

General Practitioners and Palliative Care

Subjects: Nursing

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General practitioners (GPs) are increasingly expected to provide palliative care as ageing populations put pressure on specialist services. Some GPs, however, cite barriers to providing this care including prognostication challenges and lack of confidence. Palliative care content within clinical practice guidelines might serve as an opportunistic source of informational support to GPs.

Keywords: General Practitioners ; Palliative Care ; Australian Guidelines

1. Introduction

The World Health Organisation's Declaration of Astana calls for palliative care to be both 'accessible to all' and an 'essential component of primary healthcare worldwide'^[1]. This emphasis on palliative care as a fundamental human right makes clear an expectation that palliative care should be a key responsibility of primary care clinicians, including general practitioners (GPs). In Australia, this view aligns with that of the Royal Australian College of General Practitioners (RACGP) whose standards afford 'end-of-life care' a central position within the GP scope of practice and the meaning of 'comprehensive care'^[2]. GPs themselves note similarities in focus between primary and palliative care with their mutual concern for holistic, patient-centred care inclusive of the family unit^{[3][4]}.

There appears to be an expectation that GPs will increasingly provide more palliative care as the number of people reaching old age starts to exceed the capacity of specialist palliative care services^{[5][6][7]}. Many older people will be burdened by multiple chronic comorbidities^[8] requiring ongoing GP management and care coordination. Sustainable palliative care may, therefore, hinge on a 'hierarchy of need' model, with generalists taking on basic elements of palliative care and referring patients with more complex or refractory problems to specialist palliative care^[9].

General practice palliative care offers benefits known to be valued by patients and their families, including accessibility, local knowledge, and relational continuity^{[10][11][12]}. In Australia, where general practice operates as gatekeeper to specialist care, GPs see approximately 90% of the population annually^[13]. This includes people with non-cancer life-limiting conditions such as heart failure and dementia who are often overlooked for specialist palliative care^[14]. There is also growing empirical evidence that GP involvement in palliative care provides measurable benefits including improved quality of life^{[15][16][17]}, maintenance of functional status^{[18][19]}, increased likelihood of dying at home^[20], and reduced health service use^{[16][21]} with its attendant cost savings to the health system^[22].

To date, there is no centralised mechanism for capturing Australian primary health care data detailing the amount of palliative care being provided by general practitioners^{[23][24][25]}. What current information we have comes from GP self-reports. These suggest that the majority of Australian GPs are already providing some palliative care^{[26][27]}, with GPs in rural and remote areas seeing themselves as especially responsible despite being more poorly funded and resourced than their urban colleagues^[28]. However, a considerable proportion of GPs (25–37%) report minimal if any interest or involvement in providing palliative care^{[26][29]}. Given the projected population increase in the number of older people burdened by chronic diseases, high rates of GP unwillingness to care for patients with advanced-stage disease is likely to impact on the workload of other health professionals, social care services, and informal caregivers.

GPs worldwide cite similar barriers to providing palliative care for their patients such as system-level policies and processes that restrict consultation time and remuneration for more complex assessments or home visits^{[30][31][32]}. Primary and secondary health care sector fragmentation has also created role uncertainty for GPs^{[15][26][33][34]} and contributed to poor information flow between the various health professionals involved in care^{[27][35]}. A substantial proportion of GPs, not only in Australia, cite a lack of confidence or skills to manage palliative care patients^{[36][37]}, which may reflect limited exposure to patients with end of life needs^[4] or few training opportunities^[27]. Identifying the point at which chronic or curative care should transition to palliative care^[33] and communicating prognosis to patients is challenging^[32]. Non-malignant conditions such as heart failure, dementia and COPD appear to be particularly problematic

as their less predictable trajectories can generate prognostic uncertainty for GPs [32][38][39]. The nature of the care provided might also vary between GPs. The WHO defines the domains and goals of quality palliative care as being 'the prevention and relief of suffering' achieved through 'early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' [40]. While GPs express confidence in addressing patient physical suffering through pain and symptom relief [4], they appear less confident in anticipating palliative needs via assessments early in the course of a terminal illness [17][21]. Furthermore, some GPs do not promote a 'whole-person' view of the patient when it comes to palliative care [26], avoiding discussions of emotions and spiritual and existential concerns unless raised by patients or their family members [4][11][32][41][42]. Consequently, parts of the population may be at risk of dying without having all their palliative needs met [32][43] or the opportunity to discuss, comprehend, and plan for the end of life [10][11][44].

2. Australian Guidelines

Australian GPs are aware of their need for additional training in palliative care and express a willingness to undertake it [26][27]. They also desire more local sources of information which they can easily absorb and apply in practice [26]. One possible source of information already available to GPs is clinical practice guidelines for individual chronic life-limiting conditions. Credible guidelines, developed via a systematic, explicit process by a panel comprising experts and representatives of all stakeholder groups, can provide sound support for clinical decision making, reduce uncertainty, and serve as a basis for communicating with patients [45][46]. Furthermore, guidelines for single life-limiting conditions such as heart failure often incorporate palliative care content in their attempt to cover the gamut of a condition's trajectory. Guidelines might therefore play a significant role in normalising and demystifying palliative care activities for less confident GPs by specifically addressing their role within the care team, presenting evidence on the benefits of their involvement [47], describing 'optimal' models of integrated or shared care, and providing information on expected trajectories and signs of deterioration specific to the condition in question. Guidelines could also provide GPs with information on established decision aids, tools, strategies, and prompts designed to help them overcome some of the barriers they describe. The Supportive and Palliative Care Indicators Tool (SPICT) for early detection of palliative care needs is one example [48]. Guidelines might also underline the importance of a comprehensive and holistic patient and family assessment by organising content according to the commonly accepted biopsychosocial domains.

