



Archived at the Flinders Academic Commons:

<http://dspace.flinders.edu.au/dspace/>

'This is the peer reviewed version of the following article:

Morgan, Deidre & Rawlings, Deb & Button, Elizabeth & Tieman, Jennifer. (2019). Allied Health clinicians' understanding of palliative care as it relates to patients, caregivers, and health clinicians: A cross-sectional survey. *Journal of Allied Health*. 48. 127-133.

which has been published in final form at

<https://www.ingentaconnect.com/contentone/asahp/jah/2019/00000048/00000002/art00010>

© 2019 Journal of Allied Health and Association of Schools of Allied Health Professionals

Cover Page

Title: Allied health clinicians' understanding of palliative care as it relates to patients, caregivers and health clinicians: A cross-sectional survey

Authors:

Deidre Morgan ¹	BAppSc(OT), GDip Pastoral Counselling, PG Cert Pall Care, MCISc(OT), PhD
Deb Rawlings ¹	RN, BSc (Hons), MPH
Elizabeth Button ¹	BPsych (Hons)
Jennifer Tieman ¹	BSc(Hons), MBA, PhD

¹ Palliative and Supportive Services, College of Nursing and Health Sciences, Flinders University

Corresponding author:

Dr Deidre Morgan

Lecturer

Palliative and Supportive Services, College of Nursing and Health Sciences, Flinders University

GPO Box 2100

Adelaide SA 5001

Ph: +61 8 7221 8220

NB: No FAX number

deidre.morgan@flinders.edu.au

Abstract

Purpose:

This study sought to elicit Allied Health (AH) clinicians' understanding and views about palliative care, its relevance to their clinical practice and to identify their educational needs. This paper presents the results from analysis of free text survey responses to a single open-ended question from a larger survey.

Methods:

An ethics-approved online survey was distributed to AH clinicians via email lists for the CareSearch Allied Health Hub, Allied Health Professions Australia and a range of other groups. Descriptive statistics and content analysis of free text responses were used to analyse the data.

Results:

A total of 217 AH clinicians responded to an email survey and 187 useable responses were analysed. Four themes were identified: 1. Palliative care employs a client-centred model of care, 2. Acknowledgement of living whilst dying, 3. Interdisciplinary palliative care interventions provide active care in a range of domains and 4. Characteristics of palliative care teams and settings.

Conclusion:

Allied Health clinicians plan an active role in physical, social, and psycho-spiritual care of palliative care patients and caregivers. Burgeoning numbers of palliative care patients in non-specialist palliative care settings requires AH clinicians to develop skills and competencies to work with people who have advanced disease.

Key words

Allied health, palliative care, survey, clinical practice, competencies

Introduction

Palliative care is now an established medical specialty; however, there has been a shift in the focus of clinical care which has significant implications for allied health (AH). In its early stages, the primary focus of palliative or hospice clinical care was symptom management, end-stage care and psycho-spiritual care for those with days to months to live.^(1, 2) It developed in response to a health system's limited approach to care provision for those who could not be cured and who often had a short prognosis. Care was provided by physicians, nurses and pastoral carers and primarily to people with advanced cancer. However, the scope of hospice or palliative care has expanded since its inception⁽³⁾ in response to a number of factors. These include extended prognoses for a range of diseases such as end stage organ failure, chronic neurological conditions and dementias.⁽⁴⁾ While not everyone will require specialist palliative care, everyone will need their palliative care needs addressed and care needs to occur in a range of health care settings and across the life course.⁽⁵⁾ Importantly, the trajectory towards death is not always clear for diagnoses other than cancer.^(6, 7) So how do these factors impact the AH workforce?

