



## ORIGINAL ARTICLE

# Delivery and outcomes of end-of-life care in the Australian context: Experiences and reflections of general practitioners

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## Abstract

Previous research on general practitioners' (GPs') involvement in end-of-life care has largely focused on a specific aspect of care or has provided broad overviews that failed to capture individual variations in patient management. This qualitative study aimed to explore Australian GPs' feedback and reflections on the individual-level care provided for patients in their last year of life. The findings of the study were drawn from a nation-wide survey of GPs' experiences in end-of-life care. We analysed responses from 63 GPs for 267 of the 272 reported deaths. Factors influencing delivery of optimal end-of-life care reported by GPs were categorised into four groups: patient-related factors, carer-related factors, interactions between GPs and patients/carers-related factors and broader health system issues. Each group included both barriers and facilitators. Our study highlighted importance of the emotional dimensions of therapeutic relationships with patients and their family, availability and capacity of family support and smooth communication and continuity of care between GPs and hospitals in delivery of optimal end-of-life care. Lack of these facilitators, misconceptions of palliative care and conflicts on implementing care plans among patients and their family tended to impede delivery of such care. On the basis of our findings in the present study and previous literature, we conclude that improved end-of-life care in general practice requires comprehensive approaches to supporting both the GP and family to provide care in patients' preferred place, such as enhanced palliative care training and improved availability of external support for GPs, higher levels of hospital-based services reaching into community settings and broader community-based resources for families beyond simply the healthcare system.

## KEYWORDS

end-of-life care, general practice, qualitative study, survey

Jinfeng Ding and Sharon Licqurish contributed equally to this work.

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## 1 | INTRODUCTION

Provision of high-quality palliative and end-of-life care has become a global health priority to address the needs of ageing populations (Australian Department of Health, 2018; Morrison, 2018; *The Economist Intelligence Unit*, 2015; Van Beek et al., 2013). The majority of older people experience expected deaths from causes such as cancer, cardiovascular disease, dementia, organ failure and frailty, with the use of health services substantially increasing in the last few years of life (Murray et al., 2005). It is neither realistic nor cost-effective to meet the burgeoning care demand with the limited specialist palliative care resources currently available (Brown et al., 2018; Clark et al., 2019; Knaul et al., 2018). A more sustainable model involves the delivery of palliative care by primary care physicians, with support from specialists as required (Quill & Abernethy, 2013). In many countries, this care option involves general practitioners (GPs) to a large extent (Ramanayake et al., 2016; Royal Australian College of General Practitioners, 2016).

Optimal end-of-life care should be accessible and ongoing, and requires a holistic, dynamic and proactive approach, and care providers with excellent interpersonal and communication skills (Herrmann et al., 2019a). As the primary providers and coordinators of health-care for people throughout their lifespan, GPs are well placed to provide end-of-life care (Green et al., 2018). However, GPs face complex, multifaceted challenges in providing optimal care, such as time limitations, insufficient sharing of information and support from specialists, and unsuitable payment models (Carey et al., 2019; Ding et al., 2019; Herrmann et al., 2019b; McCallan et al., 2021; Rhee et al., 2018).

Recently, a number of studies have reported on GPs' experiences and roles in providing palliative and end-of-life care (Deckx et al., 2019a, 2019b; Ding et al., 2019; Herrmann et al., 2019a, 2019b; Rhee et al., 2018; Thomas et al., 2019). However, much of the research has focused on a specific aspect of palliative care delivery—notably the medical aspects of care and interactions with other care services—(Deckx et al., 2019a; McCallan et al., 2021; Thomas et al., 2019) and few have identified the facilitators for GPs in providing such care (Herrmann et al., 2019b). In addition, these studies have often asked questions relating to the end-of-life population in general rather than individual cases, and have not fully explored individual patient management and the role of distinct relationships between GPs and each of their patients (Deckx et al., 2019a; McCallan et al., 2021; Thomas et al., 2019). Studies that ask GPs to comprehensively review and reflect their experience in caring for each patient after death could help to provide a clearer picture of the specific activities and decisions relating to end-of-life care in general practice. This new knowledge and perspective would inform how to provide tailored support for GPs to deliver optimal end-of-life care.

