

PALLIATIVE AGED CARE: COLLABORATIVE PARTNERSHIPS BETWEEN GERONTOLOGY, GERIATRICS AND PALLIATIVE CARE

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SUMMARY

Palliative aged care is rapidly developing as a specialty area, involving the collaboration and combined expertise of the fields of gerontology, geriatric care, and palliative care. The similarities and differences between these fields provide rich ground for complementing and informing each other's practice and perspectives and in working together to develop health and social policy, which acknowledge the unique factors distinguishing the experience of many elderly people with life-limiting illness. In recent years, two significant projects have been initiated in Australia: (1) the Australian Palliative Residential Aged Care Project (APRAC), which developed evidence-based guidelines for palliative aged care; and (2) the joint development of a postgraduate online program in Palliative Care in Aged Care, by the Department of Palliative and Supportive Services and the Centre for Ageing Studies, a WHO Collaborating Centre, both of Flinders University, Adelaide. Both projects have reconciled the paradigms, philosophies, and evidence-based knowledge of both palliative care and aged care to create for the first time a set of guidelines and an educational program, which will inform and influence the development of practice in this important and developing clinical area. [International Journal of Gerontology 2007; 1(3): 112–117]

Key Words: palliative aged care, aged care, clinical guidelines, collaboration, geriatrics, gerontology, palliative care, postgraduate education

Introduction

Palliative aged care is rapidly developing as a specialty area, involving the collaboration and combined expertise of the fields of gerontology, geriatric care, and palliative care. The elderly are the fastest growing demographic in developed countries, and the complexities of their care needs are increasing owing to both clinical and social factors. Improved public health and medical care have resulted in a clinical picture of longer, more complex and less predictable illness and

dying trajectories for elderly people, involving multiple comorbidities with a concomitant need for attentive planning for and addressing of needs between exacerbations or deteriorations¹. Studies suggest that the dying trajectories of the elderly now include an average of 2 or more years of disability, severe enough to require the assistance of a carer with activities of daily living².

Across most developed countries, social changes, including smaller family size, changed family structures and more women (the traditional family carer) working outside the home, mean that elderly people needing care will mostly have this provided by professional carer, both in their own homes and in institutional settings. Decreasing population trends from declining birth rates will further exacerbate workforce issues in the decades ahead.

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This has huge implications for health care systems and for education in end-of-life care for elderly people. Both education and guidelines for practice in palliative aged care must involve a recognition that providing appropriate care to this population requires more than merely transferring palliative care principles to aged care settings. The specific needs of this cohort of palliative care patients must be recognized and addressed³.

Collaboration of Gerontology, Geriatric Care and Palliative Care

Balfour Mount, at the first International Conference on Palliative Care of the Elderly in 1989, argued eloquently that palliative care, geriatrics, and gerontology were in an excellent position to work together in providing excellence in palliative care for elderly dying people⁴.

Several writers have since echoed Mount's call⁵⁻⁷. Unfortunately, the suggestion has rarely been taken up. Ross et al.⁸, in their 2002 study of the experiences of older Canadian adults who were dying, found "little evidence...of collaborative relationships among health care providers, in particular, from the fields of palliative care and gerontology/geriatrics".

In recent years, developments have begun in Australia. In recognizing the need for such a collaboration in guiding practice and educating the health workforce for Palliative Aged Care, the Australian Government initiated two significant projects in 2002:

1. the Australian Palliative Residential Aged Care Project (APRAC), which developed guidelines for palliative aged care and explored the educational needs of palliative aged care workers; and
2. the joint development of a postgraduate online program in Palliative Care in Aged Care, by the Department of Palliative and Supportive Services and the Centre for Ageing Studies, a WHO Collaborating Centre, both of Flinders University, Adelaide.

Both projects have reconciled the paradigms, philosophies, and evidence-based knowledge of both palliative care and aged care to create for the first time a set of guidelines and an educational program, which will inform and influence the development of practice in this important and developing clinical area⁹.

The similarities and differences between the paradigms of gerontology, geriatrics, and palliative care provide rich ground for complementing and informing each other's practice and perspectives and in working

together to develop health and social policy. As relatively new specialty areas, the similar histories of all three reflect a reaction to inadequate (and largely institutional) health care responses to the suffering of vulnerable members of the society⁴. All three deal with issues society tends to ignore: aging, living with life-limiting illness, and dying. Each has challenged acute, highly technological medicine and health care models⁴ and, because of this stance, has operated at the margins of health care, until relatively recent moves into the mainstream.

Yet, gerontology, geriatrics, and palliative care are also holders of discreet, separate and, at times, seemingly contradictory bodies of knowledge and skills, all of which are needed in delivering appropriate palliative aged care. Balancing healthy aging with the realities of chronic disease and the losses associated with dying, and finding better ways of maintaining function as well as comfort during disease progression, are two significant challenges which draw on a synthesis of these bodies of knowledge¹⁰.

