

How is the specialist–primary palliative care model functioning for cancer patients in the current New Zealand health system?

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ABSTRACT

AIM: Patient barriers to accessing hospice and palliative care (PC) have been well studied. Important, yet less investigated, is how cancer patients whose hospice referrals were not accepted are being cared for. This article aims to understand the referral process from PC providers' perspectives and the implications of the current palliative system for patients, families and health professionals.

METHODS: We conducted interviews with 28 healthcare professionals via Zoom. Participants worked in specialist and primary PC settings, such as hospices and aged residential care, and were based in seven Aotearoa New Zealand regions. We thematically analysed the interview transcripts.

RESULTS: We identified four themes: the state of the PC system; communication issues; unmet needs and inequities; and managing care within the current system.

CONCLUSION: The limited funding for PC and other health services is resulting in a decrease in PC services. The specialist–primary model of end-of-life supportive care in New Zealand is undermined by under-funding. The implications for cancer patients, their families/whānau and their healthcare professionals are moves towards a more biomedical model of PC, a reduction in training and unsustainable work-arounds to manage care within the under-resourced system. Considering the ageing population, urgent action is needed.

As the population ages, the demand for palliative services will increase. However, hospice care is restricted to those with the highest needs.¹ Significant evidence supports the integration of holistic palliative care (PC) for patients with advanced cancer.² In Aotearoa New Zealand, community specialist PC (henceforth specialist PC) is provided by independent hospices to patients at home and in-patient units, and supports staff and their residents in aged residential care.³ Several analyses have found wide variations in the provision of hospice and other specialist PC in New Zealand across localities and regions.^{3–5}

Hospice is just one part of PC; primary or generalist PC can be provided by general practitioners (GPs), nurses (particularly district nurses), Māori health providers, oncologists, other specialists, social workers, occupational therapists, counsellors, chaplains and so on. New Zealand policy establishes a hybrid working model of PC that is provided by non-specialists and specialists, who differ by degree of training in PC.⁶ The intention is a universal model of PC provision available to all, irrespective of setting or illness.⁷ Factors that support good

partnership between specialist and primary PC include: good communication between providers; clearly defined roles and responsibilities; opportunities to learn together; appropriate and timely access to specialist PC; and well-coordinated care.^{8,9} Communication between providers, families and patients is a recognised factor in integrated care. All of the providers (and non-providers) caring for a particular person need to have a “shared vision of care” to ensure that their care is working towards the same person-centred goals.¹⁰

A lack of integration is a long-standing challenge for the specialist–primary PC model.^{7,9} A systematic review called for research with healthcare professionals and patients about their perspectives on collaborative working in PC.⁸ Integration was explored in a cross-country United Kingdom and New Zealand comparison early after the specialist–primary model was introduced in 2011.⁹ In 2011, hospices cared for approximately 14,000 people (in an email from Hospice New Zealand, October 2024); in 2022/2023 they cared for 18,582 people, of whom 10,880 died.¹¹ Adjusting for the increase in deaths over this period (30,081 in

Table 1: Participants' healthcare sectors.

Sector	N
Community care and district nursing	10
Oncology	5
Hospice/specialist palliative care	4
Aged residential care	4
General practice	3
Hospital palliative care	2

2011 to 37,884 in 2023¹² and acknowledging that not all of the people the hospice cares for die in that reporting year), the percentage increase in the proportion of patients (and their whānau) cared for is 5.4% (in an email from Hospice New Zealand, October 2024).¹² More people in New Zealand die receiving primary PC. Close to 15 years on, another examination of how this hybrid model is operating in New Zealand is due, especially in light of funding and other challenges in the health system. We sought to understand the experiences of both specialist and primary PC providers within the current PC model of care, focussing on when a patient's referral is declined,¹ and to elicit their views on how the current system is functioning for cancer patients and their families/whānau. We focussed on cancer patients because their prognostic eligibility for hospice is clearer than other patient groups.

Methods

Critical realism underpinned this research.¹³ We consulted with various healthcare organisations about the issues most salient to them regarding PC referrals and declines and designed the study to reflect this. Ethical approval was received from the Health and Disability Ethics Committee (2023 AM 11724).

Recruitment and data collection

Participants were recruited through healthcare organisations, including the Royal New Zealand College of General Practitioners and Hospice New Zealand, as well as through networking. One focus group with six community care coordinators and 22 individual interviews, mostly over Zoom, took place in 2022. We found it adequate to establish rapport over Zoom and

discuss this subject. The medium appeared acceptable to participants. The interviews focussed on the factors contributing to hospice declining referrals, and questions included, "Have you ever had a cancer patient's referral to hospice declined?", "What was that like for you, the patient and their family?" and "What do we know about people with cancer who don't access hospice, how are they being looked after?" Transcripts were produced by a professional transcriber and offered to participants to check. Participants were given a \$50 voucher in appreciation.