This study aimed to explore Australian GPs' experiences and reflections associated with the delivery of end-of-life care for each patient in their practice and the care outcomes immediately after the patient's death.

### What is known about this topic

- End-of-life care is primarily provided in community settings where people spend most of their last year of life.
- As the primary care providers for people throughout their lifespan in community settings, general practitioners (GPs) are well placed to coordinate end-of-life care.
- Previous qualitative studies on GPs end-of-life care have often asked questions based on overall end-of-life population, and therefore failed to capture individual patient management and the role of distinct relationships between GPs and each of their patients.

### What this paper adds

- The key facilitators for optimal delivery of end-of-life care in general practice included strong doctor–patient relationships, availability and capacity of family support and smooth communication and continuity of care between GPs and hospitals, etc.
- Lack of facilitators were usually reported as the major barriers to optimal delivery of end-of-life care in general practice.
- Comprehensive approaches are required to support optimal delivery of end-of-life care in community settings, such as enhanced palliative care training and improved availability of external support, higher level of hospital-based services reaching into community settings and broader community-based resources for families beyond simply the healthcare system.

## 2 | METHODS

### 2.1 | Study design and process of data collection

This report is part of a larger study conducted from September 2018 to August 2019. In the larger study, GPs were asked to retrospectively report de-identified patient-level data on how and in what circumstances end-of-life care was provided after a notification of a patient's death in their practice. To support the data collection, our team developed a clinic-based data collection process using a modified Delphi technique involving a comprehensive literature review, interviews with GPs and other stakeholders, and a consensus study with internal and external experts from multiple disciplines. A detailed description of the development is included in a previous publication (Ding et al., 2020).

At the end of the clinic-based data collection, the following two open-ended questions were included asking GPs to freely comment on their experiences, reflections, patient outcomes and potential for improvement relating to the care provided for each deceased patient in their last year of life.

Question 1: Do you think the care for this patient could have been improved during the last year of care? (if yes, please comment).

Question 2: Are there any other comments you would like to make about providing care for this patient during the last year of life?

Participating GPs' responses to these two open-ended questions were used as the data source for the present report.

## 2.2 | Recruitment of GPs and study settings

Multiple recruitment strategies were used to invite GPs from three Australian states (Western Australia [WA], Queensland and Victoria) to participate in the larger study. A contact list of general practices was established in the three states. Invitation emails were sent to practice managers (in WA) or GPs (in Queensland and Victoria) and followed up with a phone call or personal visit to answer questions about the project, explain the process of data collection and collect written consent. Information was also extensively distributed by local primary care networks, professional GP organisations and palliative care services. We approached nearly 350 practices in WA, and in Queensland and Victoria, we directly approached approximately 220 and 130 GPs across metropolitan and regional/rural areas.

## 2.3 | Data analysis

Data were analysed inductively line-by-line, using open and axial coding techniques described by Strauss and Corbin (Strauss et al., 1998). In brief, codes were grouped into categories, which were then used to identify a set of themes. Relationships between categories and codes were analysed using focused coding techniques including discussion between researchers, and the constant comparative method to aid conceptual interpretation and analysis, and was informed by the 'theoretical questions' described by Charmaz (Charmaz et al., 2014).

Reliability of the analysis and interpretation about the emerging themes and allocated quotes were enhanced by discussions between SL (a nurse and healthcare researcher in Australia) and JD (who was trained as a nurse and researcher in China but had less experience of Australian EOL care). The final categories and conceptual analysis were discussed with the third senior researcher (AC) who is a medical doctor and epidemiologist. All the researchers involved in the data analysis had qualitative research training and experience in conducting qualitative research. Given the data collection of this study was based on free-text entry within the survey rather than interviews or focus group with GPs, we reported the study findings following the COREQ (COntrolled REporting Qualitative research) Checklist where relevant (Tong et al., 2007). Dedoose 8.0 was used to support data analysis.

## 2.4 | Ethical considerations

This study was approved by The University of Western Australia (RA/4/20/4232), The University of Queensland (# 2018000185) and

Monash University (# 15225) Human Research Ethics Committees. Written consent was obtained from all participating GPs. All three ethics committees approved waiver of consent from decedents included in the study and their families. No personalised information was requested, obtained or used at any stage of the study. All data collected in this study were de-identified and reported only at an aggregate level.

