A task service and a talking service: A qualitative exploration of bereaved family perceptions of community nursing care at the end of life

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Abstract

Background: Greater emphasis on community-based care at the end of life is supported by the premise that most people want to be cared for and die at home. As such, it is important to understand the current state of palliative care nursing within an integrated generalist-specialist model of care in the community.

Aim: To explore bereaved family perceptions and experiences of community nursing at the end of life, with a particular focus on service integration.

Design: A qualitative study design using semi-structured telephone interviews with bereaved family. A critical realist framework was used to inform the analysis of interview data and thematic analysis of data was used to identify key themes.

Setting/participants: Participants were the family carers of patients who had died within the catchment area of two large District Health Boards in Auckland, New Zealand.

Results: Twenty-three participants were interviewed. Participants described their experiences of community nursing in terms of the service they provided. Hospice nursing roles were described in terms of a “talking service” and District Nursing as a “task service.” There was minimal expectation of the general practice nurse in terms of palliative care support and little evidence of service integration.

Conclusion: Findings from this study support the need for a new integrated model of palliative care nursing which utilizes the unique skill set of nurses working across all community care settings including general practice, hospice and district nursing services. Accommodating different models of nursing care which can be responsive to patient need rather than limited to a defined service delivery model.

Keywords
Palliative care, nursing, community, hospice, home care

What is already known about the topic?

- An integrated generalist-specialist approach to palliative care is a policy priority in many countries.
- Community nursing has a significant role in the provision of generalist and specialist palliative care for people who wish to be cared for and die at home.
- There are ongoing challenges in to accessing appropriate and timely nursing care at the end of life which is often due to a lack of integration between generalist and specialist nursing services.

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What this paper adds?
- Bereaved families differentiated between the different nursing services in terms of the type of care they received from each service.
- Families expectations of the general practice nurse in terms of their role in the provision of palliative care was minimal.
- Integration of nursing services was not evident and this impacted negatively on people’s experiences of the nursing care they received.

Implications for practice, theory or policy
- A new integrated model of palliative care nursing which utilizes the unique skill set of nurses working across all community care settings including general practice, hospice and district nursing services is urgently needed.
- Further research to understand the role of the general practice nurse in the provision of palliative and end of life care in the community is required.
- Policy which is flexible in accommodating different models of nursing care which are responsive to patient need rather than limited to a defined service delivery model is needed.

Background
Globally government policy is increasingly focused on “care at home” to reduce demand for hospital-based services. Greater emphasis on community-based care at the end of life is supported by the premise that most people want to be cared for and die at home. As such, it is important to understand the current state of palliative care nursing within an integrated generalist-specialist model of care in the community. Whilst service integration in health care is complex, it is essential to achieving effective patient care across all healthcare settings.

An integrated generalist-specialist approach to palliative care is a policy priority in many countries, including Aotearoa New Zealand. This approach is predicated on complexity of palliative care need, in that people with complex need will receive support from a specialist palliative care provider, usually a hospice team. Support may be intermittent or continuous depending on the level of complexity. However, most people will have a level of palliative care need that can be managed in the community with little or no direct care from specialist palliative care. Yet, evidence to date regarding community provision of palliative care has focused predominantly on the role of the general practitioner, with less attention paid to the work of community nurses.

Globally, palliative care is considered to be integral to all nursing practice regardless of the clinical setting. In Aotearoa, New Zealand generalist palliative care is provided by nurses from general practice (or primary care) services and by district nurses (also known as home care nurses) from publicly funded community health services. In terms of specialist palliative care, hospice community nurses work within an interdisciplinary team caring for people with complex palliative care needs. Having multiple nursing services involved in the delivery of palliative care in the community can lead to fragmentation of care. However, factors such as effective communication between providers and an understanding of the roles and responsibilities of each service have been shown to support good partnership between nursing services. Yet, evidence has shown ongoing challenges to accessing appropriate and timely nursing care at the end-of-life.

A recognized barrier to appropriate care is a lack of integration between generalist and specialist palliative care community nursing services. Integration of multiple nursing roles or services in palliative care is considered to an essential component to providing high-quality care at the end of life. However, there is little evidence of how bereaved family experience the combination or integration of generalist and specialist community nursing services.

This study aims to explore bereaved family perceptions and experiences of community nursing at the end of life, with a particular focus on service integration. For the purposes of this study “community nurses” included general practice nurses, hospice community nurses and district nurses.

Methods
Research question
What are bereaved family’s perceptions and experiences of community nursing at the end of life?

