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Provision of end-of-life care in primary care: a survey of issues and outcomes in the Australian context

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ABSTRACT

Objectives To describe general practitioners' (GPs) involvement in end-of-life care, continuity and outcomes of care, and reported management challenges in the Australian context.

Methods Sixty-three GPs across three Australian states participated in a follow-up survey to report on care provided for decedents in the last year life using a clinic-based data collection process. The study was conducted between September 2018 and August 2019.

Results Approximately one-third of GPs had received formal palliative care training. Practitioners considered themselves as either the primary care coordinator (53.2% of reported patients) or part of the management team (40.4% of reported patients) in the final year of care. In the last week of life, patients frequently experienced reduced appetite (80.6%), fatigue (77.9%) and psychological problems (44.9%), with GPs reporting that the alleviation of these symptoms were less than optimal. Practitioners were highly involved in end-of-life care (eg, home visits, consultations via telephone and family meetings), and perceived higher levels of satisfaction with communication with palliative care services than other external services. For one-third of patients, GPs reported that the last year of care could potentially have been improved.

Conclusion There are continuing needs for integration of palliative care training into medical education and reforms of healthcare systems to further support GPs' involvement in end-of-life care. Further, more extensive collection of clinical data is needed to evaluate and support primary care management of end-of-life patients in general practice.

Strengths and limitations of this study

- ► This study provides novel and in-depth insights into real-world end-of-life care in Australian general practice based on individual, patient-level clinical data.
- ► This study assessed the advantages and disadvantages of both prospective and retrospective case-finding approaches in clinical end-of-life care data collection in general practice settings.
- ► The substantial challenges in engaging general practitioners in palliative care research limits the sample size, which could reduce the representativeness of the reported patients and generalisability of our findings.

INTRODUCTION

As with many populations globally, Australians are living longer with complex comorbidities. In 2017, 160 000 Australians died and more than 60% of them were over 65 years of age.[1] It is projected that the number of deaths will double by 2056.[2] Healthcare requirements increase substantially in the last year of life and many leading causes of death—such as multimorbidity, frailty and dementia—often have broadly characteristic trajectories.[3] These people are mostly managed in primary care settings by general practitioners (GPs).[4 5]

In many countries, including Australia, GPs are the major providers of healthcare throughout their patients' lifespan in primary care settings, including at end of life (EoL).[4–6] The majority of GPs therefore consider EoL care an integral part of their role in the health system.[7 8] The majority of elderly patients spend most of their last year of life in the community, either at home or in residential-aged care facilities (RACFs), and only access specialist care if the GP arranges a referral when symptoms cannot be managed.[9] GPs often have long-standing and trusting relationships with patients and their families and provide holistic care. However, there are a number of challenges facing GPs.[8 10–12]

Analysis of how patients are managed at EoL provides insight into how systems can be improved and how GPs can best be supported to provide EoL care. Examples include European Sentinel General Practitioner Networks Monitoring End of Life Care project, which routinely collects population-based data on EoL care activities from a representative group of GPs using a standardised questionnaire.[13 14] In Australia, the Palliative Care Outcomes Collaboration is currently the only programme that systematically assesses

palliative care by gathering ongoing point-of-care data, but at the time of our study, only from specialist palliative care services.[15] There are major knowledge gaps in terms of what, how, when, where and to whom EoL care is provided across general practices in Australia, which has in turn limited the capacity of local and national health agencies to support practitioners.

Our team developed a clinic-based data collection process to enable compilation of patient-level health data on EoL care activities and outcomes in general practice. We implemented the process with 63 GPs across three Australian states. This paper provides an integrated overview of the key findings of this project, such as GP's involvement in EOL care, continuity and outcomes of care, and reported management challenges in the Australian context.

METHODS

Measurements and process of data collection

Data included in this study were obtained from a follow-up GP survey conducted across three Australian states (Western Australia (WA), Queensland and Victoria). The survey formed part of a wider clinic-based data collection process to examine the context, nature and quality of care provided for patients in the last year of life in general practice. A modified Delphi technique was used in the project development, involving a comprehensive literature review, interviews with GPs and other stakeholders, and a consensus study with internal and external experts representing multiple disciplines. Detailed descriptions of the development stages are included in a previous publication.[16] Evaluation of the questionnaires demonstrated satisfactory levels of reliability and validity, with scale-level content validation index of 0.95 and Cronbach's alpha ranging from 0.67 to 0.93 for different domains.[16] In brief, the data collection process used three separate questionnaires:

1. 'Basic practice descriptors' designed to capture the general background of the participating GPs and the basic characteristics of their practice.
2. 'Clinical data query' designed to extract data from electronic medical records (EMRs).
3. 'GP-completed Questionnaire' designed to collect data from GPs about their experiences in providing EoL care for each decedent.

Participants answered the 'GP-completed questionnaire' primarily online (using Qualtrics in WA and Victoria, Checkbox in Queensland). Paper versions of the online questionnaires were made available for a small number of GPs who preferred to use hardcopy versions.

In the 'GP-completed Questionnaire', GPs were specifically asked a question regarding whether they expected the death of their patient. The following subquestion asked GPs to clarify how they made the judgement. This paper focused on patients with an 'expected' death from the GPs' perspective (thereby causes of death such as trauma were not reported). Key items reported in this study included GPs' role and involvement in care, continuity of care, symptom prevalence and control, and challenges and difficulties encountered by GPs in caring for the decadent. Examples of questions are provided as online supplemental material. (Refer to online supplemental file 1)

Recruitment of GPs and study settings

Multiple recruitment strategies were used to involve GPs. 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. Substantial assistance was received from local primary care networks, professional GP organisations and palliative care services. We approached more than 600 GPs across metropolitan, regional and rural areas.