## 3 | FINDINGS

In total, we received reports on 272 deceased patients from the 63 participating GPs. In brief, approximately half of the GPs were male (55.5%), born in Australia (54.0%) and practiced in regional or rural/remote areas (54.0%). (Table 1) On average, they had 23 years of work experience. Less than one-third had formal palliative care training (30.1%), and the right of admitting patients to hospitals (28.6%) and inpatient palliative care services (27.0%).

Of the 272 reported patients, 53.2% were female. (Table 2) They died at a median age of 82 years (IQR: 70–90 years) and most frequently from malignancy (32.5%). The most common place of death was within a residential aged care facility (31.6%). Participating GPs reported that 18.4% of patients died unexpectedly, and that the care could potentially be improved for 32.0% of patients.

Practitioners provided free-text responses to the open-ended questions in nearly all ( $n = 267$ , 98.2%) of the reports, generating a total of 8963 words and 34 words for each report on average.

We identified and grouped the factors influencing delivery of optimal end-of-life care into four categories: patient-related factors, carer-related factors, interactions between GPs and patients/carers-related factors and broader health system issues. (Figure 1).

### 3.1 | Patient-related factors

#### 3.1.1 | Preparation and acceptance

For the majority of cases, GPs described circumstances where the patients were well prepared for end-of-life, accepted their impending death and were able to die with family and palliative care support at their preferred places. The GPs described these patients' end-of-life as 'peaceful', 'dignified' and 'calm'. As one GP said:

This gentleman and his daughter and son coped very well with his terminal care and showed dignity, love and fortitude. [GP52-Case177].

#### 3.1.2 | Sudden deterioration and complex medical conditions

In contrast, a number of GPs discussed situations where their patients died unexpectedly and their sudden deterioration and death

TABLE 1 Characteristics of participating general practitioners

	n (%)
Total number	63
Gender	
Male	35 (55.5)
Female	27 (42.9)
Missing	1 (1.6)
Age group (years)	
<30	2 (3.2)
30–39	11 (17.5)
40–49	13 (20.6)
50–59	24 (38.1)
60–69	10 (15.9)
70+	3 (4.7)
Country of birth	
Australia	34 (54.0)
Outside Australia	28 (44.4)
Missing	1 (1.6)
Country of primary medical training	
Australia	47 (74.6)
Outside Australia	15 (23.8)
Missing	1 (1.6)
Locality of practice	
City (including inner and outer suburbs)	29 (46.0)
Regional (including country towns)	13 (20.6)
Rural and remote	21 (33.4)
GP Registrar <sup>a</sup>	
Yes	6 (9.5)
No	53 (84.1)
Missing	4 (6.4)
Years of GP work	
Mean ± SD	23.0 ± 13.2
Usual work hours/week	
Mean ± SD	40.7 ± 12.4
Received formal palliative care training	
Yes	19 (30.1)
No	43 (68.3)
Missing	1 (1.6)
Use of symptom assessment tools	
Yes	7 (11.1)
No	55 (87.3)
Missing	1 (1.6)
Right to admit patients to hospital	
Yes	18 (28.6)
No	41 (65.1)
Missing	4 (6.3)
Right to admit patients to hospice	
Yes	17 (27.0)

TABLE 1 (Continued)

	n (%)
No	40 (63.5)
Missing	6 (9.5)

aGP Registrar is a fully qualified medical doctor who is undertaking the advanced training in general practice required by the Royal Australian College of General Practitioners to specialise in General Practice.

