

Allied health professionals' contribution to care at end of life in aged care settings

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ABSTRACT

Background. The Australian population is aging, and the proportion of older Australians will continue to grow over the coming decades. However, there is a lack of research published on the specific roles and responsibilities of allied health professionals (AHPs) providing palliative care within an aged care context. Understanding the roles and needs of AHPs providing care during the last months of life in the community and aged care facilities could contribute to workforce planning, targeted information and improved care. **Methods.** In total, 108 eSurveys were collected between November 2019 to May 2020 from three allied health professions working in government-funded aged care; the majority of these being in residential aged care. Descriptive data are reported on the provision of care in key palliative care domains, care settings and practice activity. **Results.** Nearly all respondents reported they had worked with older Australians who had palliative care needs. However, over one-third of respondents reported low levels of confidence in supporting clients or residents with palliative care needs. The majority indicated they would benefit from additional education and training and support in palliative care. **Conclusions.** This study investigated the role of the allied health workforce in contributing to the care of older Australians at the end of life. It has also demonstrated that there are gaps in practice activity and work role that must be addressed to ensure this workforce can support older people with palliative care needs in receipt of aged care services.

Keywords: aged care, allied health, Australia, dietitians, end-of-life, home care, occupational therapists, palliative care, physiotherapists, residential aged care.

Introduction

The Australian population is aging. In the 20 years to 2020, the proportion of the population aged ≥ 65 years increased from 12.4% to 16.3% ([Australian Bureau of Statistics \(ABS\) 2020](#)). The growing number of older Australians has led to an increased demand for aged care services, with many older people presenting with complex care needs or entering residential aged care from hospital ([Australian Institute of Health and Welfare \(AIHW\) 2019](#); [Aged Care Royal Commission 2021](#)). This has contributed to a review of current aged care policy issues in Australia and issues around care of older people at the end of life ([Aged Care Workforce Strategy Taskforce 2018](#); [Aged Care Royal Commission 2021](#)). The intersect of aged care, allied health and palliative care has been reflected in the World Health Assembly 2014 statement, which recognises that palliative care should be part of comprehensive care provision across the life course, and that provision of generalist palliative care in non-acute settings is essential ([World Health Organization 2014](#)). Care for older people with palliative care needs is provided by a range of health professionals in different settings, and allied health professionals (AHPs) play a key role in this, with a particular contribution from occupational therapists, speech pathologists, dietitians, psychologists, social workers, physiotherapists, and music therapists. AHPs comprise the second largest health workforce in Australia, second only behind nurses. They are central to the continuing care of older people and are a major contributor to the care of older people in their homes, hospitals and in residential aged care facilities

(Howatson *et al.* 2015; Nielsen *et al.* 2017; Briggs *et al.* 2018; Brett *et al.* 2019; Aged Care Royal Commission 2021; Allied Health Professions Australia 2021). Data have shown that in 2020, there were 6661 permanent allied health professionals and a further 5942 agency or subcontractor allied health professionals working in residential aged care, with 1807 in permanent positions and 1752 in agency or subcontractor positions in home care, and 4022 in permanent positions and 549 in agency or subcontractor working in the Community Home Support Program (CHSP) (Australian Institute of Health and Welfare (AIHW) 2022a). For residential aged care and home care, this equates to around 2% of the workforce, and for CHSP around 4% (Australian Institute of Health and Welfare (AIHW) 2022a). Allied health engagement with aged care is influenced by the complexity of funding arrangements, availability of staff in rural and remote areas, referral processes, experiences in aged care settings in allied health training, and differences in work settings (Allied Health Professions Australia 2020; Couch *et al.* 2021). A lack of workforce data relating to allied health has also hampered both understanding of, and planning for, allied health contribution in aged care services (Department of Health 2022).