Two different data collection mechanisms were used for the decedents: prospective case-finding in WA and retrospective case-finding in Queensland and Victoria. In WA, we sent monthly reminder emails with the survey link to GPs and encouraged completion of the survey immediately after receiving notification of death between September 2018 and August 2019. Parallel retrospective case-finding occurred with GPs in Queensland and Victoria between August 2018 and April 2019. Practitioners in these states were asked to report on their care of up to 10 patients who had died within the preceding 2 years. Decedents were identified from GPs' EMRs by either the participating GP or the practice managers with assistance from researchers if required.

Data analysis

Descriptive statistics were used to assess quantitative responses from the questionnaires. In the original questionnaire, GPs were asked to rate degree of symptom relief using a Likert-5 scale (1—not at all, 5—very much). We assigned scores 1–3 as 'not well addressed' and 4–5 as 'well addressed' in this analysis. Sensitivity analyses were conducted through assigning scores 1–2 as 'not well addressed' and 3–5 as 'well addressed'. We tested for differences between prospective and retrospective case-finding mechanisms by performing χ^2, Fisher's exact tests, independent t-tests (for GPs' years of work and hours of work per week) or Mann-Whitney U tests (for patients' age at death and level of satisfaction with feedback from external services who undertook the care of the patient in the last week of life). Analyses of multiple responses were conducted using a Stata module designed for tabulation of multiple responses.[17] Missing data entries were not accounted for in analyses for comparisons between prospective and retrospective case-finding mechanisms.

The level for statistical significance was set at $p<0.05$. Stata V.15.1 (StataCorp) was used to perform all analyses.

Written consent was obtained from all participating GPs. All three ethics committees approved a waiver

of consent from the decedents included in the study and their families. No personalised information was requested, obtained or used at any stage of the study. All data were deidentified by GPs prior to submitting to the researchers. Findings are reported only at an aggregate level.

Patient and public involvement

Patients and/or the public were not involved in the design, conduct, reporting, interpretation or dissemination of this research except that two consumer representatives were invited to review the study questionnaires for content validation.

RESULTS

Characteristics of participating GPs

Table 1 shows the characteristics of the 63 participating GPs who provided at least one report. More GPs were male (55.5%), and between 50 and 59 years old (38.1%). Approximately half were born in Australia (54.0%) and practised in regional or rural/remote areas (54.0%). The majority received primary medical training in Australia (74.6%). On average, participants had 23 years of work experience and worked 40.7 hours per week. Less than one-third of GPs had ever received formal palliative care training (30.1%). They seldom used symptom assessment tools (11.1%).

Characteristics of reported patients

We received reports on 272 deaths, of which 220 (80.9%) were expected deaths (table 2). The number of expected deaths reported by participating GPs ranged from 1 to 12, with a median of 3 (IQR: 1.2–5.0) and mean of 3.5 (SD: 2.7). Patients died at a median age of 82 years (IQR: 71–90 years) and most frequently from malignancy (36.4%). The most common place of death was RACFs (35%), followed by inpatient palliative care units (24.1%), private residences (20.9%) and hospitals (18.6%).

GPs involvement, perceived role and continuity of care

GPs reported that they organised or conducted home visits (83.6%), consultations via telephone (77.7%), family meetings (70.5%) and care planning/team-care arrangement (58.6%) for more than half of patients (table 3). Many GPs considered their role to be either the primary care coordinator (53.2%) or part of the team caring for the patient at the EOL (40.4%).

In 51.8% of cases, GPs received feedback on patients' care from an external service that undertook the final week of care of the patient. T Feedback was most commonly provided by RACFs (33.3%) and least commonly provided by community nursing services (8.8%). Overall, GPs reported high levels of satisfaction with the feedback, particularly from palliative care services.

Difficult aspects of care

GPs reported that the last year of care for approximately one-third (32.7%) of patients could have been improved.

Table 1 Characteristics of participating general practitioners

	n (%)
Total no	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	
Yes	6 (9.5)
No	53 (84.1)
Missing	4 (6.4)
Years of GP work	
Mean (SD)	23 (13)
Usual work hours/week	
Mean (SD)	41 (12)
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 public hospital	
Yes	13 (20.6)
No	46 (73.0)
Missing	4 (6.4)

Continued

Table 1 Continued

	n (%)
Right to admit patients to private hospital	
Yes	8 (12.7)
No	50 (79.4)
Missing	5 (7.9)
Right to admit patients to hospice	
Yes	17 (27.0)
No	40 (63.5)
Missing	6 (9.5)

GP, general practitioner; SD, Standard Deviation .

When asked to select up to three of the most challenging tasks relating to care of the patient in the last year life, 'Physical treatment and care for the patient' (22.9%) and 'Psychological, social and existential treatment and care of the patient' (19.8%) were more frequently chosen than other tasks (table 4).

Outcomes of care

Loss of appetite (80.6%) and fatigue (77.9%) were reportedly the most prevalent symptoms among patients in the last week of life. However, these two symptoms were least likely to have been classified as 'well addressed' (31.7% for appetite, 36.5% for fatigue). Pain, with a reported prevalence of 58.1%, was most likely to have been classified as 'well addressed' (66.7%). Psychological problems had prevalence of 44.9%, and 40.0% of the cases were classified as 'well addressed' by the GP (table 5).