TABLE 2 Characteristics of reported patients

	n (%)
Total number	272
Gender	
Male	98 (44.5)
Female	117 (53.2)
Missing	5 (2.3)
Age at death	
Median (IQR)	82 (70–90)
Principal diagnosis	
Cancer	86 (32.5)
Cardiovascular disease	49 (18.5)
Neurological disease	37 (14.0)
Respiratory disease	34 (12.8)
Other	59 (21.7)
Missing	7 (2.5)
Place of death	
Residential-aged care facility	86 (31.6)
Hospital apart from palliative care	59 (21.7)
Private residence	58 (21.3)
Inpatient palliative care	56 (20.6)
Other	4 (1.5)
Missing	9 (3.3)
Expectation of death	
Yes	220 (80.9)
No	50 (18.4)
Missing	2 (0.7)
Whether the care could have been improved	
Yes	87 (32.0)
No	175 (64.3)
Missing	10 (3.7)

was not foreseen. There was often insufficient time to prepare the patient or their family:

She stayed remarkably well during most of her cancer illness, but maybe I and the other clinicians could have prepared her and the family for a sudden deterioration...This lady had serious comorbidities, which

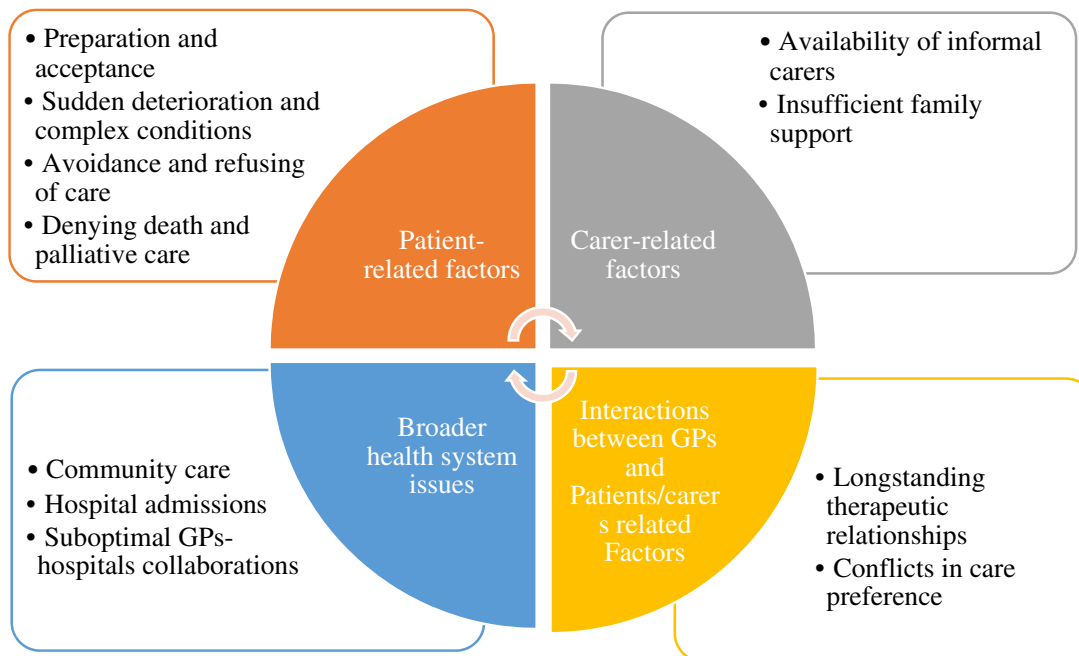


FIGURE 1 Summary of main categories and themes from qualitative analysis.

hastened the deterioration. We should have foreseen this and warned the family. [GP32-Case97].

Patients' physical and psychosocial issues were identified as challenges to GPs in providing end-of-life care. These factors included uncontrolled pain and distress, rapid and unexpected decline, complex medical conditions, the presence of dementia and psychosocial issues. These situations tended to evoke stronger grief reactions from families:

This lady was fully loaded with risk factors, had an unexpected stroke ... and died after falling in rehab (unexpectedly) and developing an acute subdural bleed. She was unable to recover (she was on anticoagulants for stroke risk) and died in hospital. It was anyway a terrible event and her family are struggling with the fallout... We are continuing to support her partner who is grieving. [GP58-Case264].

### 3.1.3 | Avoidance and refusing of care

Some GPs reported that provision of optimal care was impeded because their patients avoided or refused care. These patients refused 'most services' and were described as 'not compliant' 'aggressive' and 'resistant to discussions about advance care planning'. There were various reasons for patients not being compliant, such as financial stress, substance abuse, psychological distress and fear of medication side-effects:

As this patient was not happy with strong (narcotic) analgesia in the last phase of his life (2-3 months) and

pressed to make do with panadol/nurofen so he could communicate with his family, the palliative care team was made to feel uncomfortable. They often strongly recommended the patient use narcotics or analgesics and the family felt they were critical of the patient's decision in this area. [GP63-Case244].

