What does palliative care look like in a New Zealand aged residential care facility when patients are admitted to die?

Eileen M McKinlay, Serena V Moran, Sonya J Morgan, Pakize Sari, Jill M Kerridge, Susan RH Pullon

ABSTRACT

AIMS: New Zealanders dying in public hospitals or hospices are increasingly being discharged and admitted-to-die in aged residential care (ARC) facilities as hospitals and hospices struggle to meet demand. This study sought to investigate how care is delivered to patients admitted-to-die in an ARC facility.

METHODS: A mixed-methods case study including a clinical notes review of seven patients who died in one ARC facility within three months of admission and a focus group with ARC facility staff and visiting professionals from other organisations.

RESULTS: The clinical notes review showed a high burden of palliative care symptoms that constituted specialist palliative care, provided by ARC staff plus professionals from other organisations. Focus group data showed those involved were willing, but expressed significant concern about lack of structure and funding.

CONCLUSIONS: As our increasing and aging population reaches end-of-life, New Zealand hospitals/hospices will not be able to provide ongoing specialist palliative care and admission-to-die in ARC facilities may be a viable alternative. However, ARC facilities are not set up or staffed to provide specialist palliative care of those admitted-to-die. A specific model of care that is funded appropriately is required.
and 24.3% are admitted for the first time in the last three months of life” (p. 6). The study also shows that generally more people die in ARC facilities with chronic illnesses and dementia than from cancer, however those admitted in the last three months of life have a different illness/disease profile, with 15.9% dying from dementia, 24.0% from chronic disease and 63.0% from cancer. The Boyd et al 2019 study shows people in ARC in the last week of life with chronic illness, dementia or cancer have a similarly high symptom burden as those in other settings, and those with chronic illness or dementia have symptoms for longer than those with cancer.10

The Ministry of Health (MoH) Healthy Aging policy calls for “flexible aged residential care services that suit the needs of the increasingly diverse older population” (p. 37).11 This includes the provision of palliative care for ARC residents as they eventually reach end-of-life, and this has been accepted practice in ARC facilities for many years. The policy advocates for palliative care from a “primary healthcare workforce... trained in core palliative care practices,... to meet people's palliative care needs... (with a) specialist palliative care workforce to provide specialist clinical care”. The distinction between primary (generalist) and specialist palliative care providers has been defined and re-defined over the years, suggesting either an evolving service delivery model or difficulty in reaching agreement.12–14 However, there seems agreement that patients admitted to public hospitals and hospices with palliative care needs require specialist palliative care and those cared for in other settings require primary (generalist) palliative care. However, it is unclear what level of care people with complex palliative care needs require when discharged to-die, from public hospitals or hospices into ARC facilities.

Introducing significant numbers of imminently dying patients with complex palliative care needs from hospital and hospices into the ARC environment is problematic as staffing levels differ between hospitals, hospices and ARC facilities. In New Zealand, the Health and Disability Services (Safety) Act (2001)15 and the Health and Disability Service Standards (2008)16 specify minimum requirements for the staffing of public hospitals and ARC facilities. Boyd et al reported in 2009 that registered nurse staffing levels in ARC facilities, although compliant, were low7 and this finding has been subsequently supported.8,17,18 The current ARC staffing model (predominantly caregivers with few registered or enrolled nurses and various models of contracted medical care)17 does not easily allow for the increased acuity of and rapidly changing needs of people admitted-to-die with complex palliative care needs.10 These people often need ready access at short notice (including after-hours) to an advanced range of skills, equipment and services beyond the level of care that ARC facilities are set up or currently funded to provide.19,20

In New Zealand, people are usually financially and asset assessed for entry to ARC and those with reduced incomes and minimal assets are eligible for publicly funded care.14 Some district health boards (DHBs) have non-asset tested funding available for people with limited prognosis being admitted-to-die in an ARC facility but other DHBs do not have this and assess those admitted-to-die by the same needs assessment criteria as for age-related need,21 meaning they have to pay for palliative care. In all, ARC facilities now have an increasingly ambiguous role in palliative care provision with some calling them “de facto hospices”.4 They are now asked to admit the imminently dying, from hospital or hospice,9 as well as providing their core business; the 24-hour residential home-for-life care of older adults.16 This rapidly changing situation has had remarkably little investigation, either in New Zealand or elsewhere. Given deaths are projected to rise in New Zealand from around 30,000 a year to 55,500 a year by 206813,22 and the need for palliative care has been estimated to be required for over 80% of deaths in 2038, it is essential to explore and determine how specialist palliative care is to be delivered in ARC if it cannot be provided in public hospitals or hospices.23

This study sought to describe the features and clinical care of a purposive sample of patients admitted-to-die in a single ARC facility.
Methods

Design and setting

A single-case study (one ARC facility) with embedded cases (seven deceased people), using multiple data collection methods was used to generate an in-depth account. Case study research was considered the most suitable approach with each ‘case’ serving as a sub-unit of analysis, thus allowing for naturally occurring/real-life cases to be explored individually, and for comparisons to be made between and across cases.

