

## **Abstract**

### *Objectives*

This study aimed to obtain perspectives from key stakeholders to inform the development of Australian national guidelines for a palliative approach to aged care in the community setting.

### *Method*

A descriptive, exploratory qualitative design was used. Sampling was purposive. Data were collected during audio-taped, semi-structured, individual and focus group interviews that addressed the need for the guidelines and aimed to identify practice areas for inclusion. Thematic analysis was undertaken.

### *Results*

Interviews were conducted across Australia and included 172 participants: health care providers, consumers, volunteers, and researchers/educators. Themes emerging from the data were: *Provision of a Palliative Approach in Community Aged Care, Carer Support, Advance Care Planning, Physical and Psychological Symptom Assessment and Management, Psychosocial Support, Spiritual Support, Issues for Aboriginal or Torres Strait Islander People, Older People from Diverse Cultural and Language Groups, and Clients with Special Needs.*

### *Conclusions*

Findings underpinned development of new guideline documents.

### Key Points

- A palliative approach to home care for older people with life limiting conditions facilitates the planned implementation of palliative care principles by the usual care team.
- This study underpinned the provision of guidelines for a palliative approach in the Australian context by obtaining stakeholder perspectives.
- Findings indicated requirements for the guidelines to: address planned care delivery, and community service delivery issues, over a long trajectory, incorporating support for the family carer; consider specific needs of people with dementia, Indigenous Australians, people from diverse cultural and language groups, and people with other special support requirements; and promote psycho-social and spiritual dimensions of care as well as addressing physical symptoms.

### Key Words

1. aged
2. frail elderly
3. Practice guidelines as a topic
4. palliative care
5. qualitative research

## **INTRODUCTION**

As Australia's population ages, many older people are living for substantial periods of time with life limiting illness and increasing care needs [1]. Whereas palliative care has traditionally addressed malignant disease, there is increasing recognition that it is appropriate in progressive, life limiting, conditions that are common in old age (eg. dementia, frailty, chronic heart failure)[2]. Palliative care promotes quality of life as a priority for those who are becoming increasingly frail; it does not attempt to lengthen or shorten the person's life, but acknowledges that physical, psychological, and spiritual care are needed to ensure comfort [3]. Although the evidence base is still emerging, a recent systematic review [4] found that, when specialist palliative care services were provided, "there was consistent evidence supporting increased patient and carer satisfaction with care and reduced general health care use" (p. 130). There was also qualitative evidence that "home hospice services support families to sustain patient care at home" (p. 121).

Palliative care merits tailoring for older people drawing close to death with life limiting illness. It needs to take account of the potential for incurring high costs from using specialist palliative care when existing aged care services may be able to meet these needs when appropriately resourced, albeit with support (as needed) from specialist palliative care services. Current evidence suggests that this approach should be offered in the early stages of illness and on a needs basis [5]. A palliative approach is advocated as a suitable response to these issues within the Australian context and has been supported internationally by a number of policy and practice documents [2, 6]. This approach implements the key tenets of palliative care but care is primarily delivered by the aged care team [5] and, in keeping with a need to provide guidance for practitioners that is based upon research evidence, the Guidelines for a Palliative Approach in Residential Aged Care [5] were published in 2006 to support Australian aged care providers to provide a palliative approach in the residential setting. However, many older people receive home care towards the end of life. In the most recent national figures, as of June 2011, there were 6,904 Extended Aged Care at Home (EACH) clients and 2,969 EACH Dementia (EACHD) clients [7], with EACH and EACHD packages providing the bulk of high level home care services. From 2010 to 2011, 32% of EACH and 17% of EACHD packages ended because of the death of the client [7]. Also, in a recent national Australian consultation, older people reported a preference to remain at home until death [8] and subsequent government policy initiatives are set to support increased home care options [9].