As more older Australians approach the end of life, it is likely that increasing numbers of Australians and their care providers will need to draw on the skills and services offered by AHPs (Royal Commission into Aged Care Quality and Safety 2021a). In 2020, 161 300 deaths were registered in Australia, with the majority of these occurring among older people. Sixty-six per cent of these deaths were among people aged ≥ 75 years, with a median age at death of 79 years for males and 85 years for females (Australian Institute of Health and Welfare (AIHW) 2022b). Aged care is often involved in supporting people in the last years of life. A recent analysis showed that 67% of people aged ≥ 50 years had used at least one aged care program in the 2 years prior to death, and that this increased to 86% for those who died aged ≥ 85 years (Australian Institute of Health and Welfare (AIHW) 2021).

Palliative care addresses the physical and psychosocial needs of people who have a life-limiting illness, and aims to enable them to live well until their death regardless of their background, where they live or the setting of their care. The National Palliative Care Strategy recognises that people die in a range of care settings, including in the home, hospitals, residential aged care facilities and hospices, and that medical, nursing and AHPs will be involved in palliative care provision (Department of Health 2018). An emerging body of literature demonstrates the role of AHPs in specialist palliative care in optimising function, non-pharmacological symptom management, and supporting psychological and spiritual adjustment to deterioration and approaching death (Chahda *et al.* 2017; Eva and Morgan 2018; Morgan *et al.* 2019a; Gravier and Erny-Albrecht 2020).

However, there is limited research on how AHPs support care in the last months of life in aged care.

In Australia, the aged care system is overseen by the Australian Government, which also funds the majority of aged care services, including subsidised home care packages and residential care (Department of Health 2020). As more older Australians, and older Australians approaching end of life utilise these services, there has been increased demand for AHPs. Data from the 2018 ABS survey of those in aged care show that half of people aged >65 years with a disability (Australian Bureau of Statistics (ABS) 2018) may benefit from restorative or reablement approaches (Lewis *et al.* 2021). Most people in residential care had high care need ratings in at least one care domain, most commonly for activities of daily living, cognition and behaviour or complex health care (Australian Institute of Health and Welfare (AIHW) 2021). Residents may therefore require assistive equipment and specialist supports to maintain and optimise function (Australian Bureau of Statistics (ABS) 2018), which is core business for AHPs (Blackler *et al.* 2018; Matlick *et al.* 2019). However, the 2020 Aged Care Workforce Census and Survey showed that AHPs equate to only 2% of the residential aged care workforce (Department of Health 2021). Despite anticipated need for allied health services, there is lack of research on the specific roles and responsibilities of AHPs providing palliative or end-of-life care within an aged care context.

End of Life Directions for Aged Care (ELDAC) is a project funded by the Australian Government Department of Health and Aged Care to support quality care for older Australians at the end of life (ELDAC Project 2021). ELDAC aims to connect people working in aged care with palliative care and advance care planning information, resources and services.

Understanding the roles and needs of the allied health workforce providing care at the end of life to older Australians in receipt of aged care services could contribute to workforce planning and enable more targeted education and information resources that improve care.

The aims of this study were to:

1. Identify the roles and responsibilities of AHPs working with older Australians with palliative care needs in Australian Government-funded residential care and home care.
2. Explore AHPs' knowledge and understanding about palliative and end-of-life care.
3. Ascertain AHPs' palliative care educational, clinical and knowledge needs.

Methods

This cross-sectional study utilised electronically collected open survey (eSurvey) data from seven allied health professions: occupational therapy, speech pathology, dietetics, social

work, psychology, physiotherapy, and music therapy. Eligible AHPs completed an eSurvey between November 2019 and May 2020. This paper reports on the findings of three of these allied health professional groups, representing those with the highest proportion of responses to the eSurvey – occupational therapists, physiotherapists and dietitians. The eSurvey was designed to capture key allied health workforce characteristics as they relate to the delivery of palliative care in the residential or home care, aged care setting. Global questions on palliative care and advanced care planning, as well as demographic and workplace characteristics, are reported (See Online supplement 1: online survey)

Questions were developed, trialled and peer reviewed prior to distribution through ELDAC channels and allied health professional groups. The online survey data collection was managed through the CareSearch Research Data Management System (Tieman 2016).