The ARC facility chosen for the study (a 150-bed facility run by a charitable trust offering rest home, hospital and dementia-level care) was selected as a recognised provider of high-quality aged residential care and palliative care, and often approached by the public hospital and hospice to admit those who are dying. By studying the delivery of palliative care for those admitted-to-die in an ARC facility with an already good reputation, the features of care provided, including strengths/enablers and barriers could be closely examined.

Ethical approval to undertake the study was granted by the University of Otago Ethics Committee (HD17/071).

Participants and data collection

Data collection (between 21 March and 22 August 2018) occurred in three phases (see Figure 1). Phase one: the background issues were initially informed by views from ARC staff and relevant hospice and DHB staff, as identified by the ARC facility. This took the form of an initial information gathering, 1.5 hour, audio-recorded discussion group with ARC facility staff and staff from external organisations and a subsequent one-hour audio-recorded individual interview with the ARC general manager.

Phase two: a retrospective clinical notes review was undertaken of seven deceased people who had been admitted-to-die. A purposive sampling method guided the selection of cases with ARC facility staff asked to identify those admitted in 2017 who met the following criteria: 1) specifically admitted-to-die in the ARC facility from either a public hospital or hospice and died within three months of admission and 2) required care in the ARC facility from at least one professional external to the ARC facility, such as DHB health professionals, contracted health professionals and/or hospice nurses and doctors (this thus meeting the definition for specialist palliative care). Admission from a public hospital or hospice where the person had received palliative care and the ongoing need for interprofessional care in an ARC facility from more than one organisation signalled that the case required specialist palliative care.

The ARC staff were given the inclusion criteria and they selected all charts which met the criteria, identifying the cases admitted-to-die from hospital and hospice discharge summaries. The 12 sets of clinical notes were de-identified and copies provided to researchers so that they had no access to patient identifying information. The notes of the cases were reviewed by EM and SVM and data extracted according to a template developed by the researchers and informed by the literature, the first discussion group and individual interview. Information collected included: demographic and illness information; symptoms and day-to-day progression/deterioration, details of the clinical care and medicines given, who provided care and what input they had, details about the response to care and treatment. The template was tested with the first set of clinical records, and the categories and template were refined to include the most relevant information.

Using a diversity sampling framework, seven cases (58%) were selected to include those over and under 65 years, varying lengths of time from admission to death, different ethnicities and varying involvement by external professionals. An overview is presented in Table 1.

Of the seven, two were purposively selected as best representing issues identified across all the cases (including one over and one under 65 years old) and having clinical details which would not be recognised. The cases were considered by the research team members from the ARC facility as being mid-range complexity.

Phase three: an audio-recorded, 1.5-hour focus group with ARC facility and external professionals involved in the care of one or both of the two selected cases to allow more in-depth exploration of issues impacting the delivery of palliative care to this group of people (Table 2).
A single semi-structured focus group question guide informed by the literature, the first discussion group and individual interview was developed by the research team and covered the following topics: who, when and how does each professional contribute to the care of those admitted-to-die; perceptions of this form of collaborative care; and what enables or acts as barriers to successful collaboration between services/professionals/organizations when patients are admitted-to-die. The focus group was jointly facilitated by EM and SP who are clinicians by background and have worked in palliative care delivery.

Discussion group and focus group participants were sent study information when initially invited to participate and they signed consent forms prior to taking part. The Otago University ethics committee considered the retrospective clinical notes review to be a review/audit of de-identified deceased patient records and given likely distress raised by approaching whānau (Māori word for family group—Māori are the indigenous ethnicity in New Zealand) determined that whānau consent should not be requested.

### Table 1: Overview of the seven cases included in the clinical notes review.

| Gender | 4 females, 3 males |
| Age | 5 over 65 years, 2 under 65 years |
| Ethnicity | 3 NZ European, 2 Māori, 1 British and 1 unreported |
| Time from admission to death | 1 under 2 weeks, 3 between 2–4 weeks, 2 between 4–6 weeks, 1 over 6 weeks |
| Number of professionals external to the ARC facility involved | 3 under 3 external professionals involved, 4 over 3 external professionals involved |
| Multimorbidities (MM) (including palliative care symptoms) | arthritis, ascites, asthma, bipolar disorder, borderline personality disorder, cachexia, cataracts, diabetes, faecal incontinence, ‘falls’, Gilbert’s Syndrome, gout, hepatitis C, hyperlipidaemia, hyperparathyroidism, hypertension, hypothyroidism, ischaemic heart disease, renal failure, schizophrenia, scoliosis, substance abuse |

### Table 2: Focus group participants involved in the care of one or both selected cases.

| ARC facility staff | 1 Clinical Manager, 2 Registered Nurses, 1 Caregiver, 2 GPs¹ |
| Professionals external to the ARC facility | Hospice: 1 Former Hospice ARC liaison nurse², 2 Doctors³ (1 a former ARC GP), DHB: 1 DHB ORA liaison nurse⁴, Contracted private professionals: 1 Physiotherapist, 1 Podiatrist |