When we consider palliative care within the context of the last 12 months of life and across a range of diagnoses, there are significant ramifications for the AH workforce. Terminology used around care is confusing for clinicians and the community alike.⁽⁸⁾ "Palliative", "hospice", "terminal" and "end-of-life care" are used interchangeably in the literature and by general society. "Palliative" may be used to describe a philosophy, type of service provision, a physical building or clinical care that may be provided over the last months to weeks of life.⁽¹⁾ For the purposes of this paper, palliative care will pertain to care provided in the last weeks to months of life. Terminal care will be defined as the last days to hours of life. Palliative care may include the terminal care phase, but extends beyond it to earlier in the trajectory, reflecting both prognosis and care needs.

The World Health Organisation has identified defining characteristics of palliative care⁽³⁾. This definition highlights management of medical needs, relief of suffering and psycho-spiritual care of people who are dying. Of particular importance to AH is the reference to provision of a support system that supports active living over the course of the disease trajectory. The World Health Assembly (WHA) Palliative Care⁽⁵⁾ notes that palliative care

should be introduced early whenever possible, and across the continuum of care including inpatient and outpatient care. It also notes care is delivered via an interdisciplinary approach.⁽⁹⁾ Development of palliative care as an AH clinical speciality in recent years has led to the emergence of AH specific palliative care research and the introduction of palliative care into AH curriculums around the globe.⁽¹⁰⁾ It has also led to the development of specialist palliative care AH positions in some settings. However, palliative care cannot remain as a clinical speciality accessible only for the few, as we then run the risk of providing substandard care to a burgeoning group of people needing skilled end-of-life care.⁽¹¹⁾ This is recognised in the WHA's 2014 statement which urges member states

“to develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage scheme” (p.3).⁽⁵⁾

This study was a sub-study of a larger evaluation study that aimed to survey AH clinicians across Australia on their views about and experiences with palliative care, their educational and clinical information needs and implications for clinical practice. An evaluation was completed with a view to revising AH resources and content on the CareSearch website.^(12, 13) This paper presents the results from analysis of free text survey responses to Question 1 from the section that explored AH clinicians' perspectives about their understanding of what palliative care involved for patients, families and health clinicians. Understanding palliative care as seen through the AH lens will identify AH unique issues as they relate to palliative care service delivery. A survey of this nature with this cohort of AH has not been conducted previously. Other survey results will be reported separately.

Methods

This cross-sectional online survey was conducted from 1st November 2015 – 30th April 2016 with Allied Health professionals as represented in the CareSearch Allied Health Hub (www.caresearch.com.au). Disciplines represented in the Allied Health Hub include dietitians, music therapists, occupational therapists, physiotherapists, psychologists, social

workers and speech pathologists. Ethical approval was granted by Flinders University Social and Behavioural Research Ethics Committee (Project Reference 7014).

Survey Design

Survey questions were piloted with the CareSearch Allied Health Hub advisory group (representatives of the aforementioned Allied Health peak bodies) and the Executive Officer at Allied Health Professions Australia (AHPA) for face validity. User testing of the functionality of the online survey was also tested prior to dissemination. The 15 minute survey was purpose designed to elicit answers to the following research questions:

1. What are AH clinicians' perspectives and understanding about palliative care?
2. In what ways is palliative care relevant to AH clinical practice?
3. What are AH clinicians' educational and professional development needs as they relate to palliative care?

The 42 item survey was arranged in 4 parts, and comprised of fixed responses, Likert scales and free text responses. Survey sections included Understanding about palliative care, Educational needs, Clinical practice and Demographics. This paper evaluates responses to *Section 1, Question 1: Please describe what you think palliative care involves for patients, families and the health practitioner?* The survey was hosted on the CareSearch Research Data Management System (RDMS), a secure platform which is managed by Flinders University, South Australia. Full survey results will be reported elsewhere.

Sampling and recruitment

The invitation to participate was directed to the AH disciplines represented in the CareSearch Allied Health Hub, namely dietitians, music therapists, occupational therapists, physiotherapists, psychologists, social workers and speech pathologists. Potential respondents were contacted directly, with emails distributed to subscribers to the Allied Health Hub and Allied Health Professions Australia email lists. They were also distributed via Allied Health Professions Australia to each of the 18 organisations that they represent (over 120,000 practicing Allied Health Professionals). Each professional body then chose whether to promote the survey via email or newsletter inclusion. Potential respondents were directed to a link that enabled them to take the online survey. To extend the reach of the survey, an ethics amendment enabled dissemination via peak bodies, primary health networks, other allied health mailing lists and social media channels such as LinkedIn,

Twitter and Facebook. The email invitation to potential respondents noted the investigators and affiliations, and the purpose of the survey which was to elicit their perspectives and experiences with palliative care.