Data items

The survey comprised questions about: socio-demographic characteristics of AHPs; types of aged care services; population setting in which care is provided; specific clinical roles; advance care planning; and skills, training, knowledge and perceptions on palliative care. The eight-domain ELDAC care model was used as a framework for examining allied health activities and designing the survey (Tieman 2019).

Data collection

The eSurvey was designed to take 10–20 min to complete and no participants were individually identifiable in the data. Quantitative and qualitative data were captured, with the majority of questions closed-ended. Single or multiple answer options were provided depending on question type.

Ethics

Approval to conduct this study was obtained from the Human Research Ethics Committee of Flinders University (Ref # 8508).

Survey distribution

The professional bodies of occupational therapists, dietitians and physiotherapists were asked to distribute the eSurvey to their members via their communication channels and networks. The eSurvey was distributed over a 6-month period via electronic newsletters, websites and social media platforms including LinkedIn, Facebook and Twitter more than once, with a potential reach of 70 000 allied health professionals. A PDF version of the Participant Information Sheet and a direct link to the online survey were distributed to participants electronically. Participation and submission of the survey online implied informed consent.

Data analysis

Data extracted from the Research Data Management System (RDMS) platform were analysed using SPSS software, ver. 25.0 (SPSS Inc.). Descriptive statistics were used to analyse data. The qualitative data collected will be analysed and reported on separately.

Results

Demographic, professional and workplace characteristics

Table 1 shows the demographic, professional and workplace characteristics of all occupational therapy, dietetic, and physiotherapy respondents. Respondents were predominantly female (83.3%) and the majority were aged >41 years (51%). In total, 54.6% held a bachelor's degree only, and a large proportion of respondents had completed a postgraduate higher degree comprising a Master's and/or a Doctoral degree (40.8%). And 97.2% of respondents identified as non-Indigenous. Approximately half (52.8%) of the respondents had >10 years of experience practising as an allied health professional.

Scope of allied health practice in palliative care in aged care

Table 2 shows the scope of allied health practice in palliative care, in aged care. Although 108 respondents representing occupational therapy, dietetic, and physiotherapy groups participated in the survey, not everyone answered each question relevant to their scope of practice. Most respondents worked as a part of a multidisciplinary team (85.7%) alongside nurses, medical doctors and pharmacists. Of these, 59.0% received referrals to work with older Australians from residential aged care facilities and aged care service providers. There was widespread recognition of palliative care, as defined by the World Health Organization, with 97% acknowledging they cared for older Australians with palliative care needs or life-limiting illnesses. Almost two-thirds (60.9%) perceived that between 25 and 75% of older Australians whom they currently cared for could die in the next 12 months.

Respondents were asked how confident they were in recognising, providing, and defining their role at work for older Australians with palliative care needs. Almost two-thirds of respondents self-reported that they were completely or fairly confident in recognising (60.2%), providing care for people with palliative or end-of-life care needs (65.5%) and defining their role in working with older Australians with palliative care needs (65.3%). All (100%) of the respondents reported that they worked with older persons with dementia, and the majority worked with financially

Table 1. Demographic, professional and workplace characteristics of respondents ($N = 108$).

	<i>n</i>	%
Gender		
Female	90	83.3
Male	18	16.7
Age (years)		
20–30	30	27.8
31–40	23	21.3
41–50	26	24.1
51–64	27	25.0
65+	2	1.9
Highest academic qualification		
Diploma	5	4.6
Bachelor	59	54.6
Masters	42	38.9
Doctorate	2	1.9
Identify as being of Aboriginal and/or Torres Strait Islander descent		
Yes (Aboriginal/Torres Strait Islander)	3	2.8
No (Non-Indigenous)	105	97.2
Years practising as an allied health practitioner		
<1	6	5.6
1–5	32	29.6
6–10	13	12.0
>10	57	52.8
Current occupation		
Dietitian	39	36.1
Occupational therapist	37	34.3
Physiotherapist	32	29.6
Work setting		
Home care	27	25.0
Residential care	53	49.1
Both home care and residential care	28	25.9

and socially disadvantaged (96.6%), and culturally and linguistically diverse (95.5%) priority population groups. Just over one-quarter of all respondents (26.4%) worked with care leavers (i.e. people who lived in institutions as children, forgotten Australians and former child migrants).