Factors in Palliative Aged Care

Several factors distinguish the experience of many elderly people with life-limiting illness. These include illness trajectory, symptom presentation, physiologic and psychological changes, and social factors.

The patterns of illness and dying trajectories led Seale¹¹ to note that elderly patients are often dying of "multiple causes in a slow decline punctuated by a series of critical episodes" so that "the point at which death is expected is much less clear than in cancer".

A palliative approach with meticulous assessment, advance care planning, and the balancing of benefit and burden is essential in managing this illness trajectory well.

Symptom presentation is often more vague in very elderly people, and meanings of symptoms can be difficult to ascertain because of altered physiology, difficulty in articulating what is happening or comorbidities. Amella⁷ claims that the significance of changes in symptoms in the elderly is often unrecognized.

Diminished hearing and vision are common and significantly impact on communication.

Advanced dementia is a common complicating factor. It makes prognostication more difficult, both of the dementia itself and of accompanying medical

conditions. It affects legal competence and the ability to make advance directives and provides challenges in symptom assessment and management¹².

Pharmacodynamic and pharmacokinetic differences in the very old, due to comorbidities, decreased renal and hepatic function and polypharmacy¹³, must also be taken into account.

Social death, “the cessation of the individual person as an active agent in others’ lives¹⁴”, often occurs for ill or disabled elderly people long before physical death^{15–17}, giving rise to a high incidence of depression⁷ and suicide¹⁸. Paradoxically, the understandings of Baltes and others^{19,20} regarding adaptation in aging and the “gain/loss dynamic” have much to teach us in palliative aged care about ways older people adapt to the multiple losses of aging, in this process gaining wisdom which will serve them in dealing with the final losses of dying.

Palliative care for elderly people, particularly in institutional settings, has often been restricted to the terminal phase of illness, with widely varying levels of emotional, spiritual, and cultural support during the progressive later stages of life. Studies have shown that institutionalized care of the dying elderly is often poor in spiritual and emotional care^{21,22}, issues that are valued by people as they approach death.

Recognizing these factors allows clinicians to acknowledge the ways palliative care can and should be managed differently in this context.

Guidelines for a Palliative Approach in Residential Aged Care

The Australian guidelines, first disseminated in 2004 and updated in 2006, have been endorsed by the National Health and Medical Research Council, a significant and invaluable achievement. The guidelines signal important developments in palliative aged care at several levels of care provision, reviewing the evidence base for individual clinical practice and models of care.

The development of the guidelines has been an important process. A national interdisciplinary reference group, after an extensive and expert literature review with careful use of a standard format for evaluation of all the relevant literature that could be identified and national consultation with key stakeholders, end users and expert clinicians, informed the guidelines. Consultations included clinicians expert in aged care, palliative care, education, consumer advocacy, and

volunteering; rural and remote practitioners; and those with knowledge in dementia and cultural aspects of care. This broad consultation process has helped to frame the format, language, and recommendations in ways to optimize uptake and implementation of the guidelines. End-user involvement from early in the process, while occasionally challenging, has resulted in grounded, user-friendly guidelines with high national uptake.

Using the best available evidence, the guidelines clearly set out the parameters of the palliative approach, beginning by directly dealing with the questions of where and when a palliative approach should be implemented and by whom. The concepts of dignity and quality of life provide the underpinning for subsequent discussions of the many aspects of the palliative approach.

The guidelines are significant in a service delivery context of rapid change. Residential aged care facilities now tend to much shorter periods of stay; dependency is higher from the time of admission, with death expected in much shorter periods of time. At the same time, funding, and hence the size of most institutions, continue to evolve. Staff with a wider range of skills and from a wider range of disciplines are needed to provide the complex care more often required. Accreditation, with a focus on attainment of clinical outcomes and management of adverse events, has bolstered industry support for these guidelines¹⁰.

Palliative care in this clinical setting, as noted earlier, has “often been synonymous with the terminal phase of care only—the last few hours to few days where the process of dying is very advanced”¹⁰. The guidelines, in “expand(ing) this view to include earlier phases of the end-of-life trajectories, are likely to markedly improve care for a people with a wide range of problems”¹⁰.

As we have remarked elsewhere, “one of the most refreshing aspects of these guidelines is the breadth with which ‘interdisciplinary’ has been interpreted. Not only is there clear help for primary clinical carers of all disciplines (registered and enrolled nurses, social work, occupational therapy, physical therapy, pastoral care workers, doctors, it specifically seeks to include the ‘hotel’ staff (personal care assistants, cleaning staff, meal staff, administrative staff) and volunteers. A cornerstone of this document is its emphasis on the specific needs for upskilling and support for all these people, so integral to quality care”¹⁰.

Implementation of the guidelines has been well planned and is underway. A funded national program, including education workshops and establishing supportive networks of clinicians, has begun “the long iterative process of cultural change”⁸.

