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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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1 **Provision of end-of-life care in primary care: A survey of issues and outcomes in**

2 **the Australian context**

3

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1

Abstract

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

Methods: Sixty-three general practitioners 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 (e.g. 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 general practitioners' 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.

Key words: General practitioners, end-of-life care, care outcomes, primary care, palliative care

Running title: End-of-life care in primary care

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 generalizability of our findings.

3

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1 Introduction

2 As with many populations globally, Australians are living longer with complex co-morbidities. In 2017,

3 160,000 Australians died and more than 60 percent of them were over 65 years of age.[1] It is projected

4 that the number of deaths will double by 2056.[2] Health care requirements increase substantially in

5 the last year of life and many leading causes of death - such as multi-morbidity, frailty and dementia

6 – often have broadly characteristic trajectories.[3] These people are mostly managed in primary care

7 settings by General Practitioners (GPs).[4 5]

8 In many countries, including Australia, GPs are the major providers of healthcare throughout their

9 patients' lifespan in primary care settings, including at end-of-life (EoL).[4-6] The majority of GPs

10 therefore consider EoL care an integral part of their role in the health system.[7 8] The majority of elderly

11 patients spend most of their last year of life in the community, either at home or in Residential Aged

12 Care Facilities (RACFs), and only access specialist care if the GP makes a referral when symptoms

13 cannot be managed.[9] General practitioners often have long-standing and trusting relationships with

14 patients and their families and provide holistic care. However, there are a number of challenges facing

15 GPs.[8 10-12]

16 Analysis of how patients are managed at EoL can provide some insight into how systems can be

17 improved and how GPs can best be supported to provide EoL care. Examples include the EURO

18 SENTIMELC project (European Sentinel General Practitioner Networks Monitoring End of Life Care),

19 which routinely collects population-based data on EoL care activities from a group of representative

20 GPs using a standardised questionnaire.[13 14] In Australia, the Palliative Care Outcomes Collaboration

21 (PCOC) is currently the only program that systematically assesses palliative care by gathering ongoing

22 point-of-care data, but only from specialist palliative care services.[15] There are major knowledge gaps

23 in terms of what, how, when, where and to whom EoL care is provided across general practices in

24 Australia, which has in turn limited the capacity of local and national health agencies to support

25 practitioners.

26 Our team developed a clinic-based data collection process to enable compilation of patient-level

27 health data on EoL care activities and outcomes in general practice. We implemented the process with

28 63 GPs across three Australian states. This paper provides an integrated overview of the key findings

29 of this project, such as GP's involvement in end-of-life care, continuity and outcomes of care, and

30 reported management challenges in the Australian context.

31

4

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.

This paper focused on patients with an "expected" death (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 supplementary material. (Refer to Supplement 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

5

1   assistance was received from local primary care networks, professional GP organizations and palliative

2   care services. We approached more than 600 GPs across metropolitan, regional and rural areas.

3   Two different data collection mechanisms were used for the decedents: prospective case-finding in

4   WA and retrospective case-finding in Queensland and Victoria. In WA, we sent monthly reminder

5   emails with the survey link to GPs and encouraged completion of the survey immediately after

6   receiving notification of death between September 2018 and August 2019. Parallel retrospective case-

7   finding occurred with GPs in Queensland and Victoria between August 2018 and April 2019.

8   Practitioners in these states were asked to report on their care of up to 10 patients who had died

9   within the preceding two years. Decedents were identified from GPs' EMRs by either the participating

10 GP or the practice managers with assistance from researchers if required.

11 **Data analysis**

12 Descriptive statistics were used to assess quantitative responses from the questionnaires. In the

13 original questionnaire, GPs were asked to rate degree of symptom relief using a Likert-5 scale (1 – Not

14 at all, 5 – Very much). We assigned scores 1 – 3 as "not well addressed" and 4 – 5 as "well addressed"

15 in this analysis. We tested for differences between prospective and retrospective case-finding

16 mechanisms by performing chi-square, Fisher exact tests, independent t-tests (for GPs' years of work

17 and hours of work per week) or Mann–Whitney U tests (for patients' age at death and level of

18 satisfaction with feedback from external services who undertook the care of the patient in the last

19 week of life). Analyses of multiple responses were conducted using a Stata module designed for

20 tabulation of multiple responses (Reference to work by Ben Jann to be inserted) Missing data entries

21 were not accounted for in analyses for comparisons between prospective and retrospective case-

22 finding mechanisms.