¹This ARC contracts GPs to provide medical services and considers them to be staff.¹⁷
²Hospice ARC liaison nurses are employed by hospices to provide consultancy services to ARCs for patients with palliative care needs. Funded by MoH Innovations Funds.²⁸
³Hospice doctors provide phone consultancy services to ARC staff (including phoning ARC GPs when not on site) for patients with palliative care needs. They sometimes visit patients in ARC facilities.
⁴DHB ORA liaison nurse: a liaison nurse from the DHB Older Adult Rehabilitation & Allied Health Services.
Data analysis

Analysis of data proceeded sequentially and iteratively (Figure 1), utilising case study method which emphasises the importance of the cases being examined in their real-world context. Case selection is undertaken according to the purpose and theoretical interest of the research. In the study this was initially informed by the preliminary discussion group and individual interview and following case data extraction and summarisation, discussed in an interprofessional, interorganisational focus group. An inductive thematic process guided the analysis of all the transcribed qualitative data with transcripts first coded by one researcher (EM) and then peer-reviewed by another (SJM) and inconsistencies or alternative views resolved. Analysis of the first group discussion and individual interview informed development of the clinical notes data extraction template, which was refined after testing with the first set of clinical records. Two researchers (SVM & EM) extracted data for the first three cases, with SVM extracting data for the remaining

Figure 1: Data collection and analysis sequence.

1ARC staff included nurses, caregivers, diversional therapists, spiritual care provider, general practitioner, clinical manager, general manager.
2External professionals included: Professionals from external agencies: hospice professionals (former ARC liaison nurse and palliative medicine specialist doctor); DHB professionals (speech language therapist, Older Adult Rehabilitation & Allied Health Services (ORA) liaison nurse; Private contracted professionals (community pharmacist, community physiotherapist).
### Table 3: The seven cases.

<table>
<thead>
<tr>
<th>Case</th>
<th>Age range</th>
<th>Time: admission to death</th>
<th>Diagnoses &amp; number of multimorbidities (MM)</th>
<th>Admitted from</th>
<th>Reason for admission (as recorded in the hospital and hospice discharge summaries)</th>
<th>Enduring Power of Attorney (EPOA)</th>
<th>Advance Care Plan (ACP)</th>
<th>Public hospital admissions since ARC admission</th>
<th>Professionals involved: external organisations or private contractors (external professionals)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>70–75 yrs</td>
<td>39 days</td>
<td>Renal failure + 5 MM</td>
<td>Public hospital</td>
<td>Needed a higher level of care</td>
<td>No (NFR(^1) in hospital discharge plan)</td>
<td>DHB outpatients</td>
<td>DHB: renal, plastics, dental Hospice: ARC liaison nurse(^2) 3 doctors(^3), &amp; social worker</td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>85–90 yrs</td>
<td>27 days</td>
<td>Metastatic cancer + 4 MM</td>
<td>Home</td>
<td>Increasing abdominal pain &amp; whānau concern</td>
<td>No</td>
<td>Yes</td>
<td>0</td>
<td>DHB: district nurse Hospice: 2 ARC liaison nurses Reflexologist</td>
</tr>
<tr>
<td>C</td>
<td>55–60 yrs</td>
<td>86 days</td>
<td>Metastatic cancer + 9 MM</td>
<td>Public hospital</td>
<td>Ongoing care</td>
<td>Yes</td>
<td>Yes (3 days before death)</td>
<td>2</td>
<td>DHB: ORA liaison nurse(^4) &amp; oncologist Hospice: ARC liaison nurse &amp; doctor Physiotherapist Podiatrist</td>
</tr>
<tr>
<td>D</td>
<td>85–90 yrs</td>
<td>10 days</td>
<td>Unconfirmed metastatic cancer (late presentation); breast cancer + 3 MM</td>
<td>Public hospital</td>
<td>Ongoing care during admission</td>
<td>Not recorded</td>
<td>0</td>
<td>Hospice: ARC liaison nurse</td>
<td>Physiotherapist</td>
</tr>
<tr>
<td>E</td>
<td>75–80 yrs</td>
<td>21 days</td>
<td>Metastatic cancer + 2 MM</td>
<td>Hospice</td>
<td>Respite &amp; symptom control</td>
<td>Yes</td>
<td>Not recorded</td>
<td>0</td>
<td>Hospice: district nurse Hospice: ARC liaison nurse</td>
</tr>
<tr>
<td>F</td>
<td>50–55 yrs</td>
<td>23 days</td>
<td>Metastatic cancer + 2 MM</td>
<td>Hospice</td>
<td>Not able to cope at home</td>
<td>Not known until just prior to death</td>
<td>Not recorded</td>
<td>0</td>
<td>DHB: mental health nurse &amp; mental health worker Hospice: ARC liaison nurse &amp; doctor</td>
</tr>
<tr>
<td>G</td>
<td>85–90 yrs</td>
<td>35 days</td>
<td>Unconfirmed metastatic cancer (late presentation) + 4 MM</td>
<td>Another ARC facility</td>
<td>To be closer to whānau</td>
<td>No</td>
<td>For active treatment as per whānau wishes. No personal ACP recorded</td>
<td>2</td>
<td>DHB: ‘CAREful Team’(^5) for frail elderly</td>
</tr>
</tbody>
</table>