Table 2 Characteristics of reported patients

	n (%)
Total no	220
Gender	
Male	98 (44.5)
Female	117 (53.2)
Missing	5 (2.3)
Age at death	
Median (IQR)	82 (71–90)
Principal diagnosis	
Cancer	80 (36.4)
Cardiovascular disease	37 (16.8)
Neurological disease	29 (13.2)
Respiratory disease	25 (11.3)
Other	46 (20.9)
Missing	3 (1.4)
Place of death	
Hospital apart from palliative care	41 (18.6)
Private residence	46 (20.9)
Residential aged care facility	77 (35.0)
Inpatient palliative care	53 (24.1)
Other	1 (0.5)
Missing	2 (0.9)

IQR, Interquartile Range.

Table 3 GPs' involvement in care and continuity of care

	n (%)
Provision of service involving the GP (n=220)	
Home visit	184 (83.6)
Consultation on phone	171 (77.7)
Family meeting	155 (70.5)
Care plans/team care arrangements	129 (58.6)
Counselling	101 (45.9)
Hospital consultation	76 (34.6)
Case conference	73 (33.2)
Telehealth/videoconference	42 (19.1)
GPs' perceived role (n=188)	
Primary care coordinator	100 (53.2)
Part of a team	76 (40.4)
Referral	12 (6.4)
Feedback from external service undertaking the last week of care (n=188)	
Yes	114 (60.6)
No	35 (18.6)
Not applicable	39 (20.8)
If yes, from which services? * (total number of responses=138)	
Hospital apart from palliative care unit	28 (20.3)
Inpatient palliative care service	34 (24.6)
Community palliative care service	28 (20.3)
Community nursing services	10 (7.3)
Residential aged care facility	38 (27.5)
Level of satisfaction with feedback/communication* (Total no of responses=125)	Median (IQR)
Hospital apart from palliative care unit (n=25)	4 (4–5)
Inpatient palliative care service (n=32)	5 (4–5)
Community palliative care service (n=27)	5 (5–5)
Community nursing services (n=8)	4 (4–5)
Residential aged care facility (n=33)	4 (4–5)

*This is a multiple-answer question. For each patient, GPs could indicate that they received feedback for the last week of care from more than one external service. Percentages were calculated based on total responses.
GP, general practitioner.

Comparisons between prospective and retrospective case-finding

We received reports on 115 expected deaths from 41 GPs using prospective case-finding and 105 expected deaths from 22 GPs using retrospective case-finding. Online supplemental tables 1–5 show the results of comparisons between two groups. The two groups of GPs were

Table 4 Aspects of end-of-life care identified as difficult or challenging

	Frequency of item selection by GPs, n (%)
Whether care could have been improved (n=208)	
Yes	72 (32.7)
No	147 (66.8)
Missing	1 (0.5)
Different aspects of end-of-life care (total no of responses=384)*	
Physical treatment and care of the patient	88 (22.9)
Psychological, social and existential treatment and care of the patient	76 (19.8)
Communication, planning and decision making with the patient	45 (11.7)
Communication, planning and decision making with the family and other informal caregivers	40 (10.4)
Coordination with other services and continuity of care	22 (5.8)
Communication/information exchange with other services	25 (6.5)
Support of family and informal caregivers	50 (13.0)
Support of the patient to stay at home/be cared at home	38 (9.9)

*GPs were requested to select up to three most challenging tasks for care of each patient. Percentages were calculated based on total responses.
GP, general practitioner.

reasonably comparable (GPs in the prospective cohort were more likely to be rural and have hospital admitting rights) and no significant differences in characteristics of patients were observed between two groups. However, some differences were observed in the provision of a range of services involving GPs and prevalence and relief of a number of symptoms. The results of sensitivity analyses for levels of symptom relief by using a cut-off of 2 (ie, 1–2 as 'not well addressed' and 3–5 as 'well addressed') are presented in online supplemental table 6. The comparisons between prospectively assessed and retrospectively assessed levels of relief in fatigue and bowel problems differed from the main analysis (shown in online supplemental table 5) that used a cut-off point of 3 (ie, 1–3 as 'not well addressed' and 4–5 as 'well addressed').

DISCUSSION

This study provides an overview of the context and nature of EoL care in primary care based on individual-level clinical data across three states in Australia. This study highlighted the high prevalence of some symptoms, and GPs' concerns in providing optimal symptom relief in patients' last week of life. Respondents stated that care in the last year of life could potentially have been improved for one-third of their patients. GPs reported that they were highly involved in the EoL care of their patients, and the majority perceived that they played an important role (either as the primary care coordinator or part of a team) in the final year of care. They reported high levels of satisfaction with feedback from external services involved in their patients' last period of care.