In 2007, the Australian Government Department of Health and Ageing commissioned the development of guidelines to support practitioners providing a palliative approach to the provision of aged care in the community. It was intended that these guidelines be a companion document for the Guidelines for a Palliative Approach in Residential Aged Care [5]. This paper describes the national consultative process that gathered data to inform the development of the Guidelines for a Palliative Approach for Aged Care in the Community Setting [10, 11]. The objective of this consultation was to obtain perspectives from key stakeholders that would inform the development of the new guidelines and ensure their relevance.

## **METHODS**

### **Design**

A descriptive, exploratory qualitative design, [12, 13] allowed detailed descriptions of the perspectives of key stakeholders to be generated; these were then used to underpin the development of the new guidelines.

Ethical approval for the study was granted from Edith Cowan University (Reference 07-20 TOYE 1939) and the study was therefore conducted in accordance with the Declaration of Helsinki [14].

### **Recruitment and data collection**

In 2007, a purposive sample of key stakeholders was selected from providers and consumers of health care and other services for older adults living in the community throughout Australia. We sought to include those involved with aged care, palliative care, care specific to Indigenous Australians, and multicultural health care in rural, remote, metropolitan, and regional areas. Professional groups targeted include General Practitioners [GPs], geriatricians, and palliative care physicians; nurses working in aged care and specialist palliative care; allied health professionals; and pastoral care providers. We also targeted care workers, volunteers, and those working in culturally specific services, plus older people (aged 65 years and older, 45 years for Indigenous Australians) and carers with experience providing care to an older family member. Sampling aimed to achieve data saturation from each of the target groups (eg. urban, rural and remote participants, differing health professions), that is, we aimed to generate sufficient data from each group to reach data redundancy [15]. To be eligible for inclusion, potential participants needed to be able to speak and understand English.

A snowball sampling technique [16] was used to identify potential participants, whereby people were suggested by the reference group, project team, key aged care organisations across Australia and by participants in the study. These potential participants were contacted by email or post with an introductory letter to offer the opportunity to be interviewed. The project website was also used to disseminate information and invite participants. Individuals could elect to be involved in focus groups or face to face interviews, which were conducted in locations convenient for participants. Phone interviews were also offered to enhance regional and remote representation. All individuals who expressed an interest were provided with an information package and a guide showing questions to be covered in the interview. Written informed consent was obtained prior to participation.

The interview guide was developed by the Guideline Development Group (the authors of this paper) and reviewed by the reference group. Each interview and focus group lasted between 30 and 90 minutes, was audio tape recorded and transcribed verbatim. Participants were asked to consider the Guidelines for a Palliative Approach in Residential Aged Care [5] and suggest any changes necessary to adapt the guidelines for the community setting. Participants were then asked two key questions:

1. What are the areas that you think need to be considered when developing guidelines to assist with providing a palliative approach for aged care in the community setting?
2. Are there any issues that you feel may be specific to the community aged care setting?

### **Data analysis**

Thematic analysis was undertaken, using the six step method described by Braun and Clarke [17]. This involves familiarisation with the data, conducting initial coding, generating themes, reviewing themes for accuracy and fit, defining themes, and reporting themes. Data were managed using QSR International's NVivo (Version 7). Trustworthiness of the research process is demonstrated by its credibility, dependability, confirmability and transferability [18]. We addressed credibility in several ways. We included the interviewer in the analysis process to help ensure that the non-verbal context of the interviews was considered. Initial coding was carried out independently by an experienced qualitative researcher (RM) and the interviewer (KH), with any differences resolved via discussion and returning to the data. We obtained data from consumer and service

provider sources, and we used member checks, whereby several respondents validated the initial coding. To address confirmability, exemplars from interviews are provided to explain the themes and help illustrate how interpretations were reached. Our description of the study's methodology, including the analysis process, enhances dependability. Transferability of study findings is addressed by our descriptions of participants and details of our sample selection process.