### 3.1.4 | Denying death and palliative care

Some patients appeared to have difficulties accepting their impending death and were not fully aware of palliative care and its potential benefits. They continued active treatments until they were in the terminal phase:

[The] patient was very anxious and depressed about his condition. Unfortunately, he was still engaging in active treatment 'til not long before his deterioration and death. I did not have the opportunities to see him more frequently prior to his passing as he spent most of his time with specialist clinicians. [GP46-Case210].

## 3.2 | Carer-related factors

### 3.2.1 | Availability of informal carers

One of the major positive factors seen by GPs as facilitating optimal end-of-life care was the availability of informal carers:

He died very happy... He ate well and enjoyed Friday night with two of his daughters, assorted

grandchildren and his darling wife. He was found in bed at 7am by his wife and had been dead for some hours. They called me and I attended. All the family was there. Lots of tears and stories. Tea and cakes and food and celebrations of his life. ... A lovely story! Just what we all need. [GP58-Case266].

Timely care planning and involving family in meetings was seen as a positive strategy. As one GP stated:

A family meeting early on helped introduce myself [sic] and discuss where we were, where we wanted to be and how that was going to happen. [GP12-Case18].

### 3.2.2 | Insufficient family support

Factors relating to unavailability of informal carers, limited caregiving capacity and confidence, and dysfunctional family dynamics seriously restricted GPs' ability to provide optimal end-of-life care. It was stated that patients who had minimal family support 'died alone' or in 'isolated' circumstances. It was also challenging for GPs to provide psychosocial support for patients who lived in complicated social situations. In most of these cases, patients were transferred to hospitals or residential aged care facilities by GPs who provided support to the facilities and remained in contact, either professionally or personally:

If the patient had adequate home and family/friend support she may have been in a position to remain at home for a much longer time instead of being admitted to a RACF (residential aged care facility). [GP63-Case236]

## 3.3 | Interactions between GPs and patients/carer-related factors

### 3.3.1 | Longstanding therapeutic relationships

Longstanding relationships with the patient and other family members gave the GP a unique insight into their particular situation and challenges. The GPs in this study provided much of the psychosocial support for their patients and families, as well as providing medical care. They acted as an advocate for their patients, co-ordinated care, mediated conflicts and supported grieving families.

I used to care for the patient and her husband. Her husband has very complex psychological issues.... I supported this patient for 10years. [I] felt it was better to manage [name of the patient cited] alone as [her] husband was quite emotionally abusive towards her. [It was] a difficult situation in palliative care. [GP48-Case219]

The responses from GPs suggested the end-of-life care experiences took an emotional toll because of the longstanding therapeutic relationships, including grief and 'great sadness' when their patients died. Reflecting on the experience of caring for the patient, one GP said:

We looked after this lady and her husband. There is a family connection and the family were very grateful to the staff and medical team who looked after this couple. Both passed away when their dementia was well progressed and had stopped eating and drinking. I have enjoyed these reminiscences [about] the 10 people [who have died and were included in th study] plus [I] have good memories of all of them, but some [a] tinge of sadness. [GP48-Case267]

### 3.3.2 | Conflicts in care preference

Some GPs discussed how conflicts between recommended management and family preferences limited their ability to advocate for their patients:

Family were insistent on active management even until the last few weeks - [this] made palliative care process difficult. [GP51-Case166]

General care was not an issue, end-of-life care was unsatisfactory due to family's decision to transfer to hospital for care. [GP39-Case125]

## 3.4 | Broader health system issues

### 3.4.1 | Community care

Availability of palliative care, psychosocial care, social work and pastoral care at home or in residential aged care facilities were reported by GPs as giving patients a better end-of-life experience. Advance care planning and collaboration between healthcare providers also assisted in facilitating patients' choices for place of death and in accepting a terminal prognosis.