Our study showed that a number of symptoms, particularly fatigue and reduced appetite, were highly prevalent in patients' last week of life. These findings are consistent with previous literature.[18 19] Furthermore, GPs reported that fatigue, reduced appetite, and psychological symptoms were the most difficult to address. Similarly, a recent systematic review of EoL symptom control by Mitchell also indicated that GPs felt most confident in managing pain, but least confident in relation to fatigue and depression.[10] Given that systematic use of symptom assessment tools was uncommon, the frequencies of some symptoms could have been higher than those identified in our study. It is, therefore, unsurprising that GPs in this study reported that care for one-third of patients could have been improved in the last year of life. For the other

Table 5 Presence of symptoms and symptom relief for patients in the last week of life

	Pain n (%)	Sleep problems n (%)	Nausea n (%)	Fatigue n (%)	Loss of appetite n (%)	Breathing problems n (%)	Bowel problems n (%)	Psychological problems n (%)
Presence of symptoms	N=215	N=202	N=209	N=213	N=211	N=206	N=201	N=205
Yes	125 (58.1)	84 (41.6)	86 (41.1)	166 (77.9)	170 (80.6)	121 (58.7)	67 (33.4)	92 (44.9)
No	70 (32.6)	95 (47.0)	96 (45.9)	30 (14.1)	23 (10.9)	67 (32.5)	107 (53.2)	81 (39.5)
Unknown	20 (9.3)	23 (11.4)	27 (13.0)	17 (8.0)	18 (8.5)	18 (8.8)	27 (13.4)	32 (15.6)
If symptom reported, to what degree was it addressed?	N=117	N=81	N=80	N=156	N=161	N=115	N=60	N=90
Well addressed	78 (66.7)	37 (45.7)	49 (61.2)	57 (36.5)	51 (31.7)	70 (60.9)	28 (46.7)	36 (40.0)
Not well addressed	36 (30.8)	40 (49.4)	25 (31.3)	85 (54.5)	91 (56.5)	40 (34.8)	30 (50.0)	49 (54.4)
Unknown	3 (2.5)	4 (4.9)	6 (7.5)	14 (9.0)	19 (11.8)	5 (4.3)	2 (3.3)	5 (5.6)

two-third of patients, GPs may believe that they had done their best with the knowledge, skill and resources available to them. However, there could still be potential for care of these patients to be improved if GPs were provided with better training and support.

Among participating GPs, only one-third had ever received formal palliative care training. Practitioners rated management of physical and psychological symptoms as the top two most challenging tasks in caring for EoL patients. These correspond to the findings identified in this study that a number of symptoms (eg, fatigue, loss of appetite and psychological problems) were both highly prevalent in the last stage of life and difficult for GPs to address. Analysis of qualitative data from this project also indicated that uncontrolled symptom distress, rapid and unexpected decline, complex medical conditions, the presence of dementia and psychosocial issues were seen by GPs as significant challenges in providing EoL care (Manuscript presenting these data submitted for publication).

Lack of confidence across palliative care in general, as well as in relation to specific palliative care tasks, have been widely reported as major barriers for GPs in providing EoL care.[8 10 11] One of the major reasons recognised in European countries[20] and the USA[21 21] is the lack of standard integration of palliative care content into undergraduate medical education and family medicine/general practice curricula. It is also difficult for GPs to develop and maintain palliative care skills and knowledge due to the relatively small number of EoL patients they encounter at any one point in time. Given the substantial level of need and limited palliative care training among GPs,[22] establishment of an agreed framework for integration of palliative care into undergraduate and professional development education would help to address these knowledge gaps.[23] Design of training programmes should be sufficiently flexible to accommodate GPs' tight schedules, and could include brief online case-based study sessions and practice visits by palliative care specialists during and out of business hours.[8 12] A number of online courses for palliative care are currently available in Australia, such as Palliative Care Online Training,[24] Programme of Experience in the Palliative Approach[25] and the Palliative Care Curriculum for Undergraduates.[26] However, information on the effectiveness of these programmes is lacking and is required before further promotion. It is also important to ensure the availability of consultative support from palliative care specialists (eg, through hotlines) for GPs, particularly early career GPs and rural GPs, seeking advice on management of complex problems.[8 12]

The GPs perceived they had an important role in the EoL care for over 90% of patients, either as primary care coordinators (53%) or part of the care team (40%). This compares to a previous survey that reported 25% of Australian GPs were not involved in palliative care.[27] More than 70% of reported cases received services such as home visits, phone consultation and family meetings from GPs. The percentage of patients receiving home visits at EoL was similar to prior studies.[28 29] However, provision of services such as case conferences and hospital consultations—that often involve multidisciplinary teamwork—were less frequent. Optimal continuity of care requires not only high levels of commitment from GPs, but also close collaboration and engagement from external teams.[30] Inadequate reimbursement, time limitations, long travel distances and limited rights to visit patients at hospitals were previously identified as barriers for GPs to provide many of these services, particularly those based in rural and regional areas.[8 12] There are proposed reforms to rural care in Australia, such as new training schemes for GPs to extend and upgrade skills, and greater incentives for GPs to provide certain specialty services (eg, palliative care) and after-hour care.[31]

Clear and timely information-exchange between GPs and external services is another important indicator of good continuity of EoL care. Overall, GPs were satisfied with feedback from other services, although satisfaction with feedback from palliative care services (including inpatient and community services) exceeded those of other external services. This corresponds to the finding from our previous study that GPs often reported their information-sharing with local palliative care teams being timely and collegial.[8] Our study identified that around two-thirds of Australian GPs have difficulties in obtaining admitting rights to a private or public hospital. In Australia, complex accreditation procedures are required for GPs to be able to admit patients to a private or public hospital, which may take several years to undergo.[32] These system-related barriers could impede information-exchange between GPs and external services. Effective and consistent online communication systems could further promote real-time sharing of key information regarding EoL care.[12] Such initiatives include My Health Record[33] in Australia and Electronic Palliative Care Coordination Systems[34] in the UK.