23 The level for statistical significance was set at p < 0.05. Stata 15.1 (StataCorp, College Station, TX) was

24 used to perform all analyses.

25 **Ethical considerations**

26 Research ethics approvals for each of the participating states were received from The University of

27 Western Australia (RA/4/20/4232), The University of Queensland (2018000185) and Monash

28 University (# 15225). Written consent was obtained from all participating GPs. All three ethics

29 committees approved a waiver of consent from the decedents included in the study and their families.

30 No personalized information was requested, obtained or used at any stage of the study. All data were

31 de-identified by GPs prior to submitting to the researchers. Findings are reported only at an aggregate

32 level.

6

1 **Patient and public involvement**

2 Patients and/or the public were not involved in the design, conduct, reporting, interpretation or

3 dissemination of this research except that two consumer representatives were invited to review the

4 questionnaires used in this study for content validation purpose.

5 Results

6 **Characteristics of participating GPs**

7 Table 1 shows the characteristics of the 63 participating GPs who provided at least one report. More

8 GPs were male (55.5%), and between 50 and 59 years old (38.1%). Approximately half were born in

9 Australia (54.0%) and practiced in regional or rural/remote areas (54.0%). The majority received

10 primary medical training in Australia (74.6%). On average, participants had 23 years of work

11 experience and worked 40.7 hours per week. Less than one third of GPs had ever received formal

12 palliative care training (30.1%). They seldom used symptom assessment tools (11.1%).

13 **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)

7

	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 (standard deviation)	23 (13)
Usual work hours/week		
	Mean (standard deviation)	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)
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)

1

2 **Characteristics of reported patients**

3 We received reports on 272 deaths, of which 220 (80.9%) were expected deaths. (Table 2) Patients

4 died at a median age of 82 years (IQR: 71 – 90 years) and most frequently from malignancy (36.4%).

8

1 The most common place of death was within residential aged care facilities (35%), followed by

2 inpatient palliative care units (24.1%), private residences (20.9%), and hospitals (18.6%).

3

4

5 **Table 2. Characteristics of reported patients**

	n (%)
Total number	220
Gender	
Male	98 (44.5)
Female	117 (53.2)
Missing	5 (2.3)
Age at Death	
Median (interquartile range)	82 (71- 90)
Principal Diagnosis	
Cancer	80 (36.4)
Cardiovascular disease	37 (16.8)
Respiratory disease	25 (11.3)
Neurological disease	29 (13.2)
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)

6

7 **General Practitioners' involvement, perceived role and continuity of care**

8 GPs reported that they organized or conducted home visits (83.6%), consultations via telephone

9 (77.7%), family meetings (70.5%) and care planning/team-care arrangement (58.6%) for more than

10 half of patients (Table 3). Many GPs considered their role to be either the primary care coordinator

11 (53.2%) or part of the team caring for the patient at the end of life (40.4%).

9

1

2

3 1   In 51.8% of cases, GPs received feedback on patients' care from an external service that undertook

4 2   the final week of care of the patient. The feedback was most commonly provided by residential aged

5 3   care facilities (33.3%) and least commonly provided by community nursing services (8.8%). Overall,

6

7 4   GPs reported high levels of satisfaction with the feedback, particularly the feedback from palliative

8

9 5   care services.

10

11

12 6   **Table 3. GPs' involvement in care and continuity of care**

13

	n (%)
Provision of service involving the GP (n = 220)	
Consultation on phone	171 (77.7)
Telehealth/videoconference	42 (19.1)
Home visit	184 (83.6)
Family meeting	155 (70.5)
Case conference	73 (33.2)
Hospital consultation	76 (34.6)
Care plans/team-care arrangements	129 (58.6)
Counselling	101 (45.9)
GPs' perceived role (n = 188)	
Primary care coordinator	100 (53.2)
Part of the 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? ª (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 ª (Total number of responses = 125)	Median (interquartile range)
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)

7

10

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

4 **Difficult aspects of care**

5 General practitioners reported that the last year of care for approximately one-third (32.7%) of
6 patients could have been improved. When asked to select up to three of the most challenging tasks
7 relating to care of the patient in the last year life, "Physical treatment and care for the patient" (22.9%)
8 and "Psychological, social and existential treatment and care of the patient" (19.8%) were more
9 frequently chosen than other tasks. (Table 4)

10 **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 number of responses = 384) ^a	
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)

11

12 ^a GPs were requested to select up to three most challenging tasks for care of each patient. Percentages
13 were calculated based on total responses.