Nearly half were satisfied or very satisfied with their workplace support; however, one-third (31.3%) remained 'neutral', indicating neither satisfied or very satisfied, with a remaining 19.3% unsatisfied or very unsatisfied with workplace support. The majority of respondents (95.3%) held the view that profession-specific clinical practice should be developed to better support their work practice in palliative care. Factors limiting adequate care provision for older Australians with palliative or end-of-life care needs

included time constraints (37.8%), 'insufficient funding' (28.0%) and limited understanding of the scope of AHPs' role (25.2%).

Relevance of ELDAC Care Model domains to clinical practice

Table 3 lists the eight domains of end-of-life care for older Australians with palliative care needs and their relevance to allied health clinical practice. The top three domains were: 'Working together as a team to meet the specific needs of the individual' (94%); 'Responding to deterioration so that changing needs are identified and care plans are updated to meet new care needs' (88.0%); and 'Providing palliative care including delivering care, reassessing needs and monitoring for changes' (76.2%). Managing dying (26.5%) and bereavement (34.9%) scored the lowest level of involvement.

Discussion

This study investigates the contribution that dietitians, occupational therapists, and physiotherapists play in the care of older Australians with palliative care needs in residential aged care and in-home care settings. AHPs were aware that residents and clients could be in the last months of life and were able to articulate the need for palliative care in this population. Although AHPs are often grouped, each discipline can contribute profession-specific skills and knowledge to meet the individual needs of clients and residents. Several issues arising from this study that have implications for care of older people at the end of life warrant further discussion.

The majority of AHPs completing the survey reported that they worked in multidisciplinary teams, which is consistent with the ELDAC Care Model and seen as critical in the National Palliative Care Standards ([Palliative Care Australia 2018](#)). However, what is not clear from these findings is which disciplines comprise the multidisciplinary team, and the extent and nature of AHP engagement in the multidisciplinary team. There are general aspects of palliative care knowledge and practice needed by all health professionals, such as communication skills and recognising deterioration, but AHPs would not be expected to provide all aspects of palliative care delivery alone. The specific contributions of different AHPs in meeting the individual care needs of older people identified as palliative and/or coming to the end of their life should also be more broadly acknowledged within the multidisciplinary team context.

Also, although there appeared to be good recognition of the definition and purpose of palliative care, this did not necessarily reflect confidence in their clinical practice, with around one-third of AHPs reporting they do not feel confident in defining their work role as it related to palliative care (30%). This accords with earlier work that showed that

Table 2. Scope of allied health practice to care for older Australians with palliative care needs.

	n	%
From where do you get referrals to work with older Australians in aged care services? (Tick all that apply) (n = 99) ^A		
Referral from an aged care services provider	51	25.5
From a residential aged care facility	67	33.5
From a general practitioner or other healthcare professional	50	25.0
From the palliative care team	28	14.0
I don't get referrals to work with older Australians in aged care services	4	2.0
In your current role, do you care for older Australians with palliative care needs or who are facing life-limiting illness? (n = 88)		
Yes	85	96.6
No/Unsure	3	3.4
Have you ever cared for older Australians with palliative care needs or who are facing life-limiting illness? (n = 88)		
Yes	86	97.7
No/unsure	2	2.3
In your opinion, what percentage of older Australians whom you currently care for could die in the next 12 months? (n = 87)		
<25	31	35.6
25–50	34	39.1
50–75	19	21.8
>75	3	3.4
Do you work in a multi-disciplinary team? (n = 84)		
Yes	72	85.7
No	12	14.3
How confident are you at recognising palliative care needs in older Australians? (n = 88)		
Completely confident/fairly confident	53	60.2
Somewhat confident/not very confident/not at all confident	35	39.7
How confident are you in providing care to older Australians with palliative care needs? (n = 87)		
Completely confident/fairly confident	57	65.5
Somewhat confident/not very confident/not at all confident	30	34.4
How confident are you at defining your role at work when caring for older Australians with palliative care needs? (n = 84)		
Completely confident/Fairly confident	54	64.3
Somewhat confident/Not very confident/Not at all confident	30	35.7
How satisfied are you with workplace support in caring for those with palliative care needs? (n = 83)		
Very satisfied/Satisfied	41	49.4
Neutral	26	31.3
Unsatisfied/Very unsatisfied	16	19.3
Do clinical practice guidelines need to be developed to better support your work practice in palliative care? (n = 106)		
Yes	101	95.3
No	5	4.7
Current perceived workplace limitations (tick all that apply) (n = 77) ^B		
Workplace policy	13	9.1
Insufficient funding	40	28.0
Time constraints	54	37.8
A limited understanding of the scope of your role working with older Australians with palliative care needs	36	25.2