I feel that the community palliative care team, the local cancer nurse and specialists worked well together to look after this patient. [GP20-Case38]

### 3.4.2 | Hospital admissions

In the later stages of care, 59 of the 272 (22.4%) patients required transfer to hospital, which was their place of death. In many of these instances, GPs expressed regret that they were not more actively involved in their management. General practitioners noted that

communication issues affected the level of continuity in community care and resulted in apparently 'unnecessary' hospital admissions.

It was difficult for the patient towards the last few months of his life as he was in and out of hospital regularly due to exacerbation of his conditions, primarily CCF [congestive cardiac failure]. ...I did discuss with the general medical team about ceasing acute treatment and was planning to speak about this to his wife and him when his condition took another turn for the worse and was again hospitalised- this time he passed away within a few days. [GP46-Case211].

Occasionally, the minimal communication from hospitals may have resulted in patients pursuing futile care and also delaying the provision of palliative care.

[He consulted] different hospital / specialist for experimental care. He did this as they offered him hope. The new team didn't communicate well with me or the patient. When I saw how sick he was I organised palliative care referral. [GP62-Case231].

In some cases, the GPs felt hospital was not the ideal place of death for their patients and may have contributed to psychological distress:

The 99 year old resident underwent plastic surgery for repair of her laceration sustained after a fall - 6 weeks prior to death. This required hospital transfer which was not good for the patient's psychological problems. [GP52-Case272].

### 3.4.3 | Suboptimal GPs-hospital collaborations

Practitioners noted that there were often valid reasons for some patients to be transferred to hospital, such as lack of carer support, complex symptoms, acute illness, lack of palliative care service availability, family decisions to transfer to hospital and sudden deterioration in the absence of clear advance care planning. Divergent views between the GP and some specialists about care goals and management, and less than optimal collaboration and continuity of care between GPs and hospital staff made it difficult for the practitioner to prepare the patient and the family for the death. However, the GPs expressed a desire for opportunities to be more involved in end-of-life care for their patients who died in hospital:

I did not have the opportunity to see him more frequently prior to his passing as he spent most of his time with specialist clinicians. I would have preferred to have greater involvement in his care in his last days/months. [GP46-Case210].

Suboptimal coordination and continuity of care between GPs and hospitals were also reflected by comments that correspondence from the GP was disregarded or that GPs were not notified about the patient's discharge or death. These events often caused undue distress for patients and their family:

This patient was poorly cared for due to terrible triaging at emergency departments over the Xmas [Christmas], New Year period. Letters of referral requesting admission for investigation by me were ignored and the patient died in ICU after deteriorating rapidly at home. She and her family were denied the chance of a meaningful farewell and a chance for the patient to put her affairs in order. The patient felt ignored and frightened. [GP52-Case175].

## 4 | DISCUSSION

This study drew on GPs' experiences and reflections of supporting each individual patient in the last year of life, thereby providing direct insights into end-of-life care in community settings. Practitioners reported a number of factors influencing delivery of care, although they described the majority of deaths as well prepared. Our analysis categorised the key factors into four groups: patient-related factors, carer-related factors, interactions between GPs and patients/carers-related factors and broader health system issues, with each group having both barriers and facilitators. In their provision of end-of-life care, practitioners highlighted the importance of the emotional dimension of the therapeutic relationships with patients and their family, availability and capacity of informal carers and continuity of care with external services. The main concerns related to patients and their families' misconceptions of palliative care and conflicts regarding the care plan, as well as problematic communication between GPs and hospitals.

Although GPs recounted their experiences of managing the physical and psychosocial problems and other complex conditions, it was the relational aspects that were discussed most. Previous reports indicated that many GPs did not consider palliative care to be 'rocket science', but a natural extension of primary care (Herrmann et al., 2019a). Practitioners believe that their profession is capable of delivering optimal end-of-life care with experiential knowledge and good communication skills (Ding et al., 2019; Herrmann et al., 2019a). Therefore, it is important to support younger GPs to engage in palliative and end-of-life care, such as through providing opportunities for GP registrars to care for patients at the end-of-life, access to palliative care helplines and mentors for GPs looking after patients with palliative care needs (Ding et al., 2019). Only one-third of GPs in our study had received formal palliative care training, but our previous research identified GPs' interest in more training opportunities—particularly in rural settings (Ding et al., 2019). However, given the small number of deaths encountered by GPs each year, palliative

care education is often not prioritised before education for other more prevalent conditions (Centeno et al., 2015; Le et al., 2017).