Study design
A qualitative exploratory study design was adopted using a critical realist approach acknowledging the individual and unique situational reality of bereaved family as participants.
Setting
The study took place across two large urban District Health Board (DHB) areas in Aotearoa New Zealand. District Health Boards are publicly funded providers of healthcare for a specific population living in a defined geographical area.

Population
Participants were the family carers of patients who died between January and December 2019 whose place of residence fell within the catchment area of the two District Health Boards (DHB). Demographic data of the person who had died was included, along with details of named next of kin.

Sampling and recruitment
In order to ensure a variety of family perspectives were captured, we used purposive sampling to ensure a mix of cancer and non-cancer diagnoses were included. DHB Nurse Directors sent letters of invitation along with study information to the next of kin of people who had died during the study period. Fifty letters of invitation were sent every 2 weeks until the sample size was achieved. Potential participants were asked to contact researchers should they wish to participate. To be eligible for the study participants had to be aged over 18 years, speak English and have been recorded as the next of kin for someone who had died during the study period.

Data collection
Semi-structured telephone interviews were undertaken 6–12 months after the date of death with bereaved family carers. See Table 1 for interview schedule.

Interviews were conducted by an experienced research assistant (HG) who was also a nurse with experience in palliative care. Interviews were undertaken between June and December 2020. Verbal consent was obtained, and interviews were audio recorded and transcribed verbatim. Interviews took between 20 and 60 min and were held by telephone due to Covid-19 restrictions; evidence suggests that this approach can be a positive experience for participants and particularly support discussion of sensitive topics.13

Data analysis
A critical realist framework was used to inform the analysis of interview data. This approach acknowledges the situational reality of each participant as they describe their experiences of caring for someone at the end of life.12 An inductive approach using thematic analysis14 was used to identify key themes from the interview data. Familiarization with the data was undertaken through reading and re-reading the interview transcripts to become immersed in and familiar with their content. An initial coding framework was developed by JR and presented to the research team for further discussion. Interview transcripts were reviewed by the research team as a whole, and the coding framework was modified iteratively by the team. A sub-set of interviews were then given to each member of the team to code using the coding framework as a guide. Finally, a review of developing codes and themes was undertaken by the research team as a whole to inform the development of the final analysis framework.

Ethical approval
Ethics approval was provided by the New Zealand Health and Disability Ethics Committee (Ref: 19/CEN/78/AM03).

Table 1. Interview schedule.

| Interview schedule |
|--------------------|
| 1. From the information we have about the community nursing services you received during your family members illness we note that you had visits from: (list all the services involved such as district nursing service/community hospice nursing services/other nursing service. |
| a. Please describe what care was provided by each nursing service? |
| a. What was good about the care you received from each nursing service? |
| b. What was not so good about the care you received from each nursing service? |
| c. For those who had multiple services involved, do you think they worked well together? |
| d. What do you think could be improved about the care each nursing service provided? |
| 2. During the time you cared for your family member, did you have any contact with the practice nurse (nurses working with your family doctor) |
| a. If yes, what care did the practice nurse provide? |
| b. What was good about the care the practice nurse provided? |
| c. What was not so good about the care the practice nurse provided? |
| d. How well did the practice nurse work together with the other nurses involved in your care? |
| 3. Were you clear about what each nursing service had to offer? |
| 4. How do you think nursing services could be improved to ensure experiences of care at home are positive? |
| 5. What advice would you give to other families in your situation to ensure they received the nursing care required to care for a family member at home? |
| 6. Is there anything else you would like to share about your experiences of nursing care in the community? |
Findings

Twenty-three participants contacted the research team and agreed to be interviewed (see Table 2—participant characteristics). The research team agreed that this number of interviews achieved a level of “information power” which provided enough rich, contextual data that met the aims of the study.

Most participants were caring for parents (n = 10) or a spouse (n = 7). Most of the deceased were aged over 65 years at the time of death (n = 17). In terms of primary diagnosis, 10 of the deceased had cancer and 13 had a non-cancer diagnosis.

Thematic analysis of the data identified two key themes and a number of sub-themes

1. Perceptions of nursing roles and services
   a. Physical nursing: experiences of district nursing
   b. Talking service: experiences of hospice nursing
   c. “Did not expect her to come to the house”: experiences of general practice nursing

2. Experiences of integrated nursing services

The first theme was related to participants’ perceptions of the role of different nursing services in terms of care provision. The second theme focused on the differences and similarities across nursing services and participants’ experiences of service integration.

