in improving knowledge of the service and forward planning with patients and their families. A recurring theme from the survey respondents was a strong view that the SPCT lacked resources. Universally, the stakeholders felt there was inadequate staffing of the SPCT. This is not unique to our service and probably reflects a global issue.<sup>3</sup>

Various studies have attempted to look at different models of delivering specialist palliative care to rural areas.<sup>2,11,15</sup> Very few have evaluated and reported the success or otherwise of those models.<sup>16,17</sup> In 2015, Bakitas *et al.* completed a comprehensive review of current practice and the state of research relating to palliative care delivery in rural settings.<sup>10</sup> They concluded that education was extremely valuable and could make a significant difference for low cost. This would correlate well with the findings of our study, which highlighted the importance placed on education by different stakeholders. Developing an education strategy using the findings of this survey would be beneficial and help inform

a vision for future planning. Bakitas *et al.* also highlighted the pivotal nature of the community in developing services, and suggested a formal assessment of existing resources. They particularly mentioned the stakeholder perspective calling for better research in this area.<sup>10</sup> The results of our research may help inform rural communities geographically isolated from urban centres about how a palliative care model may work.

The study by Kelley describes a model of rural community development that fits closely with what has emerged over several years on the West Coast.<sup>2</sup> She describes four stages of development: antecedent community conditions, catalyst, creating the team and growing the programme. The WCDHB has passed through the first three stages and is now in the midst of deciding how best to grow and strengthen the team. This involves engaging the community, changing clinical practice and providing education. There is also succession planning, which must form part of any vision for the future.

Table 2. Themes and Exemplars Regarding Perceptions of SPCT Service

Theme	Exemplar
Knowledge of the Service	'Who? Wasn't aware of the SPC Services. Have had personal experiences and was not aware.' [Nurse, aged residential care]
	'I generally have a limited understanding of what they do and availability.' [Nurse, secondary service]
	'I was not aware that there was 24 hour phone advice through Nurse Maude Hospice Palliative Care Service.' [Rural Nurse Specialist]
Resources	'Night cover is as on call only currently but night shift services would be of great benefit to patients being able to remain at home.' [Nurse community]
	'Palliative care nurses are excellent but seem quite stretched, not always available. 12 days/year physician time is not enough.' [General practitioner]
Forward planning	'Sometimes patients present with problems that have been building up for a long time or could have been seen earlier by the GP. Patients seem to have a limited plan for analgesia and don't have a backup plan.' [Nurse, Emergency Department]
Communication	'I feel that there should be more training provided for not only nurses but care staff too.' [Non-government organisation]
	'Have felt there was a lack of education for patients & their families regarding what to expect during the final day/hours. However - do think this aspect is improving.' [Nurse, primary care]



Access for other health professionals to SPCTs and quality of care are challenges in providing rural palliative care services also highlighted by Kelley,<sup>2</sup> with other studies reporting similar access issues.<sup>4,5,7</sup> In contrast to the study findings by Kelley, availability of the SPCT was rated positively in this current study. Kelley further reports that the development of specialist palliative care eventually rests on securing additional staff and resources to allow senior clinicians to focus on more high-level issues, including educational strategies and policy development.<sup>2</sup> It was evident that respondents feel strongly that resources, including additional staff, are lacking. The development of a formal WCDHB end-of-life care policy may be a strategy to enhance a vision of better care for palliative patients; however, this will require commitment from the health system.

Lack of education and awareness of what resources are available to the public are recurring themes in the literature.<sup>3,4</sup> This is comparable to the results found in this current study. This finding has formed the foundation of a new focus for the two DHBs concentrating on a media strategy for improving public awareness and a review of educational resources already available in New Zealand that can be offered locally.

The major limitation of this study to inform service design is the lack of the voice of patients and family (whānau). Robinson *et al.* published a comprehensive review of rural palliative care,<sup>3</sup> describing how difficult it is to obtain patient and carer views and highlighting the lack of research in this area. What did emerge from the study by Robinson *et al.* was that the experiences and needs of families may not be dissimilar to those in urban areas, with the main difference lying in the domain of after-hours care. Evaluations of the role of telemedicine in this area may help to inform future models of rural palliative care.

In the study by Pesut *et al.*, 95 palliative care 'champions' including 25 family members in a rural area were interviewed, asking them their ideas about good palliative care, and the strengths/gaps and aspirations for end-of-life care.<sup>18</sup> The preliminary findings were presented back to the community to ensure correct representation. Outcomes showed rural communities

value being known, health professionals tend to be available and present, and that maintaining a spirit of mutuality is important. Future research within the West Coast region needs to investigate these areas within their community.

Although the local SPCT has evolved, particularly in the clinical space, more formal arrangements are recommended.<sup>9</sup> Since the survey, there has been an establishment of a Transalpine Palliative Care Leadership group consisting of management and clinicians from both Canterbury and West Coast DHBs. A work plan for this high-level group has been formed using the results of this study. The new innovations outlined in this discussion are being driven locally and are, therefore, more likely to succeed in improving care.<sup>2</sup> Ultimately, research would suggest the cornerstone of any successful model delivering quality services rests on strategic partnership and capacity building in local communities.<sup>2</sup> Whatever direction the West Coast Specialist Palliative care service now chooses to focus on in the coming years must be underpinned by these critical elements.

## Contributions

Initial research design and interview questionnaire development were conducted by AL and DD. AL, DD and FDN were involved in the data analysis and writing of the article. All the authors have read and approved the final version of the paper.

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#### COMPETING INTERESTS

None.

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