14 **Outcomes of care**

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

11

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)

12

1   **Comparisons between prospective and retrospective case-finding**

2   We received reports on 115 expected deaths from 41 GPs using prospective case-finding and 105

3   expected deaths from 22 GPs using retrospective case-finding. The supplementary tables 1-5 show

4   the results of comparisons between two groups. The two groups of GPs were reasonably comparable

5   (GPs in the prospective cohort were more likely to be rural and have hospital admitting rights) and no

6   significant differences in characteristics of patients were observed between two groups. However,

7   some differences were observed in the provision of a range of services involving GPs and prevalence

8   and relief of a number of symptoms.

9   # Discussion

10   This study provides an overview of the context and nature of EoL care in primary care based on

11   individual-level clinical data across three states in Australia. This study highlighted the high prevalence

12   of some symptoms, and GPs' concerns in providing optimal relief in patients' last week of life.

13   Respondents stated that care in the last year of life could potentially have been improved for one-

14   third of their patients. General practitioners reported that they were highly involved in the EoL care

15   of their patients, and many perceived that they played an important role (either as the primary care

16   coordinator or part of the team) in the final year of care. They reported high levels of satisfaction with

17   feedback from external services involved in their patients' last period of care.

18   Our study showed that a number of symptoms, particularly fatigue and reduced appetite, were highly

19   prevalent in patients' last week of life. These findings are consistent with previous literature.[17] [18]

20   Furthermore, GPs reported that fatigue, reduced appetite, and psychological symptoms were the

21   most difficult to address. It is, therefore, unsurprising that GPs in this study reported that care for one-

22   third of patients could have been improved in the last year of life. Similarly, a recent systematic review

23   of EoL symptom control by Mitchell also indicated that GPs felt most confident in managing pain, but

24   least confident in relation to fatigue and depression.[10] Given that systematic use of symptom

25   assessment tools was uncommon, the frequency of some symptoms could have been higher than was

26   identified in our study.

27   Amongst participating GPs, only one-third had ever received formal palliative care training.

28   Practitioners rated management of physical and psychological symptoms as the top two most

29   challenging tasks in caring for EoL patients. These correspond to the findings identified in this study

30   that a number of symptoms (e.g. fatigue, loss of appetite and psychological problems) were both

31   highly prevalent in the last stage of life and difficult for GPs to address. Analysis of qualitative data

32   from this project also indicated that uncontrolled symptom distress, rapid and unexpected decline,

13

1   complex medical conditions, the presence of dementia and psychosocial issues were seen by GPs as

2   significant challenges in providing EoL care (Manuscript presenting these data submitted for

3   publication).

4   Lack of confidence across palliative care in general, as well as in relation to specific palliative care

5   tasks, have been widely reported as major barriers for GPs in providing EoL care.[8 10 11] One of the major

6   reasons recognized in European countries,[19] the United States[20] and Australia,[20] is the lack of standard

7   integration of palliative care content into undergraduate medical education and family

8   medicine/general practice curricula. It is also difficult for GPs to develop and maintain palliative care

9   skills and knowledge due to the relatively small number of EoL patients they encounter at any one

10 point in time. Given the substantial level of need and limited palliative care training amongst GPs,[21]

11 establishment of an agreed framework for integration of palliative care into undergraduate and

12 professional development education would help to address these knowledge gaps.[22] Design of training

13 programs should be sufficiently flexible to accommodate GPs' tight schedules, and could include brief

14 online case-based study sessions and practice visits by palliative care specialists during and out of

15 business hours.[8 12] A number of online courses for palliative care are currently available in Australia,

16 such as Palliative Care Online Training,[23] Program of Experience in the Palliative Approach,[24] and the

17 Palliative Care Curriculum for Undergraduates.[25] However, information on the effectiveness of these

18 programs is lacking and is required before further promotion. It is also important to ensure the

19 availability of consultative support from palliative care specialists (e.g. through hotlines) for GPs,

20 particularly early career GPs and rural GPs, seeking advice on management of complex problems.[8 12]

21 The GPs perceived they had an important role in the EoL care for over 90% of patients, either as

22 primary care coordinators (53%) or part of the care team (40%). This compares to a previous survey