The retrospective case-finding approach used in the other two states raises concerns about data quality, given the delays between patient death and time of reporting, although it accelerated the data collection process. The prospective case-finding approach used in WA required longer follow-up of a larger number of GPs and ongoing survey reminders, but promoted timely reporting and may help to control recall issues. In this study, we identified some significant differences in some care activities and outcomes between the prospective and retrospective cohorts (refer to online supplemental tables 1-5) despite the broadly comparable characteristics of GPs and patients involved in the two data collection approaches. These discrepancies could suggest that prospective case-finding had alleviated issues with recall because of its more timely data collection in comparison to retrospective case-finding.

This study demonstrates both the feasibility and challenges of collecting clinical, population-based EoL care data in general practice. Overall there are major challenges in engaging GPs in primary care research,[35–38]

including the collection of clinical data in relation to palliative care and outcomes of individual patients. A comparable Belgian palliative care research reported that only 65 (1.6%) of the 4065 invited GPs completed at least one report.[35] In our study, 63 of the more than 600 invited GPs consented to participate and reported data for up to 12 months. The low response rate may have potentially 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. Therefore, larger-scale studies with random section of GPs and the data collection process developed by our team are required to validate findings from this study.

Our experiences indicated that key barriers for recruitment of GPs include time limitations, practice managers' intentions to 'protect' their GPs from external disruptions, lack of understanding of the significance and benefits of GP-based research participation, and concerns about data safety and privacy of their patients. Flexible recruitment strategies (eg, in-person visits to general practice, presentation of the project in GP and palliative care-related conferences and provision of appropriate reimbursement), and strong support from professional communities (eg, inclusion of GP and palliative care specialist researchers in the research team) are required to address these challenges. Clear communication of the benefits and value that the study could bring to practitioners and their patients, and timely sharing of study findings with participating GPs, would also motivate their participation and retention in the study.[35]

An important strength of this study is the individual, patient-level clinical data which provides unique, in-depth insights into real-world EoL care in Australian general practice. The relatively small sample size of both GPs and reported patients may limit the generalisability of our findings and may need to be validated in larger-scale studies in the future. However, the distributions of age and gender of the participating GPs are comparable to the national GP profile in Australia.[39] The median age and proportion of cancer deaths of reported cases were slightly higher than Australian national statistics, and this may have occurred because we excluded unexpected deaths from this report (eg, deaths arising from trauma).[40] In our study, 80.9% of all the reported deaths were classified as expected, a figure that is comparable to the previous estimates in Australia[41] and the UK.[42]

CONCLUSIONS

Primary care practitioners play an essential role in EoL care of most patients and provide high quality, compassionate care. However, EoL care for many patients could be improved with the successful management of symptoms such as fatigue, loss of appetite and depression in the last stages of the patient's life. These findings—in conjunction with low rates of palliative care training and a lack of confidence in some aspects of EoL care among GPs—suggest the need for applied training programmes in EoL at undergraduate and postgraduate levels of medical training. Reforms to support the extension of GPs' skills, provision of specialty care and after-hour care in rural areas should also be considered. Further, although there are considerable challenges, more extensive collection of clinical data from GPs is required. This would allow further exploration of the findings from this study, provide additional insights into the scope of primary care management of EoL patients, and help to support the indispensable contribution of GPs to community-based EoL care.

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Supplementary table 1. Characteristics of participating GPs by case-finding mechanisms

	Prospective case-finding n (%)	Retrospective case-finding n (%)	Comparisons by prospective vs. retrospective case-finding (P-value)*
Total number by case-finding mechanism	41	22	
Gender			
Male	20 (48.8)	15 (68.2)	0.19
Female	20 (48.8)	7 (31.8)	
Missing	1 (2.4)	0 (0)	
Age group (years)			
< 30	2 (4.9)	0 (0)	0.20
30 - 39	8 (19.5)	3 (13.6)	
40 - 49	11 (26.8)	2 (9.1)	
50 - 59	12 (29.3)	12 (54.6)	
60 - 69	7 (17.1)	3 (13.6)	
70 +	1 (2.4)	2 (9.1)	
Country of Birth			
Australia	20 (48.8)	14 (63.6)	0.42
Outside Australia	20 (48.8)	8 (36.4)	
Missing	1 (2.4)	0 (0)	
Country of primary medical training			
Australia	27 (65.9)	20 (90.9)	0.06
Outside Australia	13 (31.7)	2 (9.1)	
Missing	1 (2.4)	0 (0)	
Locality of practice			
City (inner and outer suburbs)	13 (31.7)	17 (77.3)	**< 0.001**
Regional (including country towns)	7 (17.1)	5 (22.7)	
Rural and remote	21 (51.2)	0 (0)	
GP Registrar			
Yes	3 (7.3)	3 (13.6)	0.66
No	34 (82.9)	19 (86.4)	
Missing	4 (9.8)	0 (0)	
Years of GP work			
Mean (standard deviation)	20 (12)	30 (13)	**0.003**

Usual work hours/week			
Mean (standard deviation)	42 (13)	39 (11)	0.37
Received formal palliative care training			
Yes	12 (29.3)	7 (31.8)	1.00
No	28 (68.3)	15 (68.2)	
Missing	1 (2.4)	0 (0)	
Use of symptom assessment tool			
Yes	5 (12.2)	2 (9.1)	1.00
No	36 (87.8)	19 (96.4)	
Missing	0 (0)	1 (4.5)	
Right to admit patients to public hospital			
Yes	13 (31.7)	0 (0)	**0.002**
No	26 (63.4)	20 (90.9)	
Missing	2 (4.9)	2 (9.1)	
Right to admit patients to private hospital			
Yes	7 (17.1)	1 (4.5)	0.24
No	31 (75.6)	19 (86.4)	
Missing	3 (7.3)	2 (9.1)	
Right to admit patients to hospice			
Yes	12 (29.3)	5 (68.2)	0.76
No	25 (61.0)	15 (22.7)	
Missing	4 (9.7)	2 (9.1)	

NOTE: Bold indicates significant value $P < 0.05$.