## RESULTS

Twenty-two focus group interviews and 31 individual interviews were conducted in 16 locations throughout Australia (see Figure 1). One hundred and seventy two participants were involved (see Table 1) [10, 11]. The mean age of participants was 50 years (SD=12.23, range 21-86 years). Eighty-three percent of participants (n=144) were female and 4.6% (n=8) were of Aboriginal or Torres Strait Islander descent; many (58%, n=100) worked full time.

### Findings of Qualitative Analysis

Nine themes emerged from the consultation:

#### Provision of a Palliative Approach in Community Aged Care

Participants emphasised a need to recognise the difference between a palliative approach and specialist palliative care. Health care providers expressed difficulty in knowing when to refer to a specialist palliative care team and described having clients who required palliative care but did not meet criteria that would allow them to access specialist palliative care services. Specialist palliative care was perceived as being primarily for people with cancer and a prognosis of less than six months. Participants expressed difficulties in defining when a palliative approach for aged care should be implemented in the community setting as the illness trajectory is often prolonged and prognostication is difficult for the many clients experiencing chronic illness and/or dementia. A palliative approach was believed to be left too late, with earlier discussion, planning, and implementation required.

*As soon as an independent individual meets a point where they need supporting, in whatever way it is, they are really reaching that point that their care and implementing a palliative approach needs to be reviewed across the board or discussed. Discussion and communication with everybody involved is absolutely necessary, and that's very much an area that's overlooked or done too late [15].*

Health care providers identified a gap into which many older, chronically ill people may fall between specialist palliative care services and aged care packages. That is, they required a greater level of care than that offered through an aged care package, yet they fail to meet criteria for specialist palliative care. Participants also described dementia as still often not recognised as a condition requiring palliative care. Therefore planning and implementation of end-of-life care for people with dementia was viewed as inadequate. Other issues of concern in terms of providing a palliative approach in the community settings included:

- care coordination when multiple services are involved with one client;
- poor communication and limited sharing of client information between services;
- transitions between sectors, particularly between home, hospital, and aged care facilities;
- inadequate after-hours services limiting home care in deteriorating conditions;
- difficulties accessing respite, with emergency and overnight respite particularly limited;
- a need for crisis care in the home to prevent unnecessary hospital admissions; and
- limited access to health services in rural and remote areas.

Participants emphasised the reliance on unregulated, nonprofessional care staff and volunteers for the delivery of a palliative approach for many community aged care. A recommendation was made for the development of a 'plain English' version of the guideline document for use by care workers and volunteers.

### **Carer Support**

Caregiving was described as "hard work" that may continue for several years [FG20], and pivotal to providing a palliative approach for aged care in the community and allowing fulfilment of a client's wish to die at home. Participants described how carers often forfeit their own health and wellbeing to continue caring and stressed the importance of 'caring for the carer' and monitoring impacts on the carer's physical and psychological health. Involving carers in all decision making was viewed as imperative to ensure that plans of care are appropriate and likely to succeed. Participants stressed the importance of considering the carer's wishes as well as those of the client. For example, participants explained the necessity of the family carer's support for a client to allow fulfilment of a wish to die at home.

*The person who is dying might say they want to go home to die, but the family might be unwilling to have the person come home... Whilst a lot of families have incredible aspirations to support their family member to live out their lives and finish up the way they want to, the capacity isn't always there [I19].*

There are many issues that arise with having family members perform complex tasks; however, these issues are inevitable when maintaining their family member at home, particularly towards the end-of-life. The need for appropriate resources such as simple and practical information led to a recommendation for another 'plain English' version of the documents for consumers and their carers. Participants stressed the importance of education, empowerment, and support from all care providers for carers to continue this role.