Clinical practice guidelines have an important educative role and, by encouraging clinicians to follow 'best' available practice, can build capacity and raise the quality of care [49]. This qualitative analysis of guidelines for progressive, non-curative conditions found considerable heterogeneity in the coverage of palliative care concerns across guidelines for chronic life-limiting conditions. Some of the differences inevitably and appropriately reflect condition-specific considerations, such as the relatively fuller emphasis on clinician-patient communication in the dementia guidelines. However, the rationale behind other differences, including why some domains were not addressed, is not immediately apparent. Some omissions may represent a lost opportunity to educate and guide general practitioners across the full range of considerations involved in a holistic assessment of a patient's palliative care needs.

Despite GP uncertainty as to what constitutes palliative care [26], when it might be introduced [50], and how best to communicate a transition to the end of life phase to patients [51], most guidelines analysed did not include this foundational information. The role of the 'impeccable assessment' of patient needs advocated by the WHO definition of palliative care was absent from all guidelines. Furthermore, most guidelines did not mention the availability of several well-established tools for identifying palliative care needs such as question prompts (e.g., the surprise question) or practical indicator tools such as the SPICT [48].

Standard 5 of Australia's National Palliative Care Standards stresses the importance of establishing seamless and integrated care within and between services, stating: '[w]hen working in partnership with other services, clear strategies for referral, communication and designated areas of responsibility are essential.' Although the guidelines analysed originated within the same country, they provided differing advice on the timing and responsibility for referring patients to specialist care, often without clarifying explanation or mention of a needs-based assessment. One guideline simply directed clinicians to 'refer to palliative care' [52], while another specified referral when faced with more 'challenging situations' [53]. The heart failure guideline recommended clinicians involve palliative care 'early in the heart failure trajectory' yet elsewhere stipulated referring 'advanced' patients with 'end-stage symptoms' to palliative care [52]. The COPD guidelines supported early, anticipatory involvement of palliative care running concurrent to symptom control and active treatment [53]. All guidelines may have benefited from including a conceptual model showing how palliative care might be integrated across the varied levels of patient need, illness trajectories, and different types of palliative care providers [24].

This study confirms findings that emotional and spiritual domains are often lightly addressed, if at all, in guidelines [54]. This appears to mirror clinical practice with studies reporting psychological, social, and spiritual services infrequently deployed by GPs in end-of-life care [4][55][56][57]. We would have expected, however, more consistency in approach to recommendations across the physical domain, which has been found to be dominant in other palliative care guideline content [54]. Some guidelines provided full, symptom-specific advice for the palliative phase of care while others gave no symptom management advice, perhaps considering this aspect adequately covered in earlier chapters. The 'information and communication' domain was strongest across all guidelines, with most emphasising the importance of providing clear, written and culturally appropriate information to patients and their families/carers, at least on disease-specific matters. Most guidelines also advocated for exploring and documenting personal values and priorities of patients in advance care plans. Only one, however, briefly addressed communication between clinicians which is known to be a barrier to GP care provision [18]. Confirming findings of other studies, coverage was poorest for establishing care continuity out of hours [54] and considering the needs of the bereaved [56].

The GP appears as an important 'collaborative' team member during the active treatment phase; however, the role is less clear during the palliative care phase, varying from service coordination, symptom management, or simple referrer. Although all guidelines were situated within the same national context, no guideline addressed the importance of having an effective continuum of palliative care within the Australian health care system which includes the general practitioner. Until the GP role in palliative care is clarified along with the domains and processes that fall within the GP's remit, there seems little benefit to discussions of how to assess GP competence in providing palliative care [58]. This has important implications for the safety, quality and equity of care currently being provided by general practice. Although guidelines cannot resolve concerns with service delivery mechanisms and settings, as these will be influenced by numerous local and systemic factors, recognising these constraints is important given the evidence of GPs' self-identified needs relating to palliative care [4][18][30][32][37]. The fact that these areas are not addressed across the guidelines analysed could be seen as a lost opportunity if non-specialist palliative care is deemed a policy priority and expectation and yet a significant proportion of GPs lack the confidence, education, or skills to provide it. These findings also run contra to World Health Assembly's recommendation that member states 'develop and strengthen ... evidence-based guidelines ...that adequately address ethical issues related to the provision of comprehensive palliative care, such as equitable access, person-centred and respectful care ... and to inform education in pain and symptom management and psychosocial support' [59].

Overall, there was considerable heterogeneity across guidelines as to domains covered and domain elements emphasised. Despite access to the same evidence base, no two guidelines made similar recommendations on the same aspect of care, differing in content, scope and directiveness. Summary versions of full guidelines also differed in the amount and type of information they conveyed, generally omitting much of the palliative care content. Whilst space constraints make this understandable, this still matters if time-poor GPs rely on shorter, more readily accessible guidelines rather than the considerably more informative full versions. Despite being the longest of the guideline summaries, the COPD concise guide for primary care [60] combines a visually interesting layout with concise information, effectively highlighting evidence-based recommendations while providing abundant, yet discreetly placed, practice tips, links to useful supplementary resources, and contact information for relevant local community resources such as the Quitline for smokers. This linking of the evidence of what to do with practical resources advising how to do it arguably provides GPs with more useful guidance than long resources focused purely on providing a precise appraisal of published research studies.

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