Theme 1: Perceptions of nursing roles and services

Physical nursing: participants’ experiences of district nursing

When asked about experiences of care provided by district nurses, most participants described the technical tasks district nurses undertook, such as ulcer dressings, administration of injections or catheter cares.

When you look at it the (district) nurses actually didn’t have a big part in Mum’s care. Because the only time was when we got the district nurse if the catheter blocked. (#20)

These technical nursing tasks were often referred to as “actual nursing” or “physical nursing.” If the family member did not need this type of care, then participants did not expect district nursing to be involved.

I think the District Nurse might have come once. But he didn’t require, at that stage he didn’t require any physical nursing care. Like there was the odd, the skin stuff starting but it hadn’t broken to anything serious enough to require that kind of district nursing care. (#3)

The task-focused nature of the district nurse’s approach was problematic for some participants. For example, one participant described how when the district nurses focused solely on dressing her father’s leg ulcers and did not appear to notice his worsening cognitive state.

I suppose, like when you’re visiting somebody like that, an elderly man that lives by himself, it’s about looking at the whole person and ringing the bell if there’s a problem. Like if she’s come to dress his legs, but he’s not as coherent as he normally is or whatever, they need to, and I know that also is hard, but you need to stop and say, ‘Well who am I visiting, what was he like last time?’ (#4)

However, most participants valued the care district nurses provided, describing them as having the technical skills and knowledge required to facilitate quality care whilst also educating and involving them in the care. For example, one participant described how the district nurses shared their knowledge and skills providing advice to family on caring for his mother’s chronic leg ulcers.

So, I was very impressed with their technical skills set and their ability to, what would you call it, to keep exploring possibilities. So, we ended up, I ended up quite an expert on creams, with the urea, the hydrocortisone, the, all the other technical names which I’ve forgotten now. (#20)

A talking service: participants experiences of hospice nurses

In contrast, when participants were asked about their experiences of hospice nurses, most described support which was underpinned by talking and conversation.

Well, they really just talked to her. Really, they didn’t provide any services, you know. . . (#12)

Hospice nurses were identified by some participants as having a role in support with pain management which
included conversations about the pain as well as practical things such as adjusting medications, advice about prescriptions and administering medication.

Well yeah the opportunity for him to, to talk about pain and, and to get advice and at times some prescriptions around adjusting medication. That in a sense was the main thing. (#16)

Other participants described the benefits of hospice nurses being skilled communicators and having a willingness to talk openly about death and dying. One participant reflected on how her mother and extended family saw hospice as a service for “dying people” and that this belief created an opportunity to talk openly with their family about preparing for the death of their mother.

But, yeah, they came quite early on when we were only just sort of coming, like, really acknowledging that she wasn’t gonna live forever, you know. We knew that she had cancer and that, but we weren’t really talking about that, yeah, her funeral and things like that. We weren’t talking about things like that. But then hospice came and that was actually sort of helpful because it was, like, acknowledging that, yeah, you know, she was getting near the end of her treatment. Yeah. And good to see, it was like her acknowledging it, as well, because we hadn’t talked about that sort of thing. (#10)

Some participants talked about how hospice nurses supported them in preparation for, and care around, the time of death. Conversations and providing written information about what to expect when someone was dying was a valued part of having hospice nurses visiting.

Yeah, and they also explained, they were really good. Like, they said, you know, this is what’s happening now and they said, you know, now she’s gone. And they said, before she went, they said, you know, you should bring your dad in now. So that was really good because they’d obviously seen it before and I hadn’t and I didn’t know, you know, whether she still had, you know, 24 hours. But they were able to see that was the time that we needed to be with her especially, you know? (#10)

However, for some participants the “talking service” provided by hospice nurses was not needed. One participant described how her husband did not appreciate being asked about his feelings and went on to explain that the emotional support he needed was being provided by friends and family and was not required from the hospice nurse.

And, and, you know he, he wasn’t rude to her, but he didn’t sort of appreciate that stuff about tell me how you’re feeling. And what about this feeling, and that feeling, and whatever. Because the, you know because he got a lot of emotional support, not only from me, you know but from his close friends really. So, you know I guess a person who might be living by themselves, or whatever, might be really appreciative of that sort of approach. But it, it wasn’t, it wasn’t necessary for him. (#16)

Conversely, other participants had unmet expectations about the type of emotional support they would get from the hospice nurses. For example, one participant described how when she expressed concerns about her mother, the hospice nurse was unable to help.