Data analysis

Data were exported directly from the CareSearch RDMS to Excel. Free text survey data for Question 1 were organised and managed using Excel. Conceptual concept analysis was inductive and entailed immersion in the data, development of coding categories and subcodes.⁽¹⁴⁻¹⁶⁾ Identified patterns and themes were informed by respondent perspectives and experiences relating to clinical interventions, health service and clinician factors.^(15, 17) Initial coding and subcoding was undertaken by EB, and subsequently refined by EB, DR, DM and JT.^(14, 17, 18)

Results

A total of 217 allied health professionals provided responses to this survey. Responses were not compulsory for all survey items which resulted in a range of missing data for each survey item. There were a total of 192 responses to Question 1. Of these, 187 were useable responses, while 5 were not useable as the data was corrupted or nonsensical. The number of words per response ranged from 3 to 246 and the median was 53.01. Participant responses were not identifiable by discipline unless it was explicitly stated in the response.

Respondent characteristics

Responses were received from dietitians, music therapists, occupational therapists, physiotherapists, psychologists, social workers and speech pathologists. Two Registered nurses responded to the survey and had dual roles of diabetes educator and an 'Early intervention in chronic disease coordinator'. One hundred and thirty respondents were women, 10 were men and 45 did not identify their gender.

Themes and subthemes

This analysis identified four themes which were further divided into eight subthemes. Theme and subtheme content is outlined in Table 1.

1. *Palliative care employs a client-centred model of care.*

Palliative care adopts a holistic approach to care. It aims to reduce suffering and symptom burden and optimise comfort wherever possible. The patient and family's

wishes and priorities are respected and observed. Futile medical treatment is ceased, and shifts from curative care to prioritising patients' goals. Clinicians employ 'person-centred care' aimed at supporting the patient's dignity as they approach the end of their life. A description by one participant articulates this well:

"Client centred proactive care completely based on client's wishes and values. Rapport between client, family and professional."

2. *Acknowledgement of living whilst dying.*

Palliative care involves providing care to a person with a life-limiting condition or nearing the end of their life. However, respondents highlighted that palliative care places a focus on the patient's continued engagement in active living and priority is given to enhancing quality of life over quantity of life. Acknowledgement of living whilst dying is evidenced by planning for future care, discharge planning and planning for death. A number of respondents noted that dying and death are a routine and integral part of care. This may include discussions by health care clinicians with patients and families about dying, preparing people for deterioration and supporting them as this occurs and facilitating a 'good death'. It also extends beyond care of the patient into the phases of grief, bereavement and loss for those closest to the patient. Examples of this can be seen in the following comments:

"This includes seeing a patient as more than someone facing imminent death. As with all patients, the focus is on improving what time we have left."

"Enhancing quality of life by managing symptoms and helping people engage in the activities they wish to do towards the end of their life."

3. *Interdisciplinary palliative care interventions provide active care in a range of domains.*

An active approach is taken with symptom control which includes pharmacological and non-pharmacological symptom management. Discipline specific support is also provided to patients and families and includes

- spiritual care, emotional and social support (e.g. finalising financial issues/wills within cultural contexts).
- provision of education and resources, counselling and guidance
- coordination of support services, linking patients into other services, referring on to other relevant health care professionals.
- provision of rehabilitation to increase, optimise or maintain a patient's function, and participation on meaningful activities
- education to patients and families about safety in everyday activities

Patients and families are presented with options and then supported in the decision making process. Respondents noted that palliative care should be implemented from the point of diagnosis, not simply in the terminal phase of life (weeks to days).