General practitioners in our study highlighted the misconceptions that some patients and their families held about palliative care and concerns over use of opioid analgesics. Previous studies have reported that people often negatively associate palliative care with diminished care, giving up, hopelessness or death (Bakitas et al., 2009; Chosich et al., 2020; Collins et al., 2017; Zimmermann et al., 2016). Fear of dependence and cultural attitudes were reported to impede medical use of opioid analgesics and result in inadequate pain management (Berteram et al., 2016; Vranken et al., 2016). While the concerns and care preferences of patients and their families need to be respected, the problems of late initiation/avoidance of palliative care and suboptimal symptom management due to misconceptions and misinformation about palliative care and its benefits need to be addressed. Community campaigns on addressing misperceptions, raising awareness of the benefits of palliative care and rational use of opioid analgesics among the public and patients are warranted for early integration of palliative care improved outcomes (Chosich et al., 2020; Zimmermann et al., 2016).

Carer and family resilience was an important enabler of optimal end-of-life care identified by GPs in our study. Consistent with previous research, availability of family support was regarded as the prerequisite of successful home-based management of end-of-life (Deckx et al., 2019a). Current healthcare policy and practice promotes patient-centred care (Richards et al., 2015). Palliative care, however, extends this concept to family-centred care due to the role of families as both care providers and recipients of support from health services (World Health Organization, 2002). Both the psychological and physical health of individual family carers, family dynamics and the availability and skill of family members to provide care substantially affect the 'how, when and where' a patient will be cared for as they deteriorate. Family members who take on long-term caregiving duties experience great financial burden as well as substantial physical and psychosocial distress which can exceed that of the patients they care for (Alam et al., 2020). Current trends in high income countries to promote dying 'in place of choice' requires a rethink of end-of-life care models to support families to meet this expectation (Alam et al., 2020; Deckx et al., 2019a).

In many cases, GPs cherish their long-standing relationships with their patients and their families, and consider it a privilege being chosen and trusted by patients and their family at end-of-life (Ding et al., 2019; Herrmann et al., 2019b). Their professional commitment not only relates to provision of clinical services, but extends to advocacy, psychosocial support and conflict mediation. On the other hand, death of patients sometimes brings practitioners 'some tinge of sadness' or 'regret' over not being more involved in the care, which may suggest that some GPs also need psychological support when confronting the death of their patients.

General practitioners in our study also identified broader health system issues that affect the character of end-of-life care. One of the major facilitators identified by GPs was availability of community care options, particularly the community-based palliative care

team. Although there are important differences, many developed countries have policies to support palliative care at home, including allowances and cost-reductions, in-kind/subsidised services and employment and workplace-related arrangements (e.g. paid palliative carer leave) for patients and/or carers (Maetens et al., 2017; The Royal Commission into Aged Care Quality and Safety, 2019). Maetens and Alam suggest there are still gaps between demand and supply (Alam et al., 2020; Maetens et al., 2017) and these gaps cannot be bridged with resources provided solely through the healthcare system. Establishment of sustainable end-of-life care models requires extensive personal and societal resources, such as personal, non-professional networks (e.g. friends and relatives) and non-government community-based social support programmes (e.g. social workers, trained volunteers and pastoral care) (Grindrod et al., 2018; Herrmann et al., 2019b). A broader public health approach is needed to fully mobilise the resources beyond the healthcare system (Dempers et al., 2017; Stjernsward, 2007).

Although participants acknowledged the benefits of access to medical specialists and hospital admissions when appropriate care is not available within the community, continuing management by specialist services sometimes does not recognise the role of primary care services, and formal shared-care models are rare. Hospital admissions can affect continuity of care, given GPs' limited hospital visiting rights and the incomplete and fragmented nature of information transfer between GPs and hospitals (Carey et al., 2019; Ding et al., 2019; Herrmann et al., 2019b; Mitchell et al., 2016; Rhee et al., 2018). Exclusion of GPs from the care team also has the potential to deskill GPs in this aspect of care (Ding et al., 2019).