^ANumber of AH respondents = 99. Multiple responses for this question resulted in a total of 200 responses (i.e. result contains 'yes' responses only).^BNumber of AH respondents = 77. Multiple responses for this question resulted in a total of 143 responses (i.e. result contains 'yes' responses only).

Table 3. In your current role caring for older Australians with palliative care needs, have you been involved in the following eight domains of end-of-life care?

Eight domains of the ELDAC Care Model	Yes	No	Total
	<i>n</i>	<i>n</i>	<i>N</i>
	%	%	%
Advance care planning, to be aware of the wishes and preferences of the individual	46 54.8	38 45.2	84 100.0
Recognising end of life by proactively considering whether the person could have changes indicating that death is foreseeable	45 54.2	38 45.8	83 100.0
Assessing palliative care needs, to enable comprehensive identification and planning of care	46 56.1	36 43.9	82 100.0
Providing palliative care including delivering care, reassessing needs and monitoring for changes	64 76.2	20 23.8	84 100.0
Working together as a team to meet the specific needs of the individual	79 94.0	5 6.0	84 100.0
Responding to deterioration so that changing needs are identified, and care plans updated to meet new care needs	73 88.0	10 12.0	83 100.0
Managing dying with an appropriate plan for the last days of a patient's life	22 26.5	61 73.5	83 100.0
Bereavement so that family, friends, residents and staff are supported with grief and loss	29 34.9	54 65.1	83 100.0

AHPs felt undergraduate education left them underprepared to work with people at the end of life (Morgan et al. 2019a). The need for an appropriate skill set and qualifications for all disciplines, including allied health, is recommended in the National Palliative Care Standards (Palliative Care Australia 2018).

More than half of the respondents in this study reported timing and funding constraints as a major factor limiting their ability to provide appropriate care. Further, 25% of participants reported that the scope of their role when working with people who had palliative care needs was poorly understood. The 'Matter of Care' Aged Care Workforce Strategy states there is a risk of scope creep for nursing in aged care and its role in contributing to their burn out by expecting nurses to take on jobs outside their scope of practice, rendering them unable to fully utilise their technical skills (Aged Care Workforce Strategy Taskforce 2018). However, the same document proposes that nurses extend their scope of practice to address residents' functional and cognitive needs (p. 25). Increased utilisation of AHPs' skilled expertise in optimising physical and cognitive function would not only improve older Australians' quality of life, but reduce pressure on nursing staff to take on jobs outside their scope of practice. Although approved changes to Australian legislation will require a registered nurse onsite and on duty 24 h a day, 7 days a week, which could support care for residents with palliative care needs and those coming to the end of their life, there is still a limited uptake of AHPs in RACFs and this warrants review for the reasons discussed below.