Palliative Care involves the management of symptoms whether they be physical - management of pain, nausea etc, functional - difficulty participating in everyday activities, preferred occupations etc and emotional - grief and loss, adjustment issues. It can involve empowerment where patients and family members are supported to arrange legal and end of life paperwork. For families it can involve education and support to help them to care for their family member safely and successfully.

4. *Characteristics of palliative care teams and settings*

Palliative care employs an interdisciplinary or multidisciplinary approach where health clinicians, patient and family work together to coordinate care. Several respondents suggested that health professionals need a specific set of skills or attributes. These include empathy, patience, creativity, flexibility, determination, care, compassion, honesty, respect, encouragement and effective communication skills that enable the development of rapport and provision of reassurance. A small number of respondents noted that palliative care clinicians require specialised knowledge and skills and that self-awareness may lead to self-care. Palliative care may be provided in a variety of settings, including the patient's own home, inpatient settings and respite care.

Palliative care is specialised multidisciplinary (medical, nursing, allied health) management of patients (and their families/caregivers) with life limiting illness. It seeks to optimise management of difficult symptoms to achieve care in the place desired by patient and family; either home, hospital or other care facility. Palliative care is most commonly associated with cancer illnesses, but can be any chronic and debilitating condition. It can be offered as an inpatient or in the community. Palliative care input may improve quality of life for people with advanced disease, and should be offered early in the illness trajectory, not just at end of life.

Discussion

We know that demand for palliative care is growing and will not be able to be met solely by specialist palliative care teams.⁽¹⁹⁾ Also many people at the end of life may not have needs that they require specialist palliative care intervention. However, all people at the end of life need access to palliative care that can address their particular needs.^(20, 21) Consequently, we need to anticipate that *all* health professionals will be interacting with patients and clients who may be in the last stage of their life and this will occur across all settings of care. Allied health clinicians will also be engaged clinically with those who are dying. This study has provided us with significant insights into how AH professionals conceive palliative care and how they perceive it in relation to their professional practice.

Respondents noted that palliative care employs a client-centred model of care. Given the majority of AH workforce does not work in specialist palliative care settings, we need to consider ways in which client or person centred palliative care is similar to and distinct from care of people with non-life threatening diagnoses. Palliative care and AH literature and online resources support the importance of client or person-centred care. Person-centred care principles include being respectful of the person, their autonomy, health beliefs, needs and goals, provision of clear explanations about available care options , and support of clients to achieve these goals.^(22, 23) All concerned, including caregivers, are deemed to be an equal member of the palliative care team and engaged in decision making about care.⁽²⁴⁾ Allied health supported person-centred care in palliative care would also foster shared client-therapist responsibility in achievement of goals and wellbeing in the context of end-

of-life.⁽²⁵⁾ The definitional responses highlight an awareness with the workforce of the importance of patient facing/patient led care, which is essential to the provision of palliative care. Survey findings also indicate that issues of spirituality and suffering are the remit of client-centred palliative care. Active support through to death and bereavement support of caregivers was also identified as an integral part of care.⁽²⁶⁾ However, these are not routine issues addressed by AH clinicians and will be explored in the following section.