Participants

The 28 participants' healthcare sectors are described in Table 1. Several participants had worked in specialist PC and now work in primary PC. Participants worked in Dunedin, Wellington/Hutt Valley, Waikato, Christchurch, Auckland, Bay of Plenty and the Coromandel. Further demographic information was not requested, though participants represented a range of ethnicities and ages, and included five men.

Analysis

Thematic analysis was conducted on the interview transcripts using NVivo software (Lumivero, Version 14). JY intensively read and inductively coded each transcript line-by-line to capture how participants described the issues and implications of declined referrals.¹⁴ JY created a codebook and memos of the developing categories and themes, and a research assistant applied the codebook to the remaining eight transcripts in discussion with JY's guidance. Through reflexive, iterative discussions, we developed four themes. We examined the transcripts for alignment and inconsistencies across themes and sectors.

Results

We report on four themes: the state of the PC system; communication issues; unmet needs and inequities in PC access; and managing care in the current system.

The state of the PC system

This theme described a model of PC that was changing out of necessity due to limited resourcing, because of a desire for people to have more community-based care and in response to more demand for their services. Participants described how the ageing population was increasing demand, and because oncology has adopted the promoted model of early/timely PC:² *“I’m a strong advocate, our whole department are strong advocates of early hospice referral”* (oncologist, regional hospital). The demand, combined with under-resourcing, required changes in the model of hospice care including referral/acceptance criteria, reduction of services and reduction or ceasing of educational programmes for primary PC. A hospice leader acknowledged the changing criteria and attributed it to resourcing issues. Instead of accepting previously eligible referrals, hospices were declining referrals for those who did not have immediate needs or needs that could be managed by another service.

So that’s referral criteria, it’s not the acceptance criteria. So, that can be a little bit different, and right now I know that some hospices are managing referrals based on their resource and what they can manage. (Leader, urban hospice)

The gap between the referral and the acceptance criteria was frustrating for both primary and specialist PC providers. The impact on patients was noted.

It’s really gotta be just symptom management or [hospice] don’t seem to have a lot of support [for] someone at home ... there’s often been people that I’ve felt that the hospice should’ve really been involved in earlier time but they’ve been declined... It’s just very frustrating. The oncology team had actually referred... the client was seen by hospice and then was told that he didn’t really have any real symptoms or didn’t really need the

support ‘cause he wasn’t actively dying ... [and that he] can get re-referred at a later date... I stayed on ... supporting him at home until I’ve asked the GP again to do another re-referral to hospice ... psychological support, all the other support that I thought he should’ve been getting, he is not getting. (Supportive nurse, urban community care)

This one example demonstrates several routes of referral—oncology, GP, community nurses—illustrating the complexity of specialist–primary PC. One way of managing patients was to assess and decline and then suggest they are re-referred when the need changes. Re-referral was seen as an acceptable process by specialist PC providers but less so among primary PC providers.

Staffing shortages were contributing to the capacity of specialist PC. Constraints in capacity issues means hospice must focus on higher-needs patients, usually with physical symptoms. This undermines the holistic early approach hospice favours. The specialist–primary PC model goes some way to meeting the demand by hospice acting as a consultancy-based service, and primary PC providers remain the primary carers.

So we have quite a good relationship with [local] hospice out here. So we have a, we have a fortnightly meeting with them and then we just have phone contact. Like we have a lot of shared care patients because there’s people under hospice, but also receiving treatment. So we liaise with them all the time. (Oncology nurse, urban hospital)

For patients the siloed health system, including the specialist–primary PC model, contributed to patients feeling passed around or “dumped”:

I think especially like oncology patients, they’d, sort of, feel this dumping, and so they’d kind of been through, you know, sometimes years of chemotherapy and perhaps even relationships with surgeons. And, then they, sort of, get to the point of you’re too sick now there’s nothing you can do we’re going to pass you onto your GP, and then we’re going to pass you onto hospice. And, you sort of feel that that’s probably going to be the last sort

of thing, and then you get passed off yet again [to aged residential care]. (Nurse practitioner, rural aged residential care)

Some participants identified that it relied on skilled primary PC providers to identify patients' palliative needs.

Communication issues

Changes to hospice services, such as the acceptance criteria, could have been better communicated across and within organisations.

We [put out communication about their criteria], but what we do here is if we change something that's related to primary care, we will send an e-mail that will go to the practice managers of a practice. But that relies on the practice managers filtering it through, that relies on the practitioners reading it and understanding it. (Clinical nurse specialist, urban primary care and hospice)

Participants described under-communication, where PC referrals did not contain the information required to triage the referral; slow communication, where the response was not considered to be timely enough to address the patient's needs; difficult communication, where they felt their requests and needs were not heard or dismissed; or no communication, where the communication was not responded to.