### **Advance Care Planning**

Participants spoke of the value of advance care planning, but indicated such care plans are used infrequently and are often poorly developed. Time constraints, a lack of knowledge related to the legal aspects of advance care plans, practical concern such as where to keep the documentation and who should have access, and ensuring updates of advance care plans were concerns expressed. The need for development of an advance care plan earlier, rather than later, was also stressed by participants, especially when the older person was experiencing dementia:

*And a problem with a lot of our clients too is that they haven't got the capacity to make those decisions, but it's too late and nothing has been done and that also then becomes a huge problem when you've got someone with dementia... they've lost their capacity and nobody has officially got the power to make a decision [FG1].*

### **Physical and Psychological Symptom Assessment and Management**

It was recognised that community clients experienced the same range of physical and psychological symptoms as those in Residential Aged Care Facilities. Inpatient admissions were described as often resulting from a failure to control symptoms adequately in the community. Difficulties were associated with assessments conducted by multiple care providers, lack of access

to a common database, lack of continuity of care staff, and the use of locum general practitioners (particularly after-hours). Participants also noted that psychological symptoms can be hidden by well-meaning family carers in the community setting.

Medication compliance was highlighted as a particular problem. Reasons provided for non-compliance varied, but the lack of supervision from staff was considered a major issue. Health care professionals also discussed issues associated with family carers having to dispense and administer medicines. Concerns about the use, storage, and cost of medicines were emphasised by both consumers and health care providers.

Despite a client's wish to die at home, which is supported by their families, care requirements increase and become more complex as the terminal phase approaches:

*The care at end-of-life actually becomes much more intense and time consuming. There are more agencies involved and there is a lot more happening and a lot more going on, so that sort of flows on to the family and caregivers as well [FG9].*

Participants also described limited flexibility in aged care packages to accommodate this change because of restrictions to the care hours that can be provided.

### **Psychosocial Support**

Participants felt that the level of social support was a deciding factor with regard to the older person remaining in the home. Concern was expressed over social isolation experienced by many older people in their own homes. A thorough assessment of the client's social network was seen as important. Main concerns were the 'invasion' of the care provider into the client's home and consideration that a 'clinical environment' should not be created.

Bereavement support was described as fundamental to providing a holistic approach to care, but often absent from community care services. Programs were viewed as poorly implemented and *ad hoc*. The lack of allocated funding for bereavement support was perceived as a significant barrier. There was recognition that bereavement care needs to be flexible and provided to both families and care workers:

*I think it's acknowledging that people do grieve in different ways and at different times and it's not always immediate. So I think it's having a range of strategies or a range of options that sit around that. [FG9].*

### **Spiritual Support**

Spiritual support was thought to need specific consideration in a palliative approach but the topic was not covered in great depth by participants. A difference between religion and spirituality was noted:

*I don't see spiritual support as being entirely about religion. It's the existentialist stuff. It's part of that meaning of life [FG9].*

Health care providers felt that early assessment of a client's spiritual support would enable specific needs to be identified and appropriate resources or services (religious or other) obtained if

required. Pastoral care workers were described as an important part of the multidisciplinary team and some participants felt that their role was often under-valued or misconstrued.

### **Issues for Aboriginal or Torres Strait Islander People**

When participants spoke of a palliative approach for older Aboriginal or Torres Strait Islander Peoples respectful attention to the location of care, death and dying, and traditional healing practices were emphasised. Participants described the importance of the 'right relationship' with the client, which is dictated by cultural traditions. Aboriginal Health Workers were viewed as particularly helpful 'cultural brokers', helping to overcome these barriers. Participants also emphasised the importance of building capacity among Aboriginal communities, by up-skilling and educating individuals to provide care:

*Aboriginal agencies all over often are very clear about building up their confidence, the capacity of the skill of Aboriginal People to be able to support their own people's culture. If someone is passing away, this document altogether could have a role in talking about capacity building and community development around what it means to support Indigenous communities to support people as they are finishing up [FG22].*

Health professionals expressed the need to use culturally appropriate assessment tools for Aboriginal and Torres Strait Islander Peoples. A recommendation was made for the Guidelines for a Palliative Approach for Aged Care in the Community to be produced in a user-friendly format and with accompanying documents in specific Aboriginal languages, or picture format.