23 that reported 25% of Australian GPs were not involved in palliative care.[26] More than 70% of reported

24 cases received services such as home visits, phone consultation and family meetings from GPs. The

25 percentage of patients receiving home visits at EoL was similar to prior studies.[27 28] However, provision

26 of services such as case conferences and hospital consultations - that often involve multidisciplinary

27 teamwork - were less frequent. Optimal continuity of care requires not only high levels of commitment

28 from GPs, but also close collaboration and engagement from external teams.[29] Inadequate

29 reimbursement, time limitations, long travel distances, and limited rights to visit patients at hospitals

30 were previously identified as barriers for GPs to provide many of these services, particularly those

31 based in rural and regional areas.[8 12] There are proposed reforms to rural care in Australia, such as

32 new training schemes for GPs to extend and upgrade skills, and greater incentives for GPs to provide

33 certain specialty services (e.g. palliative care) and after-hour care.[30]

14

1 Clear and timely information-exchange between GPs and external services is another important

2 indicator of good continuity of EoL care. Overall, GPs were satisfied with feedback from other services,

3 although satisfaction with feedback from palliative care services (including inpatient and community

4 services) exceeded those of other external services. This corresponds to the finding from our previous

5 study that GPs often reported their information-sharing with local palliative care teams being timely

6 and collegial.[8] Effective and consistent online communication systems could further promote real-

7 time sharing of key information regarding EoL care.[12] Such initiatives include My Health Record[31] in

8 Australia and Electronic Palliative Care Coordination Systems[32] in the United Kingdom.

9 The retrospective case-finding approach used in the other two states raises concerns about data

10 quality, given the delays between patient death and time of reporting, although it accelerated the

11 data collection process. The prospective case-finding approach used in WA required longer follow-up

12 of a larger number of GPs and ongoing survey reminders, but promoted timely reporting and may help

13 to control recall issues. In this study, we identified some significant differences in some care activities

14 and outcomes between the prospective and retrospective cohorts (refer to supplementary tables 1-

15 5) despite the broadly comparable characteristics of GPs and patients involved in the two data

16 collection approaches. These discrepancies could suggest that prospective case-finding had alleviated

17 issues with recall because of its more timely data collection in comparison to retrospective case-

18 finding.

19 This study demonstrates both the feasibility and challenges of collecting clinical, population-based EoL

20 care data in general practice. Overall there are major challenges in engaging GPs in primary care

21 research, [33-36] including the collection of clinical data in relation to palliative care and outcomes of

22 individual patients. A comparable Belgian palliative care research reported that only 65 (1.6%) of the

23 4065 invited GPs completed at least one report.[33] In our study, 63 of the more than 600 invited GPs

24 consented to participate and reported data for up to 12 months. Our experiences indicated that key

25 barriers for recruitment of GPs include time limitations, practice managers' intentions to "protect"

26 their GPs from external disruptions, lack of understanding of the significance and benefits of GP-based

27 research participation, and concerns about data safety and privacy of their patients. Flexible

28 recruitment strategies (e.g. in-person visits to general practice, presentation of the project in GP and

29 palliative care-related conferences and provision of appropriate reimbursement), and strong support

30 from professional communities (e.g. inclusion of GP and palliative care specialist researchers in the

31 research team) are required to address these challenges. Clear messaging around the benefits and

32 value that the study could bring to practitioners and their patients, and timely sharing of study findings

33 with participating GPs, would also motivate their participation and retention in the study.[33]

15

1   An important strength of this study is the individual, patient-level clinical data which provides unique,

2   in-depth insights into real-world EoL care in Australian general practice. The relatively small sample

3   size of both GPs and reported patients may limit the generalizability of our findings that need to be

4   validated in larger-scale studies in the future. However, the distributions of age and gender of the

5   participating GPs are comparable to the national GP profile in Australia.[37] The median age and

6   proportion of cancer deaths of reported cases were slightly higher than Australian national statistics,

7   and this may have occurred because we excluded unexpected deaths from this report (e.g. deaths

8   arising from trauma).[38] In our study, 80.9% of all the reported deaths were classified as expected, a

9   figure that is comparable to the previous estimates in Australia[39] and the United Kingdom.[40]

10 Conclusions

11   Primary care practitioners play an essential role in EoL care of most patients and provide high quality,

12   compassionate care. However, EoL care for many patients could be improved with the successful

13   management of symptoms such as fatigue, loss of appetite and depression in the last stages of the

14   patient's life. These findings - in conjunction with low rates of palliative care training and a lack of

15   confidence in some aspects of EoL care among GPs - suggest the need for applied training programs

16   in EoL at undergraduate and postgraduate levels of medical training. Reforms to support the extension

17   of GPs' skills, provision of specialty care and after-hour care in rural areas should also be considered.