I said to her, I’m really concerned about my mum. And she said, well, she said, I’m here to see your father, he’s the one who’s sick. And she was quite, yeah, she was quite. I was surprised because the hospice nurses that I’ve dealt with in the past have never been like that. I’ve always believed that it was the whole family that they took after, looked after, a holistic point of view. (#6)

Another participant described how he expected the hospice nurse would inquire after his emotional wellbeing while he was caring for his dying wife but that this never occurred despite a relatively long illness.

I don’t recall ever speaking to the nurses myself. Yeah. I was sort of anticipating that they would say, look, how was I doing, and how was the, you know, her progress or care, or whatever, you know, happening from my perspective. But I don’t recall ever being asked that and essentially, the contact between the hospice nurses and my wife were really conducted between them. (#9)

“Did not expect her to come to the house”: experiences of general practice nursing

Most participants disclosed that they had little input from the general practice nurses. When asked specifically about their experiences of practice nurses, many participants responded in reference to their general practitioner rather than the practice nurse.

And during this time did you have any contact with the practice nurses at the GP clinic?

No, my stepfather’s GP is a sole medical practitioner in a GP service, and no. (#3)

Well, no not really. He went to the GP because he needed to change his will and the GP had to write a letter saying, you know, he was in a good state of mind. And, no, the GP only made one visit, I think, one home visit. (#14)

However, a small number of participants had very positive experiences with their practice nurses. This was often associated with having a long-standing relationship with the practice. One participant described her father’s familiarity with the practice staff and how this meant her father received the support he needed.

. . . he’d been there forever, so you know, yeah, he was a bit like the furniture, used to walk in like he owned the place. . . . and she just handled him so beautifully and he always walked away feeling six foot tall and bullet proof and would do whatever she said. (#22)
For other participants, a positive relationship with the practice team which included the reception staff, was helpful for their family member. The relationship validated their role as a carer as the team acknowledged and acted upon their concerns.

I found the way that her GP and his practice were really good, really helpful and hurried things up. And really took her seriously. I mean, she’d been going there forever, so they all, they knew her. Yeah. They were good, and helpful to me, too, cause I used to ring up and ask about things. And they would help in terms of if I noticed something or whether I should bring her in or that sort of thing. (#8)

However, for most participants, contact with practice nurses was limited to requests for help with prescriptions or medicines rather than specifically related to palliative care.

I’d ring her up sometimes just to ask her something, you know, like Mum had diabetes and she was insulin dependent, and it had got to the point where, she did, she’d inject herself for a long time and then as she got older I started to dial up the pen so that it didn’t leave it totally in her care. Sometimes I had to ring Joyce (the practice nurse) and have a chat, but that was all, yeah, not a lot. But in terms of anything to do with appointments or, you know, prescriptions or just a little bit of advice if I needed it. (#1)

Indeed, most participants had few expectations of the practice nurse to provide care in the last year of life.

Well, the practice nurse, she sort of had a full time job. So, I never expected her to, you know, to come to the house or anything like that. (#1)

2. Experiences of integrated nursing services

There was little evidence of nursing services being well integrated and working together. Indeed, the way in which various nursing services were described by all participants suggested a strong belief that each service had a very specific role.

And that was that, you know, it was the relationship thing that was more important for George because he didn’t require physical nursing care. What he needed and got from the hospice nurses was advice in terms of managing pain. (#3)

When services came together this was problematic for some participants. For example, one participant described contacting the hospice nurse for help. When the district nurse and hospice nurse arrived at the same time there were disagreements about the plan of care which was interpreted by the participant as a “power struggle.”

I phoned the hospice nurses because they were the ones he had a relationship with, not the community district nurse. One came, a nurse came, but also at the same time the district nurse arrived, and I have to say there was a really unfortunate little power struggle going on between both nurses as to whose views should be adhered to. (#3)

Similarly, some participants found the delineation of roles confusing. One participant described frustration at the lack of clarity around which nursing service should have attended to his mother’s leaking urinary catheter.

I know once her urine bag, what do you call that, overflowed. Catheter, yeah, so that overflowed when I think the hospice people should’ve changed it. But the care assistant, they also did that sort of thing. So, I mean, we didn’t, we didn’t sort of get angry when things like that happened ‘cause it’s just really, it was hard. (#10)

Some participants described nurses working in service silos with little communication between each other.

I would take him in to see his GP but the GP, I think he was in touch on the phone with the hospice nurses. But he didn’t, I think he sort of turned Dad over to the hospice care, as far as medication and that sort of thing went. So, he stopped going to the practice after a while. . . (#6)

Some participants experienced confusion about who was visiting and what they were there to provide.