### **Older People from Diverse Cultural and Language Groups**

People from culturally and linguistically diverse backgrounds were seen to face many barriers to receiving health care services, particularly communication difficulties. Concerns were noted about making generalisations about cultural needs based upon assumptions about cultures and highlighted the need for careful assessment and cultural sensitivity:

*Because we do have to be mindful of their culture, their values and beliefs and where they're coming from in relation to death and dying [FG9].*

Sensitive information related to palliative care was viewed as needing to be communicated well, preferably in the client's own language. Participants described the use of translation services as effective, but not always readily available and often expensive. Health care professionals were seen as needing to be aware of the use of traditional medicines that might interact with conventional medications.

### **Clients with Special Needs**

Client groups which require care tailored for their individual needs were identified. These included people with mental illness and post-traumatic stress disorder, and people with neurological disorders such as Parkinson's disease and motor neurone disease. Of particular concern were clients who live alone or are experiencing dementia. With increased frailty and decline in functional ability, it becomes progressively more difficult to maintain someone in their own home without a family carer and the opportunity to choose their home as their place of death is

significantly reduced. Participants recognised a need to provide equitable home care opportunities for this group:

*I would say that close to a third of my patients are live aloners. And they are very difficult to care for. And I don't have to tell you the reality is, their admission to a facility, be it hospice or hostel, is premature simply because there is no one there. [FG1].*

## **DISCUSSION AND CONCLUSION**

This widespread consultation was undertaken to underpin the development of the Guidelines for a Palliative Approach for Aged Care in the Community Care Setting [10, 11]. Overall, community health care providers were supportive of the plan to implement a palliative approach to caring for older people in the community. Consultation findings led to the identification of key care domains that were then addressed by the guideline documents, many of which were also addressed in the guidelines provided for residential care [5] and are basic tenets of palliative care [19]. However, the community context for the new guidelines required consideration of different issues and implementation approaches.

The guidelines needed to tailor the provision of high quality community aged care for when the older person's condition is life limiting, recognising that predicting life expectancy can be problematic (eg, in dementia) [20]. In life limiting conditions, quality of life is the priority and potentially futile distressing interventions are avoided. Moreover the meticulous and coordinated planning of care, in which guiding principles are understood and agreed to by all, is essential. Therefore new guidelines were required to address this need for consistent understanding of palliative care principles, and how these principles can be operationalized in community aged care, across the identified care domains.

A key feature of the findings of this study was the recognition of the significant role that family carers have in the provision of care in the community setting. This finding is consistent with Australian Government policy, which also recognises the wishes for older people to stay at home until they die [8, 9]. Both family carers and care workers, who often have limited training, merit consideration of their own needs (eg, for psychosocial support) plus their need for information and training, in consideration of the fact that they are to deliver end-of-life care [21-23]. Our study participants recommended developing 'plain English' versions of the guideline document to address these issues. This resulted in the subsequent development of resources in two booklets, one for older people and their family carers and one for care workers.

There were limitations to this consultation. Despite the large sample there were few GPs represented. Many were approached, but time restrictions limited their involvement and we cannot claim to have reached data saturation in this target group. Time and financial constraints also restricted the number of regional and rural locations that could be involved. However, regional representation was increased by telephone interviews.

It is recognised that the development of guidelines does not, in itself, ensure the use of these guidelines by practitioners. Some of the methodological issues in evaluating the role of guidance in this field were the focus of a recent review [24]. However, reviewing and synthesizing the relevant evidence remains a necessary first step in providing guidance. The Australian Government has acknowledged the difficulties in ensuring that the guidance is made accessible to the community



of practitioners and carers by funding the distribution of the guidelines and the development of education modules based upon the guidelines. All of the resources are available for downloading from CareSearch [www.caresearch.com.au](http://www.caresearch.com.au) (click on What is Palliative Care?>National Palliative Care Program>ComPAC).

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