No-one had listened to my GP when they were requesting help from a consultant. The [hospice] consultant had a preconceived idea, which was wrong, believed it was a family issue when that wasn't the case. And I think that's something that we struggle with is when our doctors actually need help, they actually genuinely need help, and that is sad I think that we can't get that input that we need for those really complex, because it falls back on us. (Clinical nurse manager, urban aged residential care)

For those that it's a shared care model, I think the gap is around communication. That causes anxiety and confusion, for some, not all. That would be probably, and I know that from a agency, home and community support service agency I

think this is certainly what's been raised recently is the vulnerability. That they are feeling when they are caring for a patient who is palliative and there's a lack of, or of disconnect around communication. (District nursing manager, urban hospital)

Other issues, related to trust, time/capacity and the clinical hierarchy influenced communication across PC providers. Clinicians being able to access notes from other sectors' patient management systems helped immensely and could reduce duplication, e.g., care plans.

Unmet needs and inequities in access to PC

The net result of the current PC system, combined with communication issues, were unmet needs and inequities in access for some patients. This affected particular groups more so than others: some ethnicities, rural dwelling patients and some illness groups (such as dementia and those with frail-dwelling community members) lacked access to the specialist PC they potentially needed.

The hospice is two and a half hours away so all their family and friends, it creates an immense distance really, it doesn't work, you know? Those people that want to, who are dying, prefer to be around family and friends in the process and in their own homes. (GP, rural primary care)

People with English as a second language, those living in a caravan park, non-residents and people of some faiths were also identified as having unique access issues. The stress on families to meet their family members' needs as they approached the end of life without specialist PC was noted by many. Other health system factors contributing to families' stress included the inability of many GPs to conduct home visits, as well as a lack of or minimal funding for home assistance in cases where the patient resided with family, despite family members working full-time. Another issue was that hospice services seemed to be unavailable to aged care residents, though support for staff was available from aged residential care hospice liaison nurses.

It's something that hospice do really well. But, they only tend to offer that to people in the community, they don't offer it in

residential age care ... [some people] come into care and they've got all these complex psychosocial issues. (Nurse practitioner, rural aged residential care)

Unmet needs and access inequities were further compounded by the reduction in PC courses for primary providers. Both specialist PC and primary PC participants described that the PC expertise of non-specialists needed to increase, e.g., recognising delirium or dying.

Managing within an under-resourced PC system

The obvious solution to suboptimal PC is better funding to employ more staff so referrals can be accepted and staff have time to communicate, resulting in less stress and less need for gatekeeping.

There's international guidelines on when patients should be referred to palliative care ... my sense is that the hospices generally aren't resourced for that. (Palliative medicine specialist, urban hospital)

In lieu of that, primary PC participants continued to support patients and families and came up with a range of workarounds to help overcome the above issues: being a “squeaky wheel” to get what the patient needed, providing culturally appropriate care, e.g., marae or church drop-in clinics, accepting that not every primary care interaction would generate income, working overtime, upskilling and educating families, drawing on community support, making other referrals, getting the GP more involved and, for rural GPs, always being on call.

Medicine often works this way, is knowing how to game the system. You happen to know to whom you should talk in a particular situation... But it shouldn't, it's often used as a means of getting out of the constraints of an under-resourced system or the inability to refer someone in the direction in which it would be appropriate to do so. (Medical oncologist, urban hospital)

In terms of communication, thorough hand-overs during transitions between PC settings, timely access to records and virtual consultations were helpful. We observed hospital PC acting as a

bridge between hospices and primary PC. Different ways of clinicians working, such as individuals working concurrently in both specialist and primary PC, staff having flexibility in their roles, PC champions within organisations, more services provided by fewer providers and accessing the hospice consultancy service (e.g., aged residential care liaison nurses, 24/7 phone service where it existed) worked well.

These formal and informal strategies were described as how PC providers worked towards improving health outcomes for those typically disadvantaged and under-served by the health system. However, having clinicians wrangle care within a non-functional system is unsustainable and may have negative implications for the workforce, including burnout and retention issues.