A number of solutions to promote GPs' involvement are available. The Hospital in the Home (HITH) programmes are one such solution (Montalto, 2010). The HITH services, which involve multidisciplinary professionals, offer an alternative option by providing acute or sub-acute management at home for patients who would otherwise need hospital admissions (Caplan et al., 2012; Montalto, 2010). A meta-analysis indicated that the benefits of HITH included reduced mortality, readmission rates and costs of care in conjunction with increased satisfaction with care for patients and carers (Caplan et al., 2012). Similar models, such as Hospital Inreach services in Australia, have been developed to support acute care in residential-aged care facilities (Street et al., 2015). When compared with usual hospital care, these care options more often allow GPs to manage patients on behalf of the hospital and also aim to maintain GP links with patients (Caplan et al., 2012; Montalto, 2010). Such programmes are therefore more likely to support continuity of care by retaining patients' connections with their GP, and to improve quality of life by minimising disruption.

Although promoting integration of specialist care in primary care settings could facilitate care and dying in patients' place of choice, not all people want- or are able- to be cared for and die in the community. Timely access to appropriate inpatient care for patients with acute, unstable or deteriorating conditions that are not able to be managed in the community is a necessity. Communication and collaboration between GPs and hospitals are essential and may be improved by GPs being included in hospital multidisciplinary team



meetings and hospital representatives being involved in community-based case conferences. Real-time, online information-sharing systems can also provide relevant, timely information for all healthcare providers (Petrova et al., 2018).

One of the important strengths of the study is that GPs were involved from three Australian states across urban, regional and remote areas, thereby providing important insights from representatives of the different populations and work environments of Australian GPs. Each GP reported on care of an average of four patients, including those who died expectedly or suddenly (but with an underlying life-limiting illness). This gave GPs opportunities to review and reflect on care provided for patients with different circumstances and, therefore, yielded richer data and deeper insights into the nature and context of end-of-life care in general practice.

In our study, 63 of the more than 600 invited GPs consented to participate and reported care-related data for up to 12 months. A number of major barriers contributed to the low response rate, including time limitations, practice managers' intentions to 'protect' their GPs from external disruptions, lack of awareness of the significance and benefits of GP-based research and concerns about data safety and privacy of their patients. The low response rate may have resulted in a lack of representativeness and selection bias if GPs who participated in the study were more likely to have an interest or experience in palliative care compared with those who refused. For the present report, however, it is likely that participating GPs were those who have an interest or experience in palliative care and may have been relatively 'information-rich' responders. In addition, free-text questions can provide richer and deeper data compared to close-ended questions, but lack the flexibility of interviews. Therefore, compared to personal interviews, this study could have constrained our ability to further explore the emerging topics and themes of interest.

## 5 | CONCLUSIONS

Based on GPs' experiences and reflections on end-of-life care for a cohort of more than 200 patients, this study identified four broad categories of factors influencing provision of optimal end-of-life care: patient-related factors, carer-related factors, interactions between GPs and patient/carer-related factors and broader health system issues. Strong doctor-patient relationships, availability and capacity of family support and smooth communication and continuity of care between GPs and hospitals facilitate GPs ability to provide optimal end-of-life care. In contrast, lack of these facilitators limits GPs' ability to deliver this care. Our findings highlighted the importance of comprehensive approaches to developing models of care that support both the GP and family to provide care in the patients' preferred place. Broader community-based resources beyond the healthcare system are required to strengthen the support to families. Palliative care education, availability of external support and acute/hospital-based services reaching into the community could improve GPs' confidence, skills and continuity in care delivery, but need to be adopted more broadly.

## AUTHOR CONTRIBUTIONS

*Study concept and design:* Jinfeng Ding, Claire E. Johnson, Angus Cook and Geoffrey Mitchell. *Recruitment of GPs:* Jinfeng Ding, Claire E. Johnson, Angus Cook, David Chua and Sharon Licqurish. *Data collection, cleaning and analysis:* Jinfeng Ding and Sharon Licqurish. *Preparation of manuscript:* Jinfeng Ding and Sharon Licqurish. *Review of Manuscript:* Claire E. Johnson, David Chua, Sharon Licqurish, Geoffrey Mitchell, Dianne Ritson, Carolyn Masarei and Angus Cook.

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## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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