\(^1\)Not for resuscitation.  
\(^2\)Hospice ARC liaison nurses are employed by hospices to provide consultancy services to ARCs for patients with palliative care needs. Funded by MoH Innovations Funds.  
\(^3\)Hospice doctors provide phone consultancy services to ARC staff (including phoning ARC GPs when not on site) for patients with palliative care needs. They sometimes visit patients in ARC facilities.  
\(^4\)DHB ORA liaison nurse: a liaison nurse from the DHB Older Adult Rehabilitation & Allied Health Services.  
\(^5\)The DHB CAREful team (Caring for the At-Risk Elderly person who is Frail) is a specialist interdisciplinary team for the frail elderly.
four cases. A clinical case summary was produced for each case and each was discussed by the research team, with two cases chosen as representative. Analysis of the focus group data determined case-specific themes. In the final stage of analysis all data for the case study was reviewed, triangulated, integrated and synthesised and a summary of key issues identified.

Results

Background interviews
The initial individual interview with the general manager and a discussion group interview with interorganisational staff determined the key issues to include in the data extraction template.

Clinical notes review
The clinical notes included: day-to-day nursing records per eight-hour shift by ARC facility nursing and caregiving staff; separate records for: ARC divisonal therapy and some external professionals (medical progress notes and visiting therapist records); letters from some external professionals. The private contracted physiotherapist and hospice doctors or liaison nurses wrote in either or both of the day-to-day nursing records and the medical progress notes—or interchangeably. This was not uniform, making information hard to find. The day-to-day nursing records by ARC staff detailed the physical symptoms, less so the psychosocial, existential or cultural symptoms/needs and even less the needs of whānau. In situations where symptoms were challenging or poorly controlled or distress was evident (person and/or whānau), it was not unusual for there to be several pages of notes relating to one 24-hour period. In these instances the Clinical Manager often recorded her input (including from extra visits she made in the weekend or after-hours).

Key details of the seven cases (Table 3) and the day-to-day records of the two typical cases are presented in Tables 4 and 5.

Views of ARC staff and external professionals of the care of specific cases admitted-to-die in ARC
Analysis of the data from a focus group with ARC staff and external professionals revealed five key themes:

Willing—‘but’…
Both ARC staff and external professionals were willing to provide care, however they qualified their willingness with a ‘but’. This qualification was a response to several barriers: lack of time associated with ARC funding limitations; no leader/key worker to provide continuity/liaison/coordination; lack of shared electronic records and no structure or funding to plan proactive care for those admitted-to-die.

“in the afternoon it's very difficult, sometimes you get three palliative cases, they all have syringe drivers; three syringe drivers to be monitored by one nurse. And sometimes one syringe driver plays up and sometimes the other syringe driver needs to be recalibrated. That's already three patients and how about my 30 patients who need their regular medications. And family members visit in the afternoon waiting for you. And you want to sit with this patient who is actually dying…”

(ARC RN 1)

“It's the resource thing... families [think]... hospice and hospital are free... I... say to them... the hospital gets $2,000 a day for a bed... [but] ARC gets $130 and they are supposed to provide the same level of care.”

(ARC GP 2)

Environment and resident-mix mismatch
Meeting the needs of both the over-65 years and the under-65 years was challenging. Those under 65 years were often disenfranchised from whānau or had complex psychosocial needs. The ARC facility physical layout did not suit complex palliative care for either under- or over-65 year-old patients so as to enable close but private monitoring of patients and space for family to visit, but with seclusion from older adults who call-out or exhibit wandering behaviours.

“...[he] was very complex for an aged care facility because he’s got a lot of psychosocial issues... he has got some possibly mental health issues that our caregivers are not trained to deal with and even ourselves who are so used to dealing with older people all of a sudden the younger person with different needs mental health needs, physical... And... he was having severe pain and looking at the physical, the psychosocial, he must be having a bad time, with all that pain.”

(ARC RN 2)
Table 4: Case B clinical notes review: day-to-day palliative care delivery (over 65 years).