Palliative care “affirms life and regards dying as a normal process.”⁽²¹⁾ This has been conceptualised by some AH clinicians as ‘living whilst dying’⁽²⁷⁻²⁹⁾ but what does supporting the dual notion of living whilst dying look like in practice? Allied Health clinicians who work in specialist palliative care units are often (though not always) afforded additional supports to manage the demands of working with patients who will die. Those who work in traditional hospitals and community settings may receive limited or no additional support to work with patients who are dying and their families/caregivers. In a palliative care setting all team members, including AH, may talk openly with patients and caregivers about the implications of deterioration and dying within the scope of their professional discipline and in line with how much the patient and family wish to know.⁽³⁰⁾ However, in generalist settings, these processes are not as straightforward which can be a source of distress for AH clinicians. This in turn may impact ability to plan and implement care interventions with patients and caregivers. Improving and strengthening multidisciplinary shared decision making and education about ways to manage symptoms of advanced disease has been found to support multidisciplinary team members in both generalist and specialist palliative care settings.⁽³¹⁾ Coping with deterioration and death of a patient on a rehabilitation ward or acute hospital ward can be traumatic for staff. Embedding processes to support multidisciplinary team members to identify when someone may be deteriorating⁽³²⁾ and postgraduate self-directed learning can expand post graduate clinician knowledge and support development of new skill sets will support clinicians to work with palliative care patients. Two Australian examples of free online resources for clinicians are CareSearch (<https://www.caresearch.com.au/Caresearch/Default.aspx>) and End-of-Life Essentials (<https://www.caresearch.com.au/CareSearch/tabid/3866/Default.aspx>).

Respondents highlighted the role of symptom management in palliative care. Allied Health clinicians have an integral role in the non-pharmacological management of symptoms such as pain caused by positioning and/or compromised skin integrity,^(33, 34) breathlessness,^(28, 35) lymphoedema^(36, 37), anxiety⁽³⁸⁾ and difficulties with communication and oral intake.^(39, 40) There is an emerging body of literature to support and guide AH symptom management interventions both with patients and with caregivers and families.^(28, 35, 41) Increasing numbers of AH clinicians are undertaking clinical research to develop an evidence base to inform clinical practice. Allied health undergraduate and postgraduate education should incorporate palliative care considerations in training which address discipline specific symptom management techniques alongside communication and psycho-spiritual care.

Rehabilitation to improve, maintain or optimise function of patients receiving palliative care and support caregivers to manage care safely, shares similarities with traditional rehabilitation.^(38, 41) However, rehabilitation for palliative care patients in acute and rehabilitation wards poses challenges for AH clinicians. There is limited time for patients to demonstrate capacity for functional improvement in acute hospitals and inpatient rehabilitation settings. This may be further compromised if symptoms such as pain are poorly managed. Allied health clinicians play a vital role in advocating for effective symptom management and/or extended length of stay to achieve an *optimal* outcome for patients and caregivers in generalist settings. While full independence may not be achievable and deterioration inevitable, optimising patient independence, facilitation of discharge home and support of caregivers to manage this should be considered a successful rehabilitation outcome.^(34, 42, 43)

Limitations of the study

Survey distribution was reliant on partner organisations and several follow up requests were made to redistribute the survey. This paper reports on free text responses to a single question and is an overview of AH understanding about palliative care. Survey respondents were a self-selecting group of clinicians with a potential interest and understanding of palliative care. It may not be representative of AH population so not generalisable.

Conclusions:

Exploring palliative care through an AH lens has identified issues unique to AH clinicians within the context of an interdisciplinary team that also includes the patient and their caregivers. Employing a client-centred model of care, AH interventions seek to meet the patient's needs as they approach death whilst still living, whilst also supporting caregivers. Allied health clinicians have an active role in physical care (optimising function and non-pharmacological symptom management), social, emotional and spiritual care. Given the number of palliative care patients seen in non-specialist palliative care settings will only increase, there is an imperative for AH clinicians to develop skills and competencies to work with this group of people. There is also a mandate for health services and educators to upskill and support AH clinicians to provide skilled and compassionate care.