Allied health professionals' expertise lies in their skilled assessments and interventions to optimise physical and cognitive function for older people approaching the end of their life while minimising risk (Chahda et al. 2017; Nielsen et al. 2017; Blackler et al. 2018; Brett et al. 2019; Matlick et al. 2019; Sterke et al. 2021). A multidisciplinary approach with strong AHP representation is already employed in rehabilitation wards across Australia's hospitals and in the community. Multidisciplinary rehabilitation contributes to *optimising physical and cognitive function* and offers practical support and education of formal and informal carers. A rehabilitative approach has been endorsed by a 2021 World Health Organization (WHO) report on health services and palliative care (World Health Organization (WHO) 2021) as an integral part of care for those with palliative care and end-of-life needs, as it can optimise function, and reduce unwanted hospital admissions and health complications. A rehabilitative approach for end-of-life care in an aged care context could support nursing and personal care staff, and family carers while optimising older adults' safety, independence and quality of living at the end of life.

An Australian study of trajectories of functional decline at the end of life found that people, especially those with dementia, experience sustained periods of dependency on others (Morgan et al. 2019b). The Royal Commission into Aged Care Quality and Safety (2021b) was clear in its message about the potential contribution of allied health and the maintenance of quality of life and function as far as possible, including through to the end of life. As the Commission Report notes: 'Older people and their carers should be supported to balance their care needs. If older people wish to undertake social and community-based activities, or access equipment and technology to make life easier, they should be able to do so. *They should have access to a wide range of allied health services to maintain or improve their capacities and prevent deterioration as far as practicable.*' (p. 36). Assessment for, and prescription of, assistive equipment to optimise function in aged care is core business for AHPs (Nielsen et al. 2017; Blackler et al. 2018; Matlick et al. 2019; Sterke et al. 2021).

Earlier research has identified the need for free, accessible, relevant educational and professional development resources to support allied health clinical practice with people who have palliative or end-of-life care needs (Morgan et al. 2019a). Given 95% of respondents in this study indicated a need for allied health-specific clinical practice guidelines, mapping existing guidance within the allied health, aged care and palliative care peak bodies should be undertaken. Moreover, given most respondents report working with clients and residents from very diverse cultures and backgrounds, resources relating to the aged care diversity framework could facilitate widespread AHP support for person-centred care at the end of life. Both person-centred care, which looks at the whole person, not just their health problem, and consumer-directed care, which sees the older person as

in control of decisions about their care, recognise the importance of the older person in care decisions and practices (Håkansson Eklund *et al.* 2019).

Finally, with around one-third of participants working in both residential aged care and with clients on a home care package, these AHPs can face challenges in navigating multiple reporting and funding systems, adding to the complexity of their professional practice. Information and clarity about communication practices, pathways of care and integrated care processes may be of value. Digital solutions with respect to practice management and reporting to those commissioning allied health services may also be valued.

ELDAC has a potential role to play nationally by signposting to and/or developing articulated resources and guidance to support AHPs working within the aged care sector. This would complement existing palliative care training and knowledge resources, such as the Program of Experience in the Palliative Approach (PEPA) or CareSearch's Allied Health Hub funded through the Australian Government's National Palliative Care Program.

Conclusion

Allied health practitioners are a heterogeneous group of providers with specialised and unique skills, which facilitate a consumer-directed approach to care, as promoted through the aged care quality standards and is consistent with palliative care principles. This study investigated the role of the allied health workforce in contributing to the care of older Australians at the end of life. It has also demonstrated that there are gaps in practice activity and work role that must be addressed to ensure this workforce can support older people with palliative care needs in receipt of aged care services.

Limitations

This paper reports on findings from a self-selected group of allied health professionals and may therefore not represent the views of all allied health professionals working in aged care who may be providing support to an older person coming to the end of their life or with palliative care needs. Analysis of data may not capture differences between home-based aged care and residential care. Despite a considered approach to promotion and distribution and contact with the allied health professional bodies, the number of respondents was low. Again, this may affect the generalisability of the data. Data on three allied health professional groups only was included in this paper as the number of respondents for other professional groups, such as social workers or music therapists, were too low to be meaningfully analysed.

Supplementary material

Supplementary material is available [online](#).

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Data availability. The data that support this study will be shared upon reasonable request to the corresponding author.

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