* Comparisons between prospective and retrospective case-finding mechanisms were conducted using Fisher-exact test and Independent t-test (for years of work and work hours/week)

Supplementary table 2. Characteristics of reported patients with expected death by case-finding mechanisms

	Prospective case-finding n (%)	Retrospective case-finding n (%)	Comparisons by prospective vs. retrospective case-finding (P-value)[a]
Number of expected deaths	115	105	0.19
Gender			
Male	49 (42.6)	49 (46.7)	0.35
Female	66 (57.4)	51 (48.6)	
Missing	0 (0)	5 (4.7)	
Age at Death			
Median (interquartile range)	80 (70 - 89)	84 (72 - 91)	0.14
Principal Diagnosis			
Cancer	49 (42.6)	31 (29.5)	0.08
Cardiovascular disease	16 (13.9)	21 (20.0)	
Respiratory disease	12 (10.4)	13 (12.4)	
Neurological disease	10 (8.7)	19 (18.1)	
Other	27 (23.5)	19 (18.1)	
Missing	1 (0.9)	2 (1.9)	
Place of death			
Hospital apart from palliative care	24 (20.9)	17 (16.2)	0.65
Private residence	22 (19.1)	24 (22.8)	
Residential aged care facility	42 (36.5)	35 (33.3)	
Inpatient palliative care	26 (22.6)	27 (25.7)	
Other	0 (0)	1 (1.0)	
Missing	1 (0.9)	1 (1.0)	

[a] Comparisons between prospective and retrospective case-finding mechanisms were conducted using Chi-square test and Mann–Whitney U test (for Age at death only)

Supplementary table 3. GPs' involvement in care and continuity of care by case-finding mechanisms

	Prospective case-finding n (%)	Retrospective case-finding n (%)	Comparisons by prospective vs. retrospective case-finding (P-value) [a]
Provision of services involving the GP	N = 115	N =105	
Home visit	97 (84.4)	87 (82.9)	0.77
Consultation by phone	92 (80.0)	79 (75.2)	0.40
Family meeting	83 (72.3)	72 (68.6)	0.60
Care plans/team-care arrangements	82 (71.3)	47 (44.8)	**< 0.001**
Counselling	62 (53.9)	39 (37.1)	**0.01**
Hospital consultation	64 (55.7)	12 (11.4)	**< 0.001**
Case conference	53 (46.1)	20 (19.1)	**< 0.001**
Telehealth/videoconference	39 (33.9)	3 (2.9)	**< 0.001**
GPs' perceived role	N = 114	N = 74	
Primary care coordinator	61 (53.5)	39 (52.7)	0.73
Part of the team	47 (41.2)	29 (39.2)	
Referral	6 (5.3)	6 (8.1)	
Number of patients for whom GPs received feedback on care from external services	N = 115	N = 73	
Yes	61 (53.0)	53 (72.6)	**0.007**
No	22 (19.1)	13 (17.8)	
Not applicable	32 (27.8)	7 (9.6)	
If yes, from which services? (multiple answers) [b]			
Hospital apart from palliative care unit	16 (23.5)	12 (17.1)	0.89
Inpatient palliative care	16 (23.5)	18 (25.7)	
Community palliative care service	14 (20.6)	14 (20.0)	
Community nursing services	4 (5.9)	6 (8.6)	
Residential aged care facility	18 (26.5)	20 (28.6)	
Total responses	68	70	
Level of satisfaction with feedback	***Median (interquartile range)*** [b]	***Median (interquartile range)*** [b]	
Hospital apart from palliative care unit	4 (3.5 - 5)	4 (4 - 5)	0.52
Inpatient palliative care	5 (4 - 5)	5 (4 - 5)	0.56
Community palliative care service	5 (5 - 5)	5 (4 - 5)	**0.01**

Community nursing services	4.5 (3.5 - 5)	4 (4 - 5)	0.79
Residential aged care facility	5 (5 - 5)	5 (4 - 5)	**0.004**
Total responses	60	65	

NOTE: Bold indicates significant value P < 0.05.

[a] Comparisons between prospective and retrospective case-finding mechanisms were conducted using Fisher-exact test and Mann–Whitney U test (for Level of satisfaction with feedback only)

[b] This is a multiple-answer question. For each patient, GPs could indicate that they received feedback for the last week of care from more than one external service. Percentages were calculated based on the total responses

Supplementary table 4. Aspects of end-of-life care identified as difficult or challenging* compared by case-finding mechanisms

	Prospective case-finding n (%)	Retrospective case-finding n (%)	Comparisons by prospective vs. retrospective case-finding (P-value)[a]
Whether care could have been improved (n = 208)	N = 115	N = 105	
Yes	42 (36.5)	30 (28.6)	0.23
No	73 (63.5)	74 (70.5)	
Missing	0 (0)	1 (0.9)	
Different aspects of end-of-life care [b]			
Physical treatment and care of the patient	45 (18.9)	43 (29.5)	**0.008**
Psychological, social and existential treatment and care of the patient	47 (19.7)	29 (19.9)	
Support of family and informal caregivers	38 (16.0)	12 (8.2)	
Communication, planning and decision-making with the patient	28 (11.8)	17 (11.6)	
Communication, planning and decision-making with the family and other informal caregivers	26 (10.9)	14 (9.6)	
Support of the patient to stay at home/be cared at home	26 (10.9)	12 (8.2)	
Communication/information exchange with other services	20 (8.4)	5 (3.4)	
Coordination with other services and continuity of care	8 (3.4)	14 (9.6)	
Total responses	238	146	

NOTE: Bold indicates significant value P < 0.05.