18   Further, although there are considerable challenges, more extensive collection of clinical data from

19   GPs is required. This would allow further exploration of the findings from this study, provide additional

20   insights into the scope of primary care management of EoL patients, and help to support the

21   indispensable contribution of GPs to community-based EoL care.

22   **Acknowledgement**

27   **Contribution statement**

28   Study concept and design: Jinfeng Ding, Claire E Johnson, Angus Cook and Geoffrey Mitchell

29   Recruitment of GPs: Jinfeng Ding, Claire E Johnson, Angus Cook, David Chua and Sharon Licqurish

30   Data collection, cleaning and analysis: Jinfeng Ding and David Chua

31   Preparation of manuscript: Jinfeng Ding

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1   Review of Manuscript: Claire E Johnson, Christobel Saunders, David Chua, Sharon Licqurish, Geoffrey

2   Mitchell and Angus Cook

13   **Patient and public involvement**

14   Patients and/or the public were not involved in the design, conduct, reporting, interpretation or

15   dissemination of this research except that two patient representatives were invited the review the

16   questionnaires used in the study for validation purposes.

17   **Competing interests**

18   None declared.

19   **Ethics approval**

20   Conduct of the research in each of the participating states was approved by the ethics committees at

21   The University of Western Australia (RA/4/20/4232), The University of Queensland (2018000185) and

22   Monash University (# 15225), respectively.

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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)*
Number	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 care-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 death	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 care-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 care-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 care-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		0.40		**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.

[a] Comparisons between prospective and retrospective care-finding mechanisms were conducted using Chi-square test.

Examples of Key Questions included in the study

1. 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_____	☐	☐	☐

2. 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

3.   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 <u>care in the 7 days immediately prior to their death?</u> *(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

4.   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

5. 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 UP TO THREE 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_____

6. Symptoms prevalence and relief

To your knowledge, did the patient have the following symptoms during the last week 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)	☐	☐	☐	☐	☐	☐	☐	☐	☐

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1 & 2
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4
Objectives	3	State specific objectives, including any prespecified hypotheses	4
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5 and 6
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	5 & 6
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5 & 6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5 & 6
Bias	9	Describe any efforts to address potential sources of bias	16
Study size	10	Explain how the study size was arrived at	Not applicable
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	6
		(*b*) Describe any methods used to examine subgroups and interactions	6
		(*c*) Explain how missing data were addressed	6
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	Not applicable
		(*e*) Describe any sensitivity analyses	Not applicable
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	5, 6 and 7
		(b) Give reasons for non-participation at each stage	Not applicable
		(c) Consider use of a flow diagram	Not applicable

Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	7
		(b) Indicate number of participants with missing data for each variable of interest	8, 9, 10, and 11
Outcome data	15*	Report numbers of outcome events or summary measures	8, 9, 10, and 11
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	Not applicable
		(*b*) Report category boundaries when continuous variables were categorized	6
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	Not applicable
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	17
Discussion			
Key results	18	Summarise key results with reference to study objectives	14
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	16 & 17
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	14, 15, 16 &17
Generalisability	21	Discuss the generalisability (external validity) of the study results	17
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	18

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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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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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' involvement in end-of-life care, continuity and outcomes of care, and reported management challenges in the Australian context.

Methods: Sixty-three general practitioners 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 (e.g. 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 general practitioners' 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.

Key words: General practitioners, end-of-life care, care outcomes, primary care, palliative care

Running title: End-of-life care in primary care

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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 generalizability of our findings.