Reference list

1. Saunders C. The evolution of palliative care. *J Royal Soc Med.* 2001;94(9):430-2.
2. Clark D. 'Total pain', disciplinary power and the body in the work of Cicely Saunders, 1958–1967. *Soc Sci Med.* 1999;49(6):727-36.
3. World Health Organization. WHO definition of palliative care [Available from: <http://www.who.int/cancer/palliative/definition/en/>].
4. Tan H, Bloomer M, Digby R, O'Connor M. End-of-life care in an Australian rehabilitation facility for older people: staff focus groups. *Death Stud.* 2014;38(3):186-93.
5. World Health Assembly. Strengthening of palliative care as a component of comprehensive care throughout the life course: World Health Assembly; 2014 [WHA67.19, Agenda item 5.5.]. Available from: <http://apps.who.int/medicinedocs/documents/s21454en/s21454en.pdf>.
6. Carlucci A, Guerrieri A, Nava S. Palliative care in COPD patients: is it only an end-of-life issue? *Eur Respir Rev.* 2012;21(126):347-54.
7. Kelley AS, Morrison RS. Palliative care for the seriously ill. *New Engl J Med.* 2015;373(8):747-55.
8. Pastrana T, Jünger S, Ostgathe C, Elsner F, Radbruch L. A matter of definition – key elements identified in a discourse analysis of definitions of palliative care. *Palliative Med.* 2008;22(3):222-32.
9. Jünger S, Pestinger M, Elsner F, Krumm N, Radbruch L. Criteria for successful multiprofessional cooperation in palliative care teams. *Palliative Med.* 2007;21(4):347-54.
10. Buhagiar M, Downes J, Shaik A. Providing quality allied health placements in palliative care. *Focus on Health Professional Education.* 2017;18(2):36-46.
11. Rosenwax L, Spilsbury K, McNamara BA, Semmens JB. A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on? *BMC Palliat Care.* 2016;15(1):46.

12. Tieman J. Ensuring quality in online palliative care resources. *Cancers*. 2016;8(12):113.
13. Tieman JJ. Filters and hubs: shortening the distance to palliative care evidence. *Aust J Prim Health*. 2012;18(4):268-73.
14. Writing@CSU. The writing studio. Steps for conducting conceptual analysis [Available from: <https://writing.colostate.edu/guides/page.cfm?pageid=1310&guideid=61>.
15. Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs*. 2008;62(1):107-15.
16. Thomas D. A general inductive approach for analyzing qualitative evaluation data. *Am J Eval*. 2006;27(2):237-46.
17. *Cerritos College Office of Research and Planning*. A brief guide to the analysis of open-ended survey questions. [Available from: http://cms.cerritos.edu/uploads/researchandplanning/brief_guide_to_open-ended_survey_questions.pdf.
18. Corr L, Rowe H, Fisher J. Mothers' perceptions of primary health-care providers: thematic analysis of responses to open-ended survey questions. *Aust J Prim Health*. 2015;21(1):58-65.
19. Quill TE, Abernethy AP. Generalist plus specialist palliative care — creating a more sustainable model. *New Engl J Med*. 2013;368(13):1173-5.
20. Gomes B, Higginson I. Where people die (1974—2030): past trends, future projections and implications for care. *Palliative Med*. 2008;22(1):33-41.
21. World Health Organization. World report on ageing and health Geneva, Switzerland: *World Health Organization*; 2015 [Available from: <http://www.who.int/ageing/events/world-report-2015-launch/en/>.
22. *CareSearch*. Person centred care [Available from: <https://www.caresearch.com.au/caresearch/tabid/2515/Default.aspx>.
23. *Australian Diabetes Educators Association*. Person-centred care practice toolkit 2016 [Available from: <https://personcentredcare.com.au/>.
24. Crawford G, Price S. Team working: palliative care as a model of interdisciplinary practice. *Med J Aust*. 2003;179(6 Suppl):S32-S4.
25. Pizzi MA. Promoting health and well-being at the end of life through client-centered care. *Scand J Occup Ther*. 2015;22(6):442-9.
26. Mount B, Hanks G, McGoldrick L. The principles of palliative care. In: Fallon M, Hanks G, editors. ABC of palliative care. Malden, Massachusetts: *Blackwell Publishing, BMJ Books*; 2006. p. 1-3.
27. Warne KE, Hoppes S. Lessons in living and dying from my first patient: an autoethnography. *Can J Occup Ther*. 2009;76(4):309-16.
28. White KM. The role of the occupational therapist in the care of people living with lung cancer. *Transl Lung Cancer Res*. 2016;5(3):244-6.
29. Morgan DD, Currow DC, Denehy L, Aranda SA. Living actively in the face of impending death: constantly adjusting to bodily decline at the end-of-life. *BMJ Support Palliat Care*. 2017;7(2):179-88.
30. Clayton JM, Butow PN, Arnold RM, Tattersall MHN. Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients and their caregivers. *Cancer*. 2005;103(9):1965-75.