[a] Comparisons between prospective and retrospective case-finding mechanisms were conducted using Fisher-exact test

[b] GPs were requested to select up to three most challenging tasks for care of each patient. Percentages were calculated based on total responses.

Supplementary table 5. Presence of symptoms and symptom relief for patients in the last week of life by case-finding mechanisms

	Pain n(%)		Sleep problems n(%)		Nausea n(%)		Fatigue n(%)		Loss of appetite n(%)		Breathing problems n(%)		Bowel problems n(%)		Psychological problems n(%)	
Data collection mechanisms	P	R	P	R	P	R	P	R	P	R	P	R	P	R	P	R
Presence of symptoms	N = 115	N = 100	N = 115	N = 87	N = 115	N = 94	N = 115	N = 98	N = 115	N = 96	N = 115	N = 91	N = 115	N = 86	N = 115	N = 90
Yes	64 (55.7)	61 (61.0)	50 (43.5)	34 (39.1)	41 (35.6)	45 (47.9)	90 (78.2)	76 (77.5)	93 (80.9)	77 (80.2)	64 (55.6)	57 (62.6)	28 (24.4)	39 (45.3)	45 (39.1)	47 (52.2)
No	40 (34.8)	30 (30.0)	53 (46.1)	42 (48.3)	60 (52.2)	36 (38.3)	17 (14.8)	13 (13.3)	13 (11.3)	10 (10.4)	40 (34.8)	27 (29.7)	68 (59.1)	39 (45.3)	47 (40.9)	34 (37.8)
Unknown	11 (9.5)	9 (9.0)	12 (10.4)	11 (12.6)	14 (12.2)	13 (13.8)	8 (7.0)	9 (9.2)	9 (7.8)	9 (9.4)	11 (9.6)	7 (7.7)	19 (16.5)	8 (9.4)	23 (20.0)	9 (10.0)
Comparisons by prospective vs. retrospective case-finding (P-value)[a]	0.72		0.78		0.13		0.81		0.91		0.60		**0.006**		0.07	
If symptom reported, to what degree was it addressed*	N = 64	N = 53	N = 50	N = 31	N = 41	N = 39	N = 90	N = 66	N = 93	N = 68	N = 64	N = 51	N = 28	N = 32	N = 45	N = 45
Well addressed	22 (34.4)	14 (24.4)	28 (56.0)	12 (38.7)	15 (36.6)	10 (25.7)	52 (57.8)	33 (50.0)	57 (61.3)	34 (50.0)	30 (46.9)	10 (19.6)	20 (71.4)	10 (31.3)	31 (68.9)	18 (40.0)
Not well addressed	42 (65.6)	36 (67.9)	20 (40.0)	17 (54.8)	25 (61.0)	24 (61.5)	28 (31.1)	29 (43.9)	22 (23.7)	29 (42.7)	34 (53.1)	36 (70.6)	8 (28.6)	20 (62.5)	14 (31.1)	22 (48.9)
Unknown	0 (0)	3 (5.7)	2 (4.0)	2 (6.5)	1 (2.4)	5 (12.8)	10 (11.1)	4 (6.1)	14 (15.0)	5 (7.3)	0 (0)	5 (9.8)	0 (0)	2 (6.2)	0 (0)	5 (11.1)
Comparisons by prospective vs. retrospective case-finding (P-value) [a]	0.13		0.31		0.19		0.19		**0.03**		**< 0.001**		**0.006**		**0.004**	

Abbreviations: P - Prospective case-finding; R - Retrospective case-findings

NOTE: Bold indicates significant value P < 0.05.

* We assigned scores 1 – 3 as “not well addressed” and 4 – 5 as “well addressed”.

[a] Comparisons between prospective and retrospective case-finding mechanisms were conducted using Chi-square test. Data relating to “unknow” were not included in the analyses.

Supplementary table 6. Sensitivity analyses for symptom relief for patients in the last week of life by case-finding mechanisms

	Pain n(%)		Sleep problems n(%)		Nausea n(%)		Fatigue n(%)		Loss of appetite n(%)		Breathing problems n(%)		Bowel problems n(%)		Psychological problems n(%)	
Data collection mechanisms	P	R	P	R	P	R	P	R	P	R	P	R	P	R	P	R
If symptom reported, to what degree was it addressed*	N = 64	N = 53	N = 50	N = 31	N = 41	N = 39	N = 90	N = 66	N = 93	N = 68	N = 64	N = 51	N = 28	N = 32	N = 45	N = 45
Well-addressed	8 (12.5)	7 (13.2)	14 (28.0)	3 (9.7)	6 (14.6)	5 (12.8)	33 (36.7)	13 (19.7)	43 (46.2)	16 (23.5)	12 (18.8)	2 (3.9)	7 (25.0)	2 (6.3)	15 (33.3)	5 (11.1)
Not well-addressed	56 (87.5)	43 (81.1)	34 (68.0)	26 (83.9)	34 (82.9)	29 (74.4)	47 (52.2)	49 (74.2)	36 (38.7)	47 (69.1)	52 (81.3)	44 (86.3)	21 (75.0)	28 (87.5)	30 (66.7)	35 (77.8)
Unknown	0 (0)	3 (5.7)	2 (4.0)	2 (6.5)	1 (2.4)	5 (12.8)	10 (11.1)	4 (6.1)	14 (15.0)	5 (7.4)	0 (0)	5 (9.8)	0 (0)	2 (6.2)	0 (0)	5 (11.1)
Comparisons by prospective vs. retrospective case-finding (P-value) [a]	0.81		0.09		0.97		**0.01**		**< 0.001**		**0.04**		0.08		**0.04**	

Abbreviations: P - Prospective case-finding; R - Retrospective case-findings

NOTE: Bold indicates significant value P < 0.05.