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1 Introduction

2   As with many populations globally, Australians are living longer with complex co-morbidities. In 2017,

3   160,000 Australians died and more than 60 percent of them were over 65 years of age.[1] It is projected

4   that the number of deaths will double by 2056.[2] Health care requirements increase substantially in

5   the last year of life and many leading causes of death - such as multi-morbidity, frailty and dementia

6   – often have broadly characteristic trajectories.[3] These people are mostly managed in primary care

7   settings by General Practitioners (GPs).[4 5]

8   In many countries, including Australia, GPs are the major providers of healthcare throughout their

9   patients' lifespan in primary care settings, including at end-of-life (EoL).[4-6] The majority of GPs

10 therefore consider EoL care an integral part of their role in the health system.[7 8] The majority of elderly

11 patients spend most of their last year of life in the community, either at home or in residential aged

12 care facilities (RACFs), and only access specialist care if the GP makes a referral when symptoms cannot

13 be managed.[9] General practitioners often have long-standing and trusting relationships with patients

14 and their families and provide holistic care. However, there are a number of challenges facing GPs.[8 10-

15 12]

16 Analysis of how patients are managed at EoL can provide some insight into how systems can be

17 improved and how GPs can best be supported to provide EoL care. Examples include the EURO

18 SENTIMELC project (European Sentinel General Practitioner Networks Monitoring End of Life Care),

19 which routinely collects population-based data on EoL care activities from a representative group of

20 GPs using a standardised questionnaire.[13 14] In Australia, the Palliative Care Outcomes Collaboration

21 (PCOC) is currently the only program that systematically assesses palliative care by gathering ongoing

22 point-of-care data, but at the time of our study, only from specialist palliative care services.[15] There

23 are major knowledge gaps in terms of what, how, when, where and to whom EoL care is provided

24 across general practices in Australia, which has in turn limited the capacity of local and national health

25 agencies to support practitioners.

26 Our team developed a clinic-based data collection process to enable compilation of patient-level

27 health data on EoL care activities and outcomes in general practice. We implemented the process with

28 63 GPs across three Australian states. This paper provides an integrated overview of the key findings

29 of this project, such as GP's involvement in end-of-life care, continuity and outcomes of care, and

30 reported management challenges in the Australian context.

31

4

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 sub-question asked GPs to clarify how they made the judgment. 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 supplementary material. (Refer to Supplement 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

5

1 about the project, explain the process of data collection and collect written consent. Substantial

2 assistance was received from local primary care networks, professional GP organizations and palliative

3 care services. We approached more than 600 GPs across metropolitan, regional and rural areas.

4 Two different data collection mechanisms were used for the decedents: prospective case-finding in

5 WA and retrospective case-finding in Queensland and Victoria. In WA, we sent monthly reminder

6 emails with the survey link to GPs and encouraged completion of the survey immediately after

7 receiving notification of death between September 2018 and August 2019. Parallel retrospective case-

8 finding occurred with GPs in Queensland and Victoria between August 2018 and April 2019.

9 Practitioners in these states were asked to report on their care of up to 10 patients who had died

10 within the preceding two years. Decedents were identified from GPs' EMRs by either the participating

11 GP or the practice managers with assistance from researchers if required.

12 **Data analysis**

13 Descriptive statistics were used to assess quantitative responses from the questionnaires. In the

14 original questionnaire, GPs were asked to rate degree of symptom relief using a Likert-5 scale (1 – Not

15 at all, 5 – Very much). We assigned scores 1 – 3 as "not well addressed" and 4 – 5 as "well addressed"

16 in this analysis. Sensitivity analyses were conducted through assigning scores 1 – 2 as "not well

17 addressed" and 3 – 5 as "well addressed" We tested for differences between prospective and

18 retrospective case-finding mechanisms by performing chi-square, Fisher exact tests, independent t-

19 tests (for GPs' years of work and hours of work per week) or Mann–Whitney U tests (for patients' age

20 at death and level of satisfaction with feedback from external services who undertook the care of the

21 patient in the last week of life). Analyses of multiple responses were conducted using a Stata module

22 designed for tabulation of multiple responses.[17] Missing data entries were not accounted for in

23 analyses for comparisons between prospective and retrospective case-finding mechanisms.

24 The level for statistical significance was set at $p < 0.05$. Stata 15.1 (StataCorp, College Station, TX) was

25 used to perform all analyses.

26 **Ethical considerations**

27 Research ethics approvals for each of the participating states were received from The University of

28 Western Australia (RA/4/20/4232), The University of Queensland (2018000185) and Monash

29 University (# 15225). Written consent was obtained from all participating GPs. All three ethics

30 committees approved a waiver of consent from the decedents included in the study and their families.