31. Dong ST, Butow PN, Agar M, Lovell MR, Boyle F, Stockler M, et al. Clinicians' perspectives on managing symptom clusters in advanced cancer: a structured interview study. *J Pain Symptom Manage*. 2016;51(4):706-17.e5.
32. Bloomer MJ, Botti M, Runacres F, Poon P, Barnfield J, Hutchinson AM. End-of-life care for older people in subacute care: a retrospective clinical audit. *Collegian*. 2018.
33. Arbesman M, Sheard K. Systematic Review of the Effectiveness of Occupational Therapy-Related Interventions for People With Amyotrophic Lateral Sclerosis. *Am J Occup Ther*. 2014;68(1):20-6.
34. Schleinich MA, Warren S, Nikolaichuk C, Kaasa T, Watanabe S. Palliative care rehabilitation survey: a pilot study of patients' priorities for rehabilitation goals. *Palliative Med*. 2008;22(7):822-30.
35. Gysels M, Reilly CC, Jolley CJ, Pannell C, Spoorendonk F, Bellas H, et al. How does a new breathlessness support service affect patients? *Eur Respir J*. 2015;46(5):1515-8.
36. Hewitt B, Bugden E, Levinson P. Lymphoedema management in palliative care. *Cancer Forum*. 2010;34(2):83-5.
37. Cobbe S, Real S, Slattery S. Assessment, treatment goals and interventions for oedema/lymphoedema in palliative care. *Int J Palliat Nurs*. 2017;23(3):111-9.
38. Kasven-Gonzalez N, Souverain R, Miale S. Improving quality of life through rehabilitation in palliative care: Case report. *Palliat Support Care*. 2010;8(3):359-69.
39. Chahda L, Mathisen BA, Carey LB. The role of speech-language pathologists in adult palliative care. *Int J Speech-Language Pa*. 2017;19(1):58-68.
40. Pinto I, Pereira J, Campos C, Thompson J. The dietitian's role in palliative care: a qualitative study exploring the scope and emerging competencies for dietitians in palliative care. *J Palliat Care Med*. 2016;6(2):1-8.
41. Bartley C, Webb J-A, Bayly J. Multidisciplinary approaches to moving and handling for formal and informal carers in community palliative care. *Int J Palliat Nurs*. 2015;21(1):17-23.
42. Runacres F, Gregory H, Ugalde A. Restorative care for palliative patients: a retrospective clinical audit of outcomes for patients admitted to an inpatient palliative care unit. *BMJ Support Palliat Care*. 2015.
43. Javier NSC, Montagnini ML. Rehabilitation of the hospice and palliative care patient. *J Palliat Med*. 2011;14(5):638-48.

Table 1. Allied health clinicians' understanding of palliative care as it relates to patients, caregivers and clinicians - Frequency counts