So, and we didn’t, like, people would arrive, because we also had the nurses

from the agency, well, not nurses, sorry, the carers. And sometimes you’d have, like, people would come and we wouldn’t know where they were from. So that was something, I did talk to my sister before this call, as well, and said did she have any sort of feedback to share. But we both found that people would come into the house, and I don’t know if they didn’t have, like, they could’ve had badges on or something so that we actually knew exactly where they were from? (#10)

What did good nursing care look like?

Many participants discussed the importance of continuity and timing of visits across all nursing services. For example, one participant described how when district nurses communicated with them about their arrival times the experience was more positive, and family felt secure in the care that was being provided.

Well, they were always prompt, they always rang before they came. And if they were running late, they rang. You know, we weren’t sort of having to sit around and wait for them or anything like, they just had, they just seemed to have it in hand that they knew what they were doing and what their responsibilities were. And where they were going and what they were doing. (#12)

The way in which visiting nurses interacted with participants and their ill family member was an important factor
in establishing effective relationships. One participant described a negative experience with the district nurse which she put down to a “personality thing.” Her father had already established a good relationship with the hospice nurse early on in his illness and this was an important factor in deciding who to call when he needed help.

But also disadvantaged by the fact that in a sense there was, she [district nurse] didn’t have the relationship with him because the first relationship he [her father] had established, was with the Hospice nurses. And that was that, you know, it was the relationship thing that was more important for him because he didn’t require physical nursing care. What he needed and got from the Hospice nurses was advice in terms of managing pain. (#3)

Most participants described good experiences of care across all nursing services. The most positive experiences were characterized by a well-established relationship or connection between the nurse and the family member.

Apart from probably towards the end the consistency of the same person coming, so that they knew him and they knew how to handle him, he could be quite grumpy (laugh), and respond to him well. And he saw them as part of his wider family I suppose. (#4)

**Discussion**

Previous studies related to the role of community nurses in palliative care have largely focused on district nurses’ experiences of providing care for people at the end of life. To the best of the authors’ knowledge, this study is the first of its kind to explore bereaved families’ experiences of a range of community nursing services in palliative care. Findings show that bereaved families have diverse experiences that are dependent on the service involved. District nurses were seen as providers of nursing tasks and physical care while hospice nurses were described in terms of conversations and advice. In addition, families’ experiences of general practice nurses in relation to palliative care was limited to telephone advice, usually regarding medications and accessing prescriptions. Arguably, this differentiation between nursing services in the way palliative care is provided does not align well with a holistic approach to palliative care that attends to the physical, emotional, psychosocial and spiritual domains of a person.

General practice is increasingly being seen as an interprofessional team of health care professionals responsible for leading the care for people living in the community with a life-limiting illness. In this study, care from practice nurses was largely limited to telephone advice however this was positively received by most participants. Evidence has shown high patient satisfaction in the care received from practice nurses, particularly in chronic disease management. However, findings from this study highlighted that bereaved families had little expectation of the practice nurse providing palliative care at home. A recent systematic literature review exploring the role of general practice teams in end of life care from the perspectives of patients and families found that although they valued a multidisciplinary approach to care, there was no reference to the general practice nurse in any of the studies included in the review. This gap in the evidence indicates that the role of the general practice nurse requires further research attention.

Findings from this study show that district nurses work focused on technical nursing tasks, such as administration of medications, ulcer dressings and catheter cares. Difficulties in moving beyond the nursing task at hand has been explained by the way in which busyness and efficiency is measured in district nursing. For example, busyness attached to a task which only a district nurse can provide such as a wound dressing, is valued more in terms of efficiency compared to other aspects of district nursing care such as psychological support or “befriending.” In addition, evidence has shown that patients and carers knowledge of district nursing is limited to physical care of patients and that this knowledge does not develop beyond what is provided. This limited knowledge of what a district nurse can provide is considered a barrier to requesting care beyond the physical task, such as psychological and emotional support. Indeed, such task-based nursing which is focused solely on physical care continues to be identified as a potential barrier to providing patient centered care. Furthermore, concentrating solely on physical tasks does not align well with the philosophy of palliative care or nursing care, more broadly. However, participants in the current study perceived these nursing tasks as “actual” nursing care and valued them, particularly when they were carried out with kindness and empathy.