31 No personalized information was requested, obtained or used at any stage of the study. All data were

6

1 de-identified by GPs prior to submitting to the researchers. Findings are reported only at an aggregate

2 level.

Patient and public involvement

4 Patients and/or the public were not involved in the design, conduct, reporting, interpretation or

5 dissemination of this research except that two consumer representatives were invited to review the

6 questionnaires used in this study for content validation purpose.

Results

Characteristics of participating GPs

9 Table 1 shows the characteristics of the 63 participating GPs who provided at least one report. More

10 GPs were male (55.5%), and between 50 and 59 years old (38.1%). Approximately half were born in

11 Australia (54.0%) and practiced in regional or rural/remote areas (54.0%). The majority received

12 primary medical training in Australia (74.6%). On average, participants had 23 years of work

13 experience and worked 40.7 hours per week. Less than one third of GPs had ever received formal

14 palliative care training (30.1%). They seldom used symptom assessment tools (11.1%).

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	

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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 (standard deviation)	23 (13)
Usual work hours/week	
Mean (standard deviation)	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)
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)

1

2   **Characteristics of reported patients**

8

1 We received reports on 272 deaths, of which 220 (80.9%) were expected deaths. (Table 2) The number

2 of expected deaths reported by participating GPs ranged from 1 to 12, with a median of 3

3 (Interquartile range: 1.2-5.0) and mean of 3.5 (standard deviation: 2.7). Patients died at a median age

4 of 82 years (IQR: 71 – 90 years) and most frequently from malignancy (36.4%). The most common

5 place of death was within residential aged care facilities (35%), followed by inpatient palliative care

6 units (24.1%), private residences (20.9%), and hospitals (18.6%).

7 **Table 2. Characteristics of reported patients**

	n (%)
Total number	220
Gender	
Male	98 (44.5)
Female	117 (53.2)
Missing	5 (2.3)
Age at Death	
Median (interquartile range)	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)

8

9 **General Practitioners' involvement, perceived role and continuity of care**

10 GPs reported that they organized or conducted home visits (83.6%), consultations via telephone

11 (77.7%), family meetings (70.5%) and care planning/team-care arrangement (58.6%) for more than

12 half of patients (Table 3). Many GPs considered their role to be either the primary care coordinator

13 (53.2%) or part of the team caring for the patient at the end of life (40.4%).

9

1   In 51.8% of cases, GPs received feedback on patients' care from an external service that undertook

2   the final week of care of the patient. The feedback was most commonly provided by residential aged

3   care facilities (33.3%) and least commonly provided by community nursing services (8.8%). Overall,

4   GPs reported high levels of satisfaction with the feedback, particularly the feedback from palliative

5   care services.

6   **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 the 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? ª (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 ª (Total number of responses = 125)	Median (interquartile range)
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)

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10

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

4 **Difficult aspects of care**

5 General practitioners reported that the last year of care for approximately one-third (32.7%) of
6 patients could have been improved. When asked to select up to three of the most challenging tasks
7 relating to care of the patient in the last year life, "Physical treatment and care for the patient" (22.9%)
8 and "Psychological, social and existential treatment and care of the patient" (19.8%) were more
9 frequently chosen than other tasks. (Table 4)

10 **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 number of responses = 384) ᵃ		
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)

11

12 ᵃ GPs were requested to select up to three most challenging tasks for care of each patient. Percentages
13 were calculated based on total responses.

14 **Outcomes of care**

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

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)

12

1 **Comparisons between prospective and retrospective case-finding**

2 We received reports on 115 expected deaths from 41 GPs using prospective case-finding and 105

3 expected deaths from 22 GPs using retrospective case-finding. The supplementary tables 1-5 show

4 the results of comparisons between two groups. The two groups of GPs were reasonably comparable

5 (GPs in the prospective cohort were more likely to be rural and have hospital admitting rights) and no

6 significant differences in characteristics of patients were observed between two groups. However,

7 some differences were observed in the provision of a range of services involving GPs and prevalence

8 and relief of a number of symptoms. The results of sensitivity analyses for levels of symptom relief by

9 using a cut-off of 2 (i.e. 1 – 2 as "not well addressed" and 3 – 5 as "well addressed") are presented in

10 supplementary table 6. The comparisons between prospectively assessed and retrospectively

11 assessed levels of relief in fatigue and bowel problems differed from the main analysis (shown in

12 supplementary table 5) that used a cut-off point of 3 (i.e. 1 – 3 as "not well addressed" and 4 – 5 as

13 "well addressed")

Discussion

15 This study provides an overview of the context and nature of EoL care in primary care based on

16 individual-level clinical data across three states in Australia. This study highlighted the high prevalence

17 of some symptoms, and GPs' concerns in providing optimal relief in patients' last week of life.