<table>
<thead>
<tr>
<th>Interprofessional cross organisational team meetings:</th>
<th>nil.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of/reasons for ARC GP visiting patients:</strong></td>
<td>x9 in 27 days (initial assessment of symptoms, ongoing assessment of pain, nausea and constipation). One recorded phone discussion between ARC staff and the GP.</td>
</tr>
<tr>
<td><strong>Number of/reasons for contact by professionals external to the ARC facility:</strong></td>
<td></td>
</tr>
<tr>
<td>DHB district nurse</td>
<td>x1 in 27 days (advice on timing of Fentanyl patches).</td>
</tr>
<tr>
<td>Hospice ARC liaison nurse</td>
<td>x3 in 27 days (review admission to ARC, management of pain and nausea, follow-up). One ARC request for advice from ARC liaison nurse in week 3 but not responded to.</td>
</tr>
<tr>
<td>Hospice doctor</td>
<td>x1 phone contact from Hospice ARC liaison nurse (discussion about use of anti-nausea medicine).</td>
</tr>
<tr>
<td>Reflexologist</td>
<td>x1 in 27 days.</td>
</tr>
<tr>
<td><strong>Regular medicines</strong> (list of all medicines prescribed over the 27 days—changes to combination and doses of medicines in this time): colecalciferol, cyclizine, docusate sodium with senna, domperidone, fentanyl (patches), metoprolol, omeprazole, ovestin, paracetamol, simethicone</td>
<td></td>
</tr>
<tr>
<td><strong>PRN medicines:</strong></td>
<td>x148 prns in 27 days clonazepam, cyclizine, docusate sodium with senna, hyoscine butylbromide, lactulose, midazolam, morphine sulphate injectable, morphine sulphate tablets</td>
</tr>
<tr>
<td><strong>PRN opiate analgesia given within last two weeks of life:</strong> morphine sulphate tablets x10 doses and subcutaneous morphine sulphate x18 bolus doses by indwelling subcutaneous needle.</td>
<td></td>
</tr>
<tr>
<td><strong>Syringe driver:</strong> started 24hrs before death.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Week 1</th>
<th>Week 2</th>
<th>Week 3</th>
<th>Week 4: (six days)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Main problems:</strong> pain, sacral tenderness, indigestion, blister on one leg, swallowing difficulties</td>
<td><strong>Main problems:</strong> pain, sacral pressure area, blisters on both legs, poor sleep</td>
<td><strong>Main problems:</strong> pain, pressure areas, leaking blisters, fatigue, nausea, vomiting, constipation, bloating</td>
<td><strong>Main problems:</strong> pain, several sacral pressure areas, many leaking leg blisters, nausea, low mood, agitation, anxiety, secretions, involuntary twitching</td>
</tr>
<tr>
<td><strong>Recorded instances of patient reported unrelieved symptoms or distress:</strong> x18</td>
<td><strong>Recorded instances of patient reported unrelieved symptoms or distress:</strong> x12</td>
<td><strong>Recorded instances of patient reported unrelieved symptoms or distress:</strong> x19</td>
<td><strong>Recorded instances of patient reported unrelieved symptoms or distress:</strong> x17</td>
</tr>
<tr>
<td><strong>Recorded instances of family/whānau reported distress:</strong> nil</td>
<td><strong>Recorded instances of family/whānau reported distress:</strong> nil</td>
<td><strong>Recorded instances of family/whānau reported distress:</strong> nil</td>
<td><strong>Recorded instances of family/whānau reported distress:</strong> x3</td>
</tr>
<tr>
<td><strong>Team involved:</strong> ARC facility professionals: care givers, GP, clinical manager, physiotherapy assistant, RNs</td>
<td><strong>Team involved:</strong> ARC facility professionals: care givers, GP, clinical manager, physiotherapy assistant, RNs</td>
<td><strong>Team involved:</strong> ARC facility professionals: care givers, GP, clinical manager, physiotherapy assistant, RNs</td>
<td><strong>Team involved:</strong> ARC facility professionals: care givers, GP, clinical manager, physiotherapy assistant, RNs</td>
</tr>
<tr>
<td><strong>External professionals:</strong> DHB district nurse, hospice ARC liaison nurse</td>
<td><strong>External professionals:</strong> reflexologist</td>
<td></td>
<td><strong>External professionals:</strong> Hospice ARC liaison nurse, hospice doctor</td>
</tr>
</tbody>
</table>
**Table 5:** Case C clinical notes review: day-to-day palliative care delivery (under 65 years).