The greatest contribution of these guidelines in the short term may be the explicit and detailed mapping of the current evidence base in this emerging area, revealing clearly what is not yet known, in a carefully constructed matrix to inform future research.

Palliative Aged Care Education

The postgraduate courses initiated by and developed with the support of the Australian Government complement well the education process inherent in the uptake of the guidelines. The postgraduate studies challenge students’ thinking, not only about evidence-based clinical practice, but also about the philosophies, principles, paradigms, and policy that influence that practice.

During the development of the courses, the collaborative partnership between gerontology, clinical geriatrics, psychology and sociology of aging, pharmacology, and palliative care enabled significant conversations between faculty members from the different specialties regarding the philosophies and policies of each paradigm. As these are the major influences on palliative aged care, these philosophical debates impinge very much on the development of palliative aged care as a discreet area of clinical practice. Education in this area must create awareness within students of the philosophical underpinnings of policy and practice and their individual, organizational and structural impacts.

Conversations between different fields of expertise bring their own complexities. There are often presumptions of shared meaning and language, when common terms are used by both groups. Often, however, the terms have discreet meanings within each field and conversers may find that they are speaking at cross purposes. Further still, the meaning of terms may vary between paradigms operating within the same discipline. It is crucial to clarify meanings of shared terminology, not only for each discipline, but as far as is practical, for each individual within disciplines, as understandings and the paradigms and philosophies from which each works may vary significantly.

In developing the courses in Palliative Care in Aged Care, several conversations were based on the range of

interpretations of the terms “healthy aging”, “positive aging” and “successful aging”, terms commonly encountered in texts and policies on aging. Understandings of these terms in relation to death and dying differed from “dying has nothing to do with aging” through to “part of the aging process is preparation for dying”, reflecting the variety of thought in gerontology regarding aging itself.

Successful aging is considered to include: the freedom from disability or disease; maintaining high levels of cognitive and physical function; ongoing social involvement; and productive activity²³. While psychologists acknowledge that success is ultimately evaluated according to one’s own values about what makes a “good life”, physical health seems to be generally accepted as a necessary factor in successful aging. What does this say to the sufferers of progressive, chronic or life-limiting illness? Where do the concepts of “healthy dying” or “dying well” fit into this paradigm?

Policies on positive aging and healthy aging are promoted by governments and organizations internationally²⁴. Defining what is meant by such terms is crucial. Do documents associated with such policies include the possibility of growth and health through the experience of illness, disability or dying as part of the concept? A simplistic view of healthy, positive or successful aging is an understandable response to ageism and the “medicalization” of aging. It has echoes in the ideological promotion of the “good death” in the early days of the palliative care movement as a response to inadequate care of the dying. However, the limited perspectives of simplistic notions of positive aging and a good death do not allow for the broad range of realities of older people, including those who are dying. Such limited ideological positions can exert pressure on the elderly, whether they fit the prevailing definition of successful aging or not. When these ideological positions are enshrined in public policy, their power is even greater.

We need a paradigm that recognizes the paradoxes and integrates the notions of “living until we die”, quality of life, healthy aging and healthy dying within a recognition of the multiple realities of older people, including older, frail and dying people. Palliative Aged Care may well provide the arena in which a balanced view of healthy aging and healthy dying will be more clearly enunciated.

As the range of philosophical positions and paradigms relating to healthy aging were represented across

the faculty within the project team, these became very real discussions for us, highly pertinent to decision-making about the content and philosophy of the postgraduate courses. The discussions raised questions such as:

- What is needed to enable older people to age and die in ways which are congruent with their lives?
- What must we learn across disciplines and fields of knowledge to equip us as health care professionals in providing excellence in palliative care for elderly people?
- How do theories of aging influence attitudes to dying and to practices and support for those needing palliative care?
- How do policies promoting healthy aging help or hinder a healthy dying?
- Does the danger of a limited ideology of “successful aging” mirror the danger of a limited ideology of a good death?

The policy and clinical implications of these and further inter-paradigm discussions are significant at this stage of the development of this emerging specialty area of clinical practice. Students of the postgraduate courses have the opportunity to explore these questions and to integrate them into their practice and the policies of their organizational settings, as well as to gain a strong clinical grounding in the assessment and management of physical, psychosocial, spiritual and cultural aspects of palliative aged care. Creating a new body of clinical academic work from the integration of different fields of knowledge can produce a rich synthesis and an opportunity for students to contrast and critique differing perspectives, including their own. Crucial to the further development of this emerging field and ultimately the quality of care for elderly people with a life-limiting illness is the education of leaders in the field in conceptual and clinical knowledge and skill bases.

Conclusions

While care of elderly people with life-limiting illnesses has always taken place in a variety of ways, recognition of the particular factors affecting this cohort has led to the development of palliative aged care as a specialty area of practice, with a growing body of knowledge and skills. Collaboration between gerontology, geriatrics, and palliative care have involved rich and rewarding processes in developing education and guidelines for

practice in this emerging field of practice. Further collaboration and research will continue its growth.

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