* We assigned scores 1 – 2 as “not well addressed” and 3 – 5 as “well addressed”

[a] Comparisons between prospective and retrospective case-finding mechanisms were conducted using Chi-square test or Fisher's exact test. Data relating to “unknow” were not included in the analyses.

Examples of Key Questions included in the study

1. Expectation of death

Was this patient's death expected to you?

☐	No→if No >>>>> (free text question pop up) Please comment why were you surprised? _____ _____
☐	Yes→if Yes >>>>> (question a and b pop up) a. How did you become aware that this patient would die in the foreseeable future? (tick all that apply) ☐ I made the judgement based on patient's condition, investigation and other information ☐ Through information from the medical specialist(s) ☐ Through information from palliative care health professional(s) ☐ Through information from home-care nursing staff(s) ☐ Through information from the patient or his/her relative(s) ☐ Other, namely_____ ☐ Not applicable, because_____ b. Approximately, how long before death did you become aware that this patient would die in the foreseeable future? _____ days before death OR _____ weeks before death OR _____ months before death

2. Provision of services involving GPs

Did you provide or participate in the following services for this patient in the last year of life? (tick all that apply)

	Service	Yes	No	Not applicable
a	Consultation on phone	☐	☐	☐
b	Telehealth/videoconference consultations	☐	☐	☐
c	Home visits/Residential care visits	☐	☐	☐
d	Family meeting	☐	☐	☐
e	Case conference	☐	☐	☐
f	Hospice consultation	☐	☐	☐
g	Hospital consultations	☐	☐	☐
h	Care plans/ Team-care arrangements	☐	☐	☐
i	Counselling	☐	☐	☐
j	Other, specify_____	☐	☐	☐

3. GP perceived role in caring for the patient

Which of the following statements best describes your role in coordinating care for this patient in their last 12 months of life?

☐	For the most part, I was the individual who was primarily responsible for coordinating the care for the patient during the last 12 months of their life
☐	For the most part, I was part of a team that was responsible for coordinating the care for the patient during the last 12 months of their life
☐	The patient was referred to another individual or agency who became responsible for coordinating and providing most of the care for the patient during the last 12 months of their life

4. Feedback from external services that undertook the last week of care of the patient

Did you receive any communication/feedback/summaries (verbally or in writing) about the patient's care from the service which undertook care in the 7 days immediately prior to their death? *(section will appear more than one time if more than one option was ticked in part a)*

☐	Not applicable (i.e. last episode of care was provided by myself without others services involved)
☐	No
☐	Yes→if Yes (question b pop up)

a. From which services? (tick all that apply)

☐	Hospital apart from the palliative care unit
☐	Palliative care unit in hospital or Inpatient hospice
☐	Community palliative care service
☐	Community nursing service
☐	Residential aged care facility
☐	Other, specify_____

b. How satisfied were you with the communication between you and this service?

☐	Not at all
☐	A little bit
☐	Somewhat
☐	Quite a bit
☐	Very much

5. Whether the last year of care could have been improved?

Do you think the care for this patient could have been improved during the last year of care?

☐	No
☐	Yes

6. Difficult tasks in caring for the patient

What do you think were the most difficult aspects of caring for this patient and/or the carers in the last year of life? Please choose <u>UP TO THREE</u> of the most difficult:

☐	Physical treatment and care of the patient
☐	Psychological, social and existential treatment and care of the patient
☐	Communication, planning and decision making with the patient
☐	Communication, planning and decision making with family and other informal caregivers
☐	Coordination with other services and continuity of care
☐	Communication/information exchange with other services
☐	Support of family and informal care caregivers
☐	Support of the patient to stay at home/ be cared at home
☐	Other, specify_____

7. Symptoms prevalence and relief

To your knowledge, did the patient have the following symptoms during the <u>last week</u> prior to death? (tick all that apply)

		Yes >>>>>(scales on the right appear)	**No**	**Unknown**	→*If Yes*, to what degree were these symptoms addressed?					
					0 Unknown	1 Not at all	2 A little bit	3 Somewhat	4 Quite a bit	5 Very much
a	Pain	☐	☐	☐	☐	☐	☐	☐	☐	☐
b	Sleep problems	☐	☐	☐	☐	☐	☐	☐	☐	☐
c	Nausea	☐	☐	☐	☐	☐	☐	☐	☐	☐
d	Fatigue	☐	☐	☐	☐	☐	☐	☐	☐	☐
e	Reduced Appetite	☐	☐	☐	☐	☐	☐	☐	☐	☐
f	Breathing problems	☐	☐	☐	☐	☐	☐	☐	☐	☐
g	Bowel problems	☐	☐	☐	☐	☐	☐	☐	☐	☐
h	Psychological problems (e.g anxiety, depression)	☐	☐	☐	☐	☐	☐	☐	☐	☐