<table>
<thead>
<tr>
<th>Interprofessional cross organisational team meetings: nil.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of/reasons for ARC GP visiting patients:</strong> x16 in 86 days (2 months 29 days) (initial assessment of symptoms, discussion of care with patient, changes in medication). Three recorded phone discussions between ARC staff and the GP.</td>
</tr>
<tr>
<td><strong>Number of/reasons for contact by professionals external to the ARC facility:</strong></td>
</tr>
<tr>
<td><strong>DHB ORA liaison nurse</strong> x5 in 3 months (transport to the public hospital and support at consultations, general support, discussed ACP).</td>
</tr>
<tr>
<td><strong>DHB Oncology specialist</strong> x3 in 3 months (reassessment).</td>
</tr>
<tr>
<td><strong>Physiotherapist</strong> x1 in 3 months (supply of pressure relieving mattress).</td>
</tr>
<tr>
<td><strong>Podiatrist</strong> x2 in 3 months (assessment and treatment of foot infection).</td>
</tr>
<tr>
<td><strong>Hospice ARC liaison nurse</strong> x4 in 3 months (assessment, management of pain and constipation, follow-up).</td>
</tr>
<tr>
<td><strong>Hospice doctor</strong> x2 in 3 months (assessment plus a verbal order for syringe driver medicines).</td>
</tr>
<tr>
<td><strong>Regular medicines</strong> (list of all medicines prescribed over the three months—changes to combination and doses of medicines in this time): amlodipine, budesonide, dexamethasone, docusate sodium with senna, gabapentin, gefitinib, glycerine, haloperidol, levitiracetam, lorazepam, macrogol 3350 plus electrolytes, metoclopramide, morphine sulphate injectable, morphine sulphate suspension, morphine sulphate sustained release, morphine sulphate tablets, omeprazole, ondansetron, paracetamol, sertraline.</td>
</tr>
<tr>
<td><strong>PRN Medicines:</strong> x89 prns in 3 months: aluminium—magnesium hydroxide, lorazepam, macrogol 3350 plus electrolytes, morphine sulphate tablets, salbutamol</td>
</tr>
<tr>
<td><strong>PRN opiate analgesia given within last 2 weeks of life:</strong> x14 doses of morphine sulphate tablets additional to regular oral opiate.</td>
</tr>
<tr>
<td><strong>Syringe driver:</strong> started 24hrs before death.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Month 1</th>
<th>Month 2</th>
<th>Month 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Main problems:</strong> pain, constipation, ‘declining’ medication (analgesia and/or laxatives), behavioural issues, mood instability</td>
<td><strong>Main problems:</strong> ‘declining’ medication, pain, constipation, managing anxiolytic intake, behavioural support, mood instability, skin breakdown on foot</td>
<td><strong>Main problems:</strong> pain, constipation, skin breakdown on foot, anxiolytic intake, behavioural support, mood instability, poor mobility and unstable</td>
</tr>
<tr>
<td><strong>Recorded instances of patient reported unrelieved symptoms or distress:</strong> x15</td>
<td><strong>Recorded instances of patient reported unrelieved symptoms or distress:</strong> x6</td>
<td><strong>Recorded instances of patient reported unrelieved symptoms or distress:</strong> x33</td>
</tr>
<tr>
<td><strong>Recorded instances of family/whānau reported distress:</strong> estranged from family</td>
<td><strong>Recorded instances of family/whānau reported distress:</strong> estranged from family</td>
<td><strong>Recorded instances of family/whānau reported distress:</strong> estranged from family</td>
</tr>
<tr>
<td><strong>Team involved:</strong></td>
<td><strong>Team involved:</strong></td>
<td><strong>Team involved:</strong></td>
</tr>
<tr>
<td><strong>ARC facility professionals:</strong> care givers, GP, clinical manager, RNs</td>
<td><strong>ARC facility professionals:</strong> care givers, GP, clinical manager, RNs</td>
<td><strong>ARC facility professions:</strong> care givers, GP, clinical manager, RNs</td>
</tr>
<tr>
<td><strong>External professionals:</strong> DHB ORA liaison nurse; hospice ARC liaison nurse, hospice doctor, oncology specialist.</td>
<td><strong>External professionals:</strong> DHB ORA liaison nurse, hospice ARC liaison nurse, hospice doctor, oncology specialist, physiotherapist, podiatrist</td>
<td><strong>External professionals:</strong> DHB ORA liaison nurse; hospice ARC liaison nurse, hospice doctor, oncology specialist, physiotherapist</td>
</tr>
</tbody>
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High complex palliative care needs

Those in the focus group felt those admitted-to-die often have a short dying trajectory, a more rapid decline and often more intense and difficult to control symptoms compared with the end-of-life trajectory of the frail elderly residents.

“I do the sign-offs for residential care and they are coming in later, we do more and more hospital sign-offs as opposed to rest home level sign-offs and they are sicker when they come in... and staying at residential care shorter but they're more unwell when they get into residential care.” (DHB ORA Liaison Nurse—for definition see Table 2)

“Now we can have people who go into aged residential care and within two weeks they’re dead. You had no ability to establish a relationship with them or their family and it is, it’s really hard.” (Hospice Doctor 1)

Staff and external professionals needed to work swiftly and effectively to create a connection with patients and whānau and collectively manage complex needs. Despite complexity of those admitted-to-die in ARC facilities being similar to those in hospices, ARC staff numbers and skill-mix were noted to be quite different, particularly the lack of 24-hour access to GPs for medical assessment. ARC facility staff acknowledged they did not have the full range of specialist equipment or employ the same range of professionals or skill-sets as public hospitals or hospices.

“So since our [Hospice ARC liaison] roles have been in place—the referrals [requests from ARC] have just become unsustainable, [the Hospice ARC liaison service] can no longer as a service sustain the amount of referrals... there’s an overwhelming need for support because the complexity of care has risen so much.” (Hospice ARC Liaison Nurse—for definition see Table 2)

“The patients themselves are a lot more complex too though with your multi co-morbidities, you’re having to deal with all sorts of medical issues that probably weren’t dealt with in the past.” (ARC RN Clinical Manager)

Person/whānau expectations of ARC care for those admitted-to-die

People being discharged or transferred from hospital or hospice to-die in ARC were reported as often having difficulty in accepting this. Often they (and theirwhānau) did not understand they were dying or have an advance care plan (ACP) or enduring power of attorney (EPOA) and they felt aggrieved at the ARC financial cost (if they did not meet the ARC asset and income threshold). ARC staff felt they were viewed as not as skilled in palliative care delivery as hospice or hospital staff. Participants (both ARC facility staff and external professionals) found they had to actively advocate for the skills of the ARC staff.

“We... [the ARC facility] have residents that come in that don’t accept that they are dying... So we’ll get a discharge summary from the hospital saying this person is palliative but then when we go to start the conversations both the patient and the family have got a totally [different] idea about what we had initially thought.” (ARC RN Clinical Manager)

“How does the cross organisational model work for those admitted-to-die?

Participants described challenges in providing palliative care which involved input from several organisations and suggested improvements. ARC staff and professionals from other organisations felt their efforts to provide care were currently rather disjointed and sought a more explicitly collaborative role.

“What is needed... [is] a certain repository of experience within a team of people like you have in a hospice within singular aged care facilities because I don’t think the whole of [the region’s ARC facilities] actually should be doing palliative care... [For] people who are going to die within three to six months I think you should designate [an ARC] and... increase their skills. So you’ve got...[a] group... and you have a team approach and you have the skills.” (ARC GP 1)

“If you don’t [integrate with the ARC staff] you’re going to fail. And I think that our professional responsibility is to make sure we do integrate ourselves.” (Contracted Podiatrist)
Synthesis

In summary, the case reviews showed the group of people admitted-to-die in ARC facilities and who come from hospitals and hospices have high and complex palliative care needs caused by multimorbidity (MM), often including advanced cancer. In reality, akin to the interprofessional care provided by specialist palliative care providers (hospice, hospital palliative care team), people admitted-to-die in ARC (from hospital or hospice) continue to require interprofessional input from a broad range of health and social care professionals (ARC staff, private contractors or those employed by DHBs and hospice ARC liaison staff).

In the focus group, ARC staff and external professionals freely discussed undertaking huge and willing efforts to provide complex, interprofessional palliative care to the patient and whānau, some of whom (person and/or whānau) have not accepted the person is dying. In contrast to organisations funded to offer specialist interprofessional palliative care, they repeatedly described face-to-face and online communication among the staff and between the professionals from external organisations as being extremely limited by lack of time, resource and structure. Together, the synthesised data paints a rich picture of well trained, willing and committed staff, but poorly co-ordinated and significantly underfunded to provide care for patients and whānau with complex and urgent palliative care needs.

Discussion

This is the first New Zealand study to report the care of cases admitted-to-die within three months of admission in ARC, including those under 65 years. The study demonstrated a high burden of palliative care symptoms requiring what should be defined as specialist palliative care provided by ARC facility staff plus professionals from hospice, DHBs and private contractors. Those involved from other organisations were willing to be involved but expressed significant concerns about lack of ARC facility structure and MoH funding for the intensity this form of care required and largely operated through goodwill to support the ARC facility staff and the person and their whānau.

A strength of the single case study, multiple methods approach is the ability to combine a detailed clinical notes review with interview and the focus group data to provide a rich description of each patient’s care over the course of their admission and thus enhance the credibility of the results. A limitation is the singular focus on one ARC facility (known to be a recognised high-performing facility). Also, the study did not set out to explore or compare the palliative care of home-for-life residents who die from frail old age decline, or to compare the end-of-life symptoms of those in the admitted-to-die group with those dying in hospital or hospice. Neither did it explore the views of people admitted-to-die or their whānau. The study highlights areas for further research about ARC palliative care for the admitted-to-die group including the optimal use of ‘on request/PRN’ medicines for symptom control in ARC; impact of the palliative care work on ARC staff when balanced with the care of home-for-life residents; palliative care professional development requirements for ARC staff; particular needs of under-65 year-olds admitted-to-die in ARC; and perceptions by the public about ARC facilities being suitable places to be admitted-to-die.

This study adds to existing New Zealand research, which has signalled an increase in number of those admitted-to-die in ARC facilities. The MoH Healthy Aging Policy acknowledged the need for specialist palliative care for those admitted-to-die “as we live longer, we can expect increasing numbers of people with more complex conditions and comorbidities” (p.43), but it did not specify how specialist palliative care should be delivered within ARC, as this care is not the same as the primary palliative care given for ‘uncomplicated deaths’. The clinical notes review showed the symptoms of those admitted-to-die were typical of end-of-life decline (physical, psychosocial, existential) but that they were significant, complex and fluctuating, and required specialist palliative care with input from external professionals not typically employed by ARC facilities. This is a high-performing ARC organisation and despite professionals being responsive and a range of medicines given at different times; symptoms, other concerns and distress were
not always relieved. Similar to Connolly et al’s New Zealand study of those who died in ARC after transfer from public hospital, in this study it was not always clear to those involved (patient, whānau) that the person was imminently dying. Only one case had a documented EPOA and ACP with the lack of an ACP known to be barrier to initiating palliative care.31

Significant structural, funding and environmental barriers to effective palliative care in ARC were identified in this study. Funding barriers:

- No specific DHB funding for the admitted-to-die group means ARC facilities cannot afford to employ sufficient staff with an ideal skill mix and this likely restricts their ability to pay contracted external professionals;
- No specific health system funding to support collaborative, interorganisational specialist palliative care and limited MoH Innovations Funding for hospice ARC liaison nurse consultation;28
- Variability in how DHBs fund people admitted-to-die in ARC. Some DHBs have specific palliative care funding and do not charge the person, some fund the person’s care through respite care funding, others apply income/asset testing and the person may be required to pay for ARC facility care (care they had received at no-cost in hospital or hospice prior to discharge).

Structural barriers:

- No DHB-wide common electronic platform to enable ARC staff and professionals from other organisations to communicate and collaborate in care planning;
- No DHB-wide pool of specialist clinical resources for ARC facilities to care for the admitted-to-die group (eg, syringe drivers, specialist beds and chairs, pressure relieving equipment).

Environmental barriers:

- Inappropriate ARC facility spatial layouts for the admitted-to-die group. Currently these people and their whānau are placed in rooms interspersed with home-for-life residents. The admitted-to-die generally require separate private space with enough room for whānau to visit and stay when near death. Staff need to be able to undertake close but private monitoring, ideally near their work station. Those under 65 years admitted-to-die appear to have particular spatial and privacy needs, especially if young families are involved.

Issues, solutions and future research

We believe two overarching issues are highlighted by this research.

First, the model of palliative care delivered to this group of patients including those under 65 years (patients discharged-to-die from hospitals or hospices) meets the criteria for being specialist palliative care. Specialist palliative care expectations are defined in national standards including the need for interdisciplinary expertise, yet the current DHB funding for hospital-level ARC care is inadequate to cover the required level of ARC staffing, the need for input from external professionals and the required clinical and environmental resources.

As a solution, we recommend a specific classification and funding stream should be considered for those admitted-to-die and requiring specialist palliative care in ARC (this has been proposed in Australia), perhaps initially limiting this funded model of care to selected ARC facilities. The model of care would specify the ideal professional mix of ARC facility staff and the training and support needs of staff members; the type of environment and equipment needed for care (including the needs of under-65-year-olds); arrangements for medical assessment including after-hours care; memoranda of understanding to include external professionals. Such a model could draw on proven consultative structures which use liaison staff to provide clinical advice and education. A role for a pharmacist skilled in palliative care should be considered to support the use of medicines for symptom control in ARC facilities. Better integration of the pharmacist’s role in ARC facilities has been proposed in the past by the Ministry of Health and the outcomes of this role has been well researched in hospices particularly advising on the balance between the use of regular vs ‘as requested (PRN)’ medicines and the timing of syringe driver initiation.
Secondly, we believe people admitted-to-die in ARC are not routinely receiving interprofessional specialist palliative care (a recognised international industry standard routinely applied in hospices and public hospitals).38–42 In this study interprofessional specialist palliative care was provided in ARC by a combination of DHB staff, staff from other organisations and contracted professionals and because of a lack of structure relied on good will. Hospice staff (ARC liaison nurses and hospice doctors) play an important consultative and support role to ARC staff but in this study hospice consultative input was in some cases limited and not always timely, even though hospice and ARC staff knew each other well and were geographically close. It is unclear why this variability occurred.

As a solution, we recommend a clinical pathway be developed to formalise cross organisational input from DHBs, hospices and others to provide interprofessional specialist palliative care in ARC, including how this care will be led. Research in Australian ARC facilities (funded in a similar way to New Zealand) rely on the input of external professionals for those admitted-to-die and have developed formal mechanisms to achieve this.43,44 To support this form of care an electronic shared record with care planning functions would facilitate ease of and more effective communication between all the professionals involved;45 as well as assessing the real-time use of medicines for symptom control. The current hard-copy written record requires professionals to be onsite to read and write.

Taken together these solutions would result in a model of care to deliver specialist palliative care in ARC for those admitted-to-die with an appropriate structure and funding to ensure it is sustainable long-term.

**Competing interests:**
Pakize Sari and Jill Kerridge are staff members at the aged care facility where the research took place.

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