Discussion

The effect of the hospice not being able to accept (or at least consult with) all referrals was frustrating for both specialists and primary PC participants, though it was noted by one hospice leader as the ideal. Patients are missing out on care that clinicians have identified there is a need for, resulting in additional stress for their families and healthcare providers.¹⁵ There is also an inability to provide evidence-based care (early referrals of new cancers) due to current constraints.¹⁶ This means the health system is not serving its purpose, and the discontinuities may cause staff to leave, resulting in even worse outcomes for patients. The need to reduce primary PC training by specialists is undermining the functionality of the specialist–primary model. This study sits within the context of a whole health system that is lacking funding and staff,^{17–19} and also has integration and communication issues. Similar issues in the present study were identified in a survey of health professionals and service users by the National Palliative Care Work Programme.²⁰ Improvements could be made in communication between providers including regular case discussions. However, as an aged residential care manager articulated, you only get one chance with a dying person and their family. High-quality PC, whether primary or specialist, is important for the bereavement of living relatives; it also improves patients' quality of life and reduces secondary care use.^{2,21} If the current PC system has room for improvement for cancer patients, then it is likely to be even worse for other patient groups because the hospice

model serves cancer patients most often.¹¹

This transformation is important because the reality of the current PC system does not match the philosophy of early, or at least timely, PC for all people with serious and advanced diseases.⁵ This philosophy may create expectations among patients and primary PC providers that people with advanced diseases receive early PC, but it is not possible to provide early (or timely for some) PC for all patients due to the shortage of specialist PC. Specialist PC may not be beneficial for all patients as some may not have complex PC needs and can be well cared for by primary PC. Given the scarcity of specialist PC resources, questions have shifted from whether to provide PC to when to provide it, to which patients, what to provide to whom and who should provide it.²² The necessitated return to focus on symptoms (a biomedical model) over other support (a biopsychosocial-spiritual model) is at odds with the original intention of hospice and Te Whare Tapa Whā approach.^{23,24}

Participants were concerned that any reduction in services meant people's needs would be overlooked and that it may disproportionately affect particular groups. Ethnicity is an essential and evidence-based marker of need.²⁵ Hospice appears to be providing access to services equitably for Māori, as in 2022/2023, Māori comprised 13% of hospice patients, a figure that closely aligns with their proportion of total deaths (12.5%).^{11,12} Participants commented on some inequities among groups and situations. We need approaches to PC delivery that take into account intersecting inequities (e.g., racism, classism, ageism, ableism, sexism), groups that experience social disadvantages and PC access barriers (e.g., people experiencing mental distress, homelessness, poverty), and other social situations (e.g., rurality, English as a second language, mistrust in the health system).²⁶ Enhancing equity in PC access requires an inclusive, diverse, person-centred approach with community, structural, policy and system-level support with staff as diverse as the patients.

The specialist–primary PC model has many dimensions and includes providers and interactions with various models and indicators.²² Work is underway to develop core service components in specialist PC in New Zealand.⁵ Even though a model will need to be tailored to each region, while variation still remains, the unifying elements of such models are collaboration, coordination, communication and acknowledging the value of other providers.^{27,28} Establishing shared care models and transition models between primary and specialist

PC settings may help.^{22,27,28} Articulating where on the spectrum of the “Consulting-Shared-Takeover Framework” specialist–primary providers are operating may help to describe, understand and assess how teams are working together, and their efficacy.²⁸ The five domains are: 1) what aspects of care (*scope*) are addressed by the specialist PC clinician? 2) who *prescribes* the treatments? 3) what *communication* occurs between the PC clinician and the patient's lead clinician? 4) who provides the *follow-up* visits and what is their frequency? and 5) who is the *most responsible practitioner*? Using the Consultation-Shared-Takeover Framework can support the sustainability of a service.²⁸ A more coordinated system with explicit modes of working together would mean that health professionals do not need to develop unsustainable makeshift strategies to circumvent the suboptimal PC system to ensure patients get the care they need. At a minimum, transparent acceptance (as opposed to referral) criteria and triaging systems should enhance the trust in, and effectiveness of, the specialist–primary PC model in New Zealand.

A strength of this research is the range of participants from different sectors, including both primary and specialist PC, to gain a fuller picture of the system and how it is working. However, we did not interview participants from all regions, so there may be further challenges and/or workarounds we have not identified due to the regional variation in PC services. Cancer deaths are easier to predict than other disease types, so findings may not apply to all patients at the end of life.

Conclusion

This research has identified that at times there is a lack of integration and communication between specialist and primary PC. Participants attributed the deterioration of this model to poor planning/under-funding, increased demand, lack of training for primary PC, siloed working, lack of effective communication channels and access to records, and workforce issues including the pandemic. The under-funding of PC is contributing to suboptimal PC provision, likely contributing to difficult experiences at the end of life for all involved. We echo calls for more funding for PC with equity built into it—for both primary and specialist—because at present, PC is not resourced for the philosophy of care espoused.^{18,19} While the specialist–primary PC model is entrenched, the challenges need further

remediation to ensure workforce sustainability and patient- and family-centred care, especially considering the ageing population.²⁹ From this research we have developed a resource for primary palliative care providers to help them think about how they can continue to support patients

and families who are dying without hospice.³⁰ Future research should seek patients' perspectives on the specialist–primary PC model and explore who health professionals see as being responsible for PC transformation (clinicians, managers, systems, policy, etc.).

COMPETING INTERESTS

Richard Egan is on the Mirror Counselling Board.
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