Theme 1: Palliative care employs a client centred model of care	
<p>1. <i>Palliative care is holistic and aims to improve comfort, reduce stress and actively values patient priorities.</i></p>	<ul style="list-style-type: none"> - Palliative care aims to increase the comfort of the patient and minimize stress/suffering/burden. (47) - Palliative care involves utilizing a holistic approach to care. (44) - The patient's (and family's) wishes are listened to and their choices and what is important to them are respected. (43) - Futile medical treatments are stopped, and there is a shift from a "curative" focus towards prioritizing the patient's goals. (34) - Palliative care involves the health clinician utilizing a "client care" or "person-centered care" approach. (30) - Supporting the patient's dignity during the end of their life is an important aspect of palliative care. (17)
Theme 2: Acknowledgement of living whilst dying	
<p>2. <i>Palliative care involves working with a patient with a life limiting condition and includes consideration of death and dying.</i></p>	<ul style="list-style-type: none"> - Palliative care involves a patient with a life-limiting condition and/or someone who is nearing the end of their life. (99) - A focus is placed on living and the patient's life, and priority is given to quality of life over quantity of life. (79) - Palliative care involves planning for future care, planning for discharge, and planning for death. (28) - Palliative care extends beyond care during the patient's life & into the phase of grief, bereavement, & loss for those close to the patient. (21) - Considers dying and death as a routine part of care, which includes: preparing people from death, helping people to accept death, talking about death, and helping to create a "good death." (16) - Involves adjustment to change and/or a journey through stages. (9) - Healthcare professionals are providing support to patients and families at a time that is very difficult for them. (3)
Theme 3: Interdisciplinary palliative care interventions provide active care in a range of domains	
<p>3. <i>Interdisciplinary palliative care interventions provide active care across a range of domains.</i></p>	<ul style="list-style-type: none"> - An active approach (2) is taken to symptom control or symptom management (52) and includes the provision of medication, and nutrition advice and management of pain.(28) - Health professionals working in palliative care assess (2), treat, manage,& address a range of symptoms (28) - Palliative care involves taking a proactive approach to care and should be initiated early in the illness (7) - Palliative care is implemented from the point of diagnosis (5)

<p>4. <i>Palliative care provides support in a range of domains as well as pharmacological management.</i></p>	<ul style="list-style-type: none"> - Allied health clinicians working in palliative care provide discipline-specific support to patients and families, including: <ul style="list-style-type: none"> o Emotional issues/support (39) o Cultural issues/support (5) o Social issues/support (including financial, wills, etc.) (26) o Spiritual issues/support (41) o Physical issues/Support (34) - Health care professionals working in palliative care provide education, counselling, information, resources, and guidance (24) - Health care professionals working in palliative care help to coordinate support services, link patients to other services, and refer to other health care professionals (12) - Health Care professionals are involved in the provision of counselling to patients and/or families (11) - Patients and families are presented with options and the patient is supported in the decision making process. (10) - The patient's and family's safety must be considered when providing support/treatment (6) - Palliative care can offer complementary therapies (1)
<p>5. <i>Palliative care may involve rehabilitation to optimise function and support participation in everyday activities.</i></p>	<ul style="list-style-type: none"> - Palliative care can involve provision of rehabilitation (4) in order to increase/optimize/maintain the patient's function (11) - The patient's independence is supported (8) and they are assisted to engage/participate (8) in meaningful (3) activities. (8)
<p>Theme 4: Characteristics of palliative care teams and settings</p>	
<p>6. <i>Palliative care involves multidisciplinary and/or interdisciplinary teams.</i></p>	<ul style="list-style-type: none"> - Palliative care involves an interdisciplinary or multidisciplinary team approach, where different health care providers (& patient & family) work together, collaborate, and coordinate to provide patient care. (31) - Rapport is developed between the patient, family and healthcare professionals. (3) - Palliative care involves nursing (3)
<p>7. <i>Working in palliative care requires healthcare professionals to have a specific set of skills/attributes.</i></p>	<ul style="list-style-type: none"> - Palliative care requires health professionals to have certain personal qualities (e.g. empathy, patience, creativity, flexibility, communication skills, determination, care/compassion, honesty, respect, encouragement, reassurance). (27) - Palliative care requires health professionals to have specific skills/specialized knowledge/experience. (8) - Health professionals working in palliative care must have self-awareness and undertake self-care. (4) - Palliative care is rewarding for healthcare professionals and provides job satisfaction. (2)
<p>8. <i>Palliative care delivery is implemented in a range of health care and home settings and as required.</i></p>	<ul style="list-style-type: none"> - Palliative care can be provided in a variety of settings (including the patient's own home and inpatient settings). (16) - Palliative care can involve an element of respite. (3) - The duration of palliative care provision is not fixed and is unpredictable.(5) - Palliative care support services need to be available at all times. (2)