In contrast to what might be considered a time limited, task focused district nursing service, hospice nurses prioritize the time required to provide holistic care for people living with a life limiting illness. Advanced communication skills are an essential skill for hospice nurses to support people as they prepare for death and bereavement. Examples from this study have demonstrated the value bereaved family place on hospice nurses having sensitive conversations with patients and family about issues related to end-of-life care.

Whilst, evidence has shown there are significant benefits of hospice support for people with a life limiting illness and their families, there are also ongoing concerns about persistent inequities in the provision of hospice care. The oldest old, some ethnic groups and those living in rural or deprives areas continue to be under represented in referrals to hospice. Furthermore, factors such as an aging population and people living longer with
incurable illness means that hospice resources will out-
strip demand if other nursing services are not supported
to provide good end of life care.28

Findings from this study also suggests that the hospice
nurse may need to rely on other nursing services in order
to meet the physical needs of patients. Conversely, dis-
trict nurses may require the support of hospice nurses in
terms of complex symptom management and difficult
conversations related to death and dying. Finally, the role
of the general practice nurse and how they might work
together with other nursing services has not been well
explored in the palliative care literature. Various
approaches have been identified to improve service inte-
gration including proactive communication and role
negotiation between specialist and generalist palliative
care clinicians.29 However, the evidence suggests there is
no one size fits all model. Furthermore, in order to
achieve seamless care involving multiple providers of pal-
liative care, services must work in partnership at all levels
of an organization including administrative, organiza-
tional and clinical.30

Findings from this study provided evidence of compas-
sonate person-centered care across all three nursing ser-
vices. However, the lack of integration in how services
worked together, impacted negatively on families experi-
ences. A systematic review of the literature showed that
when care is well integrated, there is a perceived improve-
ment in the quality of care, increased patient satisfaction
and improved access to care.31 However, the complexity of
healthcare systems makes service integration challenging32
and this may be compounded by the model of specialist-
generalist palliative care adopted in many countries.

The involvement in end of life care of non-government
organizations, such as hospice, and government funded
services, such as district nursing and general practice, can
result in role confusion, inequitable resourcing and power
struggles that inhibit effective collaboration.33 However, it
has been argued that effective inter-professional inte-
gration can be achieved when there is a shared mission
between services, along with a focus on redesign at a ser-
vice level rather than at an organizational level.34

Overall, findings from this study suggest that experi-
ences of community palliative care nursing are dependent
on the service and role of the nurse. Whilst one would
expect there to be differences between generalist and
specialist palliative care nursing care, this study has high-
lighted an inequity in the type of palliative care people
receive which is dependent on the nursing service they
receive. For example, with an increasing demand for spe-
cialist palliative care services combined with a limitation
in available resources1 there is a risk that the care pro-
vided by hospice nurses may not be available to everyone.
Similarly, the task focused approach of district nursing
along with an increasing volume of work32 may limit their
ability to prioritize a patient-centered approach.

Strengths and limitations

Key strengths of this study are that data was collected
from family who had a lived experience of caring for
someone at home at the end of life and were supported
by a range of different nursing services. However, there
are some limitations to the study which need to be
acknowledged. Firstly, the study was located in two
District Health Boards in a large urban area of New
Zealand. There is local, national and international vari-
ation in how community nursing services are provided
which may limit the generalizability of the study findings.
However, similar configurations of community nursing
services are evident in other healthcare systems.35,36

Finally, the COVID-19 related countrywide lockdown
meant that telephone interviews needed to be used to
collect data which may have impacted on the quality of
the data. However evidence12 suggests that for many par-
ticipants’ telephone interviews provide an opportunity to
be more engaged with the interviewer particularly when
discussing sensitive topics.

Conclusion

Findings from this study support the need for a new inte-
grated model of palliative care nursing which utilizes the
unique skill set of nurses working across all community
care settings including general practice, hospice and dis-
trict nursing services. This is particularly important given
that for most nurses, palliative care is only one compo-
nent of their overall workload. Further research is needed
to understand how nursing services can be supported to
work better together across the generalist-specialist com-
unity care continuum. Healthcare policy needs to be
flexible in accommodating different models of nursing
care which can be responsive to patient need rather than
limited to a defined service delivery model.

Author contributions

JR, MG, LW, and JP were involved in the study design and
secured funding for this project. RI was involved in identifi-
ing eligible participants and HG carried out the data collection. JR,
MG, LW, NA, and HG were involved in the analysis and interpre-
tation of data. All authors were involved in writing the paper
including revisions and approval of the final version.

Data management and sharing

To protect participants privacy, no original data can be released
however supplementary material may be provided on contact-
ing the lead author.

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