18 Respondents stated that care in the last year of life could potentially have been improved for one-

19 third of their patients. General practitioners reported that they were highly involved in the EoL care

20 of their patients, and many perceived that they played an important role (either as the primary care

21 coordinator or part of the team) in the final year of care. They reported high levels of satisfaction with

22 feedback from external services involved in their patients' last period of care.

23 Our study showed that a number of symptoms, particularly fatigue and reduced appetite, were highly

24 prevalent in patients' last week of life. These findings are consistent with previous literature.[18] [19]

25 Furthermore, GPs reported that fatigue, reduced appetite, and psychological symptoms were the

26 most difficult to address. Similarly, a recent systematic review of EoL symptom control by Mitchell also

27 indicated that GPs felt most confident in managing pain, but least confident in relation to fatigue and

28 depression.[10] Given that systematic use of symptom assessment tools was uncommon, the frequency

29 of some symptoms could have been higher than was identified in our study. It is, therefore,

30 unsurprising that GPs in this study reported that care for one-third of patients could have been

31 improved in the last year of life. For the other two-third of patients, GPs may believe that they had

32 done their best with the knowledge, skill and resources available to them. However, there could still

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1 be potential for care of these patients to be improved if GPs were provided with better training and

2 support.

3 Amongst participating GPs, only one-third had ever received formal palliative care training.

4 Practitioners rated management of physical and psychological symptoms as the top two most

5 challenging tasks in caring for EoL patients. These correspond to the findings identified in this study

6 that a number of symptoms (e.g. fatigue, loss of appetite and psychological problems) were both

7 highly prevalent in the last stage of life and difficult for GPs to address. Analysis of qualitative data

8 from this project also indicated that uncontrolled symptom distress, rapid and unexpected decline,

9 complex medical conditions, the presence of dementia and psychosocial issues were seen by GPs as

10 significant challenges in providing EoL care (Manuscript presenting these data submitted for

11 publication).

12 Lack of confidence across palliative care in general, as well as in relation to specific palliative care

13 tasks, have been widely reported as major barriers for GPs in providing EoL care.[8 10 11] One of the major

14 reasons recognized in European countries,[20] the United States[21] and Australia,[21] is the lack of standard

15 integration of palliative care content into undergraduate medical education and family

16 medicine/general practice curricula. It is also difficult for GPs to develop and maintain palliative care

17 skills and knowledge due to the relatively small number of EoL patients they encounter at any one

18 point in time. Given the substantial level of need and limited palliative care training amongst GPs,[22]

19 establishment of an agreed framework for integration of palliative care into undergraduate and

20 professional development education would help to address these knowledge gaps.[23] Design of training

21 programs should be sufficiently flexible to accommodate GPs' tight schedules, and could include brief

22 online case-based study sessions and practice visits by palliative care specialists during and out of

23 business hours.[8 12] A number of online courses for palliative care are currently available in Australia,

24 such as Palliative Care Online Training,[24] Program of Experience in the Palliative Approach,[25] and the

25 Palliative Care Curriculum for Undergraduates.[26] However, information on the effectiveness of these

26 programs is lacking and is required before further promotion. It is also important to ensure the

27 availability of consultative support from palliative care specialists (e.g. through hotlines) for GPs,

28 particularly early career GPs and rural GPs, seeking advice on management of complex problems.[8 12]

29 The GPs perceived they had an important role in the EoL care for over 90% of patients, either as

30 primary care coordinators (53%) or part of the care team (40%). This compares to a previous survey

31 that reported 25% of Australian GPs were not involved in palliative care.[27] More than 70% of reported

32 cases received services such as home visits, phone consultation and family meetings from GPs. The

33 percentage of patients receiving home visits at EoL was similar to prior studies.[28 29] However, provision

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1 of services such as case conferences and hospital consultations - that often involve multidisciplinary

2 teamwork - were less frequent. Optimal continuity of care requires not only high levels of commitment

3 from GPs, but also close collaboration and engagement from external teams.[30] Inