ORIGINAL RESEARCH

The role of palliative care nurse practitioner in promoting end-of-life care in residential care facilities

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ABSTRACT

Background and objective: The neglect of older people at the end of life in residential care documented in the Australian Royal Commission into Aged Care and Quality and Safety mandates urgent solutions to improve care. This integrative literature review aimed to explore the potential role of the palliative care nurse practitioner (PC-NP) in promoting quality end of life in residential care.

Methods: Databases Medline, Emcare, PsychINFO and CINAHL were searched from January 2010 to April 2022. Full text of primary articles meeting inclusion criteria encompassing residents living in residential care settings, the role of the PC-NP in supporting quality dying were obtained and independently screened to determine final studies for review. Findings were thematically analysed. Two reviewers independently extracted data and assessed level of evidence and quality ratings for both quantitative and qualitative studies.

Results: Of 12 articles meeting eligibility criteria, four specifically focused on the PC-NP or the palliative care nurse in residential care, seven examined the generic nurse practitioner role, and one the aged care nurse role in supporting palliative care. Themes common to all roles including positive patient outcomes, advance care planning, hospital avoidance, staff education and enhanced communication with families. Themes specific to the PC-NP included meeting end-of-life needs, end-of-life prescribing, and enhancing the role of the General Practitioner.

Conclusions: Although reflected in only a handful of studies, this integrative review has provided preliminary insights into potential contributions of the PC-NP to quality end-of-life care for residential care residents.

Key Words: Palliative care, Nurse practitioner, Long-term care, Nursing home

1. INTRODUCTION

Older people living in residential care facilities (RCF) are not always afforded their internationally guaranteed human rights to the highest attainable standard of health at the end-of-life.[1] In Australia, this was borne out in the recent Royal Commission into Aged Care and Quality and Safety, in which two of 148 recommendations stated that a new Aged Care Act should aim to ensure (i) generally, high quality care in a safe environment to protect the rights of older people to be free from neglect, mistreatment and harm resulting from poor

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quality care; and (ii) specifically, the right to fair, equitable and non-discriminatory access to palliative and end-of-life care.[2] However, Australia is not alone in this recognition of shortfalls at the end of life, especially in a COVID-limited world.[3]

Australia has also recognised the need for capacity building in the nursing workforce in meeting these shortfalls. An Australian inquiry investigating the provisions of the Public Health Amendment Bill (Registered Nurses in Nursing Homes 2020) was held to investigate understaffing and the need for mandated Registered Nurses (RNs) in RCF to provide comprehensive care, including end-of-life care to residents.[4] This Inquiry drew attention to the need for RNs and specialist palliative care nurses in RCF to assess the palliative care needs of residents and provide both pharmacological and non-pharmacological strategies to prevent suffering. This too remains relevant to the international nursing workforce.[5]

A long-identified area of need in this setting is the assessment and treatment of pain, which is frequently underdiagnosed and poorly managed at the end of life, significantly compromising quality of life.[6] Access to pain relief is a human right and opioids are often pivotal in the management of this.[7,8] Opioids are administered by RNs for whom titration of opioids with continual pain assessment for effective pain relief is part of scope of practice.[9] In the absence of RNs in RCF, residents are often transferred to hospital to access treatment and care that could otherwise be managed in the RCF, which is usually their place of choice for end-of-life care.[10]

Older people living in RCF have a human right to equitable access to the highest quality of health at the end of life. Quality end of life, or quality dying is generally considered as dying that is free from avoidable distress and suffering, and that approximates patient and family wishes, as well as clinical, cultural, and ethical standards.[1,11,12] Select groups internationally have started to recognise that the palliative care nurse as an advanced practitioner (PC-NP) working in RCF would be uniquely placed to provide specialized, advanced, clinical skills and knowledge for the relief of distress and suffering for residents and families at the end of life.[9,13,14] However, while the role of the PC-NP in hospice and other settings has been generally described, their specific roles and contributions to achieving quality dying in RCF is only just beginning to emerge in the face of the COVID-19 pandemic.[15–18]

Recognising that the needs of older people at the end-of-life living in RCF are often neglected, there is an imperative to identify the potential contributions of the PC-NP to promoting quality end of life for residents in RCF. It is likely that the PC-NP can support a framework that ensures that these aspirations are achieved.[19] The role of the PC-NP is in its clinical infancy and further research is required to ensure that this focused specialised knowledge is utilised and resourced to meet the complex needs of vulnerable people in RCF.[20]

Objectives

Using the frame of a modified PICo (Population, Interest, Context) question, this integrative literature review aimed to answer: What is the role of the palliative care nurse practitioner in promoting quality end of life in Residential Care Facilities?[21–24]

2. METHODS

Integrative review methodology was chosen.[25] Integrative reviews are important in building nursing science and adding to the evidence base in new and evolving areas of nursing practice, and as such was ideally suited to exploring pragmatic solutions to this major contemporary issue in health care.[25,26] Moreover, this review type in particular is most geared to enhancing perceived usefulness of findings to inform practice, hitherto a major obstacle to review uptake.[27]

2.1 Inclusion and exclusion criteria

Published peer reviewed literature were reviewed to identify primary data of any design (qualitative or quantitative) and screened for eligibility defined by the PICo elements, which included 1) the target vulnerable population of older people, 2) palliative care input of the PC-NP role in any element of quality dying (as defined earlier) and, 3) the RCF context.

English and full text research published between January 2010 and April 2022 were included. The restriction to 2010 was chosen because the role of the NP has only emerged within the last decade, with the specific role of the PC-NP only emerging in the last five years and their specific role in RCF being a completely novel concept.

Articles were excluded if they were systematic reviews or meta- analyses, commentaries, editorials, letters, or grey literature. Studies were also excluded if they did not meet the target population such as dying in community home care and palliative care provided in hospital settings.

2.2 Search strategy

The following multiple databases were utilised: Medline, Emcare, PsycINFO and CINAHL (Medline, 2022; Emcare, 2022; PsycINFO, 2022; CINAHL, 2022) using PRISMA reporting guidelines.[28] Search terms aimed at identifying studies on the role of the PC-NP were used.

Based on the PICo question, the following items or combinations of search terms were used:

1) "nurse practitioner" OR "advanced practitioner" AND
2) "palliative care" OR "end of life care" AND
3) "residential care" OR "nursing home"

The search was limited to studies in English. The articles were progressively screened on title first, followed by abstract and finally, full text.[23] For the final included papers, a data collection tool was used to capture authors, setting, study characteristics and findings, as well as quality, bias and evidence appraisal (see below).[29]

2.3 Data synthesis: Thematic analysis

The thematic analysis in this integrative review utilised methodology of Braun and Clarke (2006) by identifying patterns in the data using a checklist to ensure a rigorous approach to identifying key themes.[30] This methodology is flexible and can highlight differences and similarities across a data set and allow for both social and psychological interpretation of data. The process of thematic analysis requires the collection of data, coding interesting features, collating the codes into themes to generate a thematic map, refining themes and final analysis relating back to the research question and literature.

2.4 Quality, bias and evidence appraisal

Quality ratings of quantitative studies were appraised using the Albert Heritage foundation for Medical Research Standard Quality Assessment Criteria.[31] The checklist assesses study design and appropriateness, subject selection, random allocation and blinding, outcome measures and statistical methods, reporting of results and conclusions.[31]

Qualitative studies were rated using the Attree and Milton's (2006) checklist to evaluate methodological quality such as research aims and objectives, appropriateness of study design, sampling methods, data collection, analysis and results, reflexivity, usefulness, and ethical considerations.[32] Each checklist item is rated from A (no or few flaws) to D (significant flaws threatening validity).

The level of evidence of quantitative studies was assessed using Oxford Centre of Evidence-based Medicine hierarchy (OCEBM) (Levels 1-4). Level 1 (highest level of evidence) included RCTs, Level 2 included cohort studies, low quality RCTs and ecological studies, Level 3 included cohort and case-control studies, and Level 4 included case series and poor-quality cohort and case-control studies.[33]

A second rater independently scored selected papers for quality. Differences in scoring were discussed until consensus was reached and a final rating was determined (see Appendix 1).

3. RESULTS

The Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) flowchart for study selection is shown in Figure 1.[28] Electronic database searches identified a total of 175 citations, amongst which 12 publications met the criteria for inclusion. Of the 12 studies, four studies specifically focused on the role of the PCN-NP or the palliative care nurse in RCF, seven studies examined models involving or roles of the generic Nurse Practitioner in RCF, and one study examined the role of aged care nurses in RCF in supporting palliative care. Seven studies emanated from the United States, four emanated from Australia and one from Canada.

Seven qualitative, five quantitative studies were identified. Of the seven qualitative studies, three used focus groups, two were descriptive studies, one utilised semi-structured interviews and one was a quality framework. The qualitative studies were all ranked as A standard on the Attree and Milton's (2006) checklist except for one article that was ranked as quality level B because the study was a quality framework design which inherently presents a positive frame, thereby increasing bias.[34] The quantitative rankings ranged from 72%-93% on the Albert Heritage criteria with all five quantitative articles rated as 2 on the OCEBM Levels of evidence.[31,33]

Several key themes were identified which were common to both the more generic NP/Aged Care role and the specific PC-NP role. These are elaborated upon as follows.

3.1 Positive patient outcomes

Patient outcomes were a key theme in all twelve articles.[35–37,39–46]

Eight of the twelve articles identified that NPs contributed to ensuring that residents were able to have a "good death". This was consistently seen as a death in one's place of choice (the RCF), relief of treatable burdensome symptoms in a timely manner by someone with expert knowledge of complex comorbidities, and well-prepared ACP discussions with clarified goals of care.[35,36,38,39,43–45]

Eight articles discussed family communication and liaison provided by NPs as factors that contributed to a resident achieving a "good death" by preparing families for end of life, discussing preferred place of death and focusing on quality of life.[35,37–39,41–43,46]

3.2 Advance care planning (ACP)

Involvement in ACP and ensuring compliance with such were identified consistently as important roles of the NP to ensure that goals of care were supportive of a good death.

This included residents determining their own goals of care to prevent unnecessary hospital admissions and reducing non-beneficial care at the end of life.[35–39,42–46]

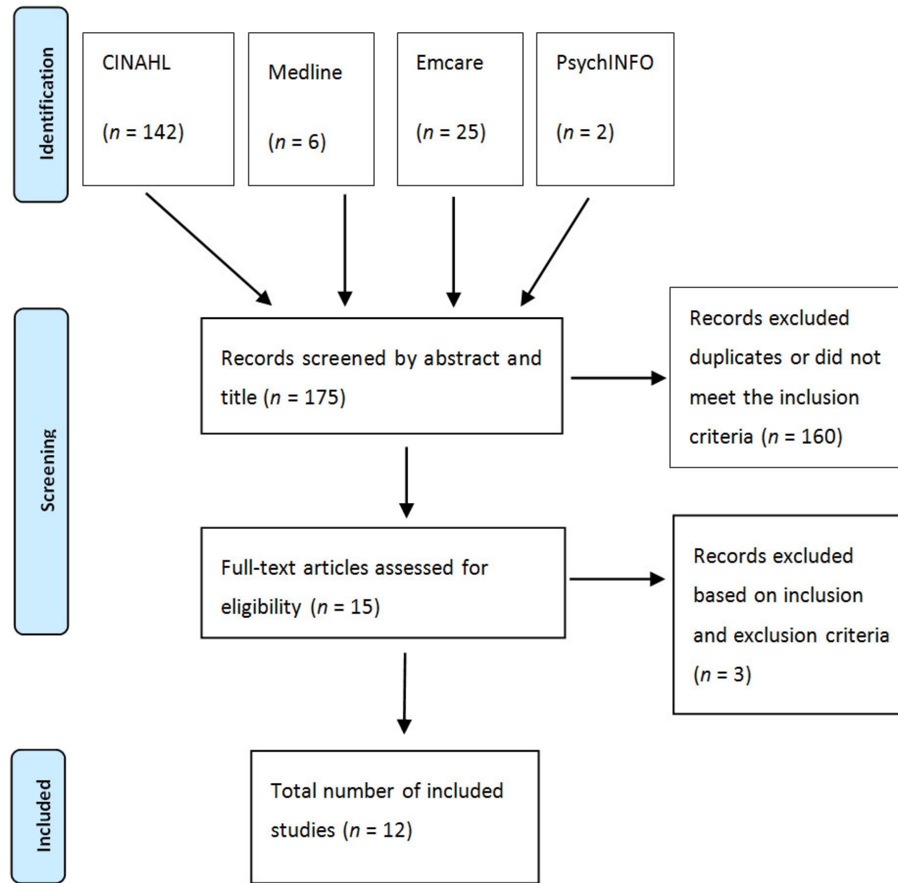

Figure 1. Flow chart for search, screening, and selection process

3.3 Hospitalisation avoidance

NPs played a significant role in preventing unnecessary hospitalisation. Two articles emanating from the same research group examined the cost saving of residents who had specialist palliative care consultations based on reduced rates of hospitalisations.[41,42] Further to this, five additional articles identified that specialist palliative care in RCF provided by NPs also reduced hospital admissions though planning for symptom management, treatment in place and advance care planning discussions to identify preferred place of death.[35,38,39,43,45]

3.4 Staff education

NPs had a key role in educating staff in the management of the complex issues often found in palliative care to improve quality outcomes for residents.[39,43] Kaasalainen et al. (2013) identified the barriers to quality end-of-life care imposed by inadequate education of unregulated workers in aged care. They described the benefit of NPs as coaches and mentors in palliative care using collaborative team-focused learning to empower staff to provide "good deaths" for residents. Mullaney et al. (2015) detailed the role of NPs to educate staff in end-of-life discussions to support "good deaths". Three studies described how palliative care rounds mediated by a PC-NP supported staff education in RCF.[35,38,45]

3.5 Enhanced family communication

As discussed earlier, implicit in the notion of quality dying is family support and communication. Eight studies referenced communication with families about end of life. The NPs role in communication with families was linked to high satisfaction of families,[40,44] better opportunities to talk about death and dying and to establish goals of care through ACP.[35,37–39,42,43] Further acting in their leadership and education role, NPs enhanced staff confidence in talking about death and dying with families.[46]

3.6 The role of the PC-NP

The specific contribution of the PC-NP was examined separately. While sharing some of the emergent themes evident

above, such as staff education, reducing hospitalisation and optimising preferred place of death, additional themes that emerged from the three studies[35,38,45] that specifically examined the role of the PC-NP in RCF included:

3.6.1 *Meeting needs at the end of life*

Three studies emerging from the same group identified the benefits of PC-NP facilitated palliative care needs rounds in RCF.[35,38,45] Such rounds included regular (monthly) onsite clinical meetings facilitated by the PC-NP, using case-based discussion and education with formulation of care plans, goals of care and ACP discussions.

Although the three studies were from the same group, and all focused on palliative care needs rounds, different methodology added rigour to the results, thereby identifying the needs round as an innovative new model of care. Chapman et al. (2018) used a quasi-experimental design of methodology demonstrating higher rates of preferred place of death and shorter hospital days in the intervention group who received specialist palliative care compared with the control group who received usual care. Johnston et al. (2019) used thematic analysis of focus groups to identify a broad range of themes including normalising death, prompt symptom management, reduced hospitalisation and ACP. Finally, Samara et al. (2021) using a quality improvement framework, recognised the value of the palliative care needs round in the context of the COVID-19 pandemic, where rapid innovation was required to identify how PC-NPs could provide the same level of expertise while minimising face to face visits. This resulted in the increased use of telehealth.

3.6.2 *Prescribing for end-of-life symptom relief*

A very specific and specialised role of prescribing at the end of life was a recurrent theme. All three PC-NP articles acknowledged the benefits of PC-NPs as prescribers of anticipatory end-of-life medications, including but not limited to opioids, to benefit residents.[35,38,45] Johnston et al. (2019) and Chapman et al. (2018) discussed the role of the PC-NP in prescribing anticipatory end-of-life medications providing timely access at end of life. Samara et al. (2018) also described the value of the PC-NP in deprescribing nonessential medication at end of life. Further to this was the ability of the PC-NP in providing symptom management of respiratory distress in COVID-19 but also relief of symptom burden in non-COVID related illness. Linking with other themes of hospital avoidance, the ability to prescribe and provide treatment in place was key.[35]

3.6.3 *Enhancing the role of the general practitioner (GP)*

The PC-NP emerged as both a conduit between staff and GPs, and families and GPs, enhancing trust and communication between all parties.[35,38,45] There was also evidence that PC-NPs were a resource that could provide timely symptom management for end of life, hence providing an additional supportive service for GPs.[38,45]

4. DISCUSSION

This integrative review aimed to answer the question: What is the role of the PC-NP in promoting quality end of life for residents of residential care facilities? As far as we are aware, this is the first integrative review to focus on the PC-NP role in promoting quality dying in RCF. The paucity of research in this area was demonstrated by a yield of only 12 articles meeting the final inclusion criteria, of which only four addressed the specific role of the PC-NP or palliative care nurse in RCF. Notwithstanding this, the included studies were of relatively high quality, including both the quantitative and particularly, the qualitative studies.

When considering the roles of generic nurse practitioners, this review has identified impact on a range of specific outcomes at the end of life in RCF. These included: improved patient outcomes, ACP, hospitalisation avoidance, staff education and enhanced communication with families. Additionally, key specific roles identified in relation to the PC-NP included prescribing for end-of-life symptom relief and acting synergistically with GPs. Collectively, these outcomes suggest a significant role in enhancing quality dying for RCF residents, by addressing symptom relief to relieve distress and approximating patient and family wishes alike, consistent with our earlier conceptualisation of quality dying.[1,11,12]

In achieving these outcomes, in addition to the obvious support of residents, a vital role in providing both staff and family support was evidenced in many of the papers, regardless of whether they addressed generic NP or specific PC-NP roles. Clearly, staff and family support go hand-in-hand in achieving quality dying for residents in RCF. Such support is crucial for particular diseases such as dementia, where there is a profound need for staff and family support and education, including in relation to ACP.[35] Chapman et al. (2018) highlighted the specific need for ACP for people with dementia, which is often not acknowledged as a terminal diagnosis. Liu et al (2012) noted the needs of families of people living with dementia for better communication with physicians and more emotional support, both of which were enhanced by the NP role.[40] Albers et al. (2014) have emphasised that implicit to the provision of compassionate end-of-life care for people living with dementia is understanding and addressing the significant emotional and physical burden borne by nursing staff, including the emotional burden involved in communicating with families about death and dying.[47]

The identified literature illustrated the specialised role of the PC-NP in early identification and treatment of a range of common symptoms and comorbidities occurring at the end of life.[39] This extends beyond pain relief[44] to mouth and skin care, hydration and management of agitation states[38] which is often undertreated in RCF, particularly agitation associated with delirium.[48–50] Importantly, with their expanded scope of practice, PC-NPs can treat these symptoms in place, relying equally on prescribing essential medications and de-prescribing non-essential medications.[38,43] In particular, de-prescribing at the end of life requires a specific palliative care advanced skill set for discussion with both GPs and families, a role that the PC-NP is uniquely placed to undertake as "clinical gatekeepers".[51]

Taking advantage of these unique skills, the PC-NP can facilitate treatment in place and hospital avoidance.[41,42] Transfer to hospital is often a risk-management strategy driven by fear of potential repercussions of complaints, lawsuits or policy non-compliance, yet of little proven value to residents at the end of life.[44] For example, in 2014, an Australian Coroner recommended transfer to hospital for residents in RCF who had falls involving head strike. A subsequent retrospective cohort study of 366 RCF residents sent to Emergency Departments found that only 6% had intracranial haemorrhage and no patient had neurological surgery, questioning the value of hospitalisation.[52] The PC-NP role in avoiding unnecessary hospitalisation thereby enhancing preferred place of death is a significant contributor to quality dying. Initiatives such as the Palliative Care Core of the Optimizing Patient Transfers, Impacting Medical Quality, and Improving Symptoms: Transforming Institutional Care (OPTIMISTIC) Project utilizes these very NP skills elaborated in the identified literature.[53]

The synergistic role with primary care identified in this review is particularly important in the face of concerns that GP services are unable to meet the needs of RCF residents at the end of life. This has been acutely felt during the COVID-pandemic with doctors less accessible and often working off-site.[18,38] Notably, with their expanded scope of practice for prescribing, PC-NPs are ideally placed to address these shortfalls to facilitate quality dying.[54] In the face of GP shortages and the challenges of providing time-consuming assessment and management of complex comorbidities at the end of life, the PC-NP can also reduce GP workload burden.[55,56]

Although none of the reviewed articles specifically mentioned training and supportive policies for the NP role, the implementation, development and sustainability of a NP role or service requires organisational support, a business case and governance. Various standards and policies across the world have laid out guidelines about this.[57–59] More specific policies may be required for PC-NP.

4.1 Limitations

This integrative review yielded only 12 studies of which only four focused on the specific role of the PC-NP. While one study explored the benefits of NPs over unregulated workers, the specific advantages of the PC-NP over generic NP have not been tested.[39] Further, although specific outcomes with regards to hospitalisation avoidance have been robustly examined, other outcomes in relation to quality dying have been explored in a preliminary manner. Although qualitative studies have generated rich data capturing the experience of staff and families, future studies must examine concrete, quantifiable outcomes (e.g., patient and carer quality of life measures, care satisfaction measures, and burden measures) in relation to operationalised criteria for quality dying and the efficacy of PC-NP service provision in RCF. Finally, there may be limited generalisability in the findings as the role of the NP is likely influenced by the specific structural, cultural and financial healthcare models.

This integrative review did not examine grey literature which may have increased publication bias as studies with negative and no results are less likely to be published.[60] In the face of a barren literature, grey literature may have yielded more ethnographic descriptions of PC-NP contributions to end-of-life care in the RCF.

4.2 Implications for health care practice

Capacity building of the nursing workforce is an imperative during the United Nations Decade of Heathy Ageing (2021-2031).[8] PC-NPs are recognised as advanced practitioners with defined job descriptions within the public and private health sectors.[9,13] In 2019, there were approximately 1745 endorsed NPs in Australia specifically, working across a variety of settings, although the number of PC-NPs are unknown.[61] A cost benefit analysis report highlighted that NP models improved the care delivery in the aged care sector but it identified a significant gap in the NP workforce.[62] With the complexity of care needs of older people and the potential benefits of PC-NP service provision, aged care providers, managers, and policy makers have an imperative to consider integration of NP models of care into core business.

4.3 Implications for education

This integrative literature review has detailed the benefits of the palliative care needs round.[35,38,45] The palliative care needs round is a model of care that is PC-NP led that has successfully reduced hospital admission through timely symptom management and early ACP to clarify goals of

care at end of life. The palliative care needs round provides education and support to RCF to identify deterioration and residents at risk of dying and escalate concern to the PC-NP and GP resulting in increased capability and capacity in staff. Forbat et al. (2020) identified that staff education plays an important role in improving end-of-life care in RCF.[63] This innovative educational model of care warrants further exploration in RCF to provide quality person-centred care.

4.4 Implications for future research

Notwithstanding its limitations, this review illustrated a range of potential contributions of the PC-NP in promoting better end-of-life care in RCF, currently constrained by a range of barriers and inadequate resources.[54] Although the PC-NP role is recognised, there is lack of research on PC-NPs specifically. This integrative review identified the value of the NP in providing palliative care to RCF but only four of the articles were specific to the PC-NP. This warrants further research demonstrating the value of the PC-NP model in the aged care setting to direct policy and future practice.

5. Conclusion

The needs of residents living in RCF are often neglected at the end of life, manifesting in inhumane treatment and poor symptom management at end of life. It is imperative to review and identify opportunities to address these human rights breeches. The PC-NP is ideally positioned to do this as front-line professionals and leaders to drive change in practice. This literature review – the first of its kind – is the first step in research knowledge translation of better understanding of quality dying in RCF.[26]

Conflicts of Interest Disclosure

The authors declare that there is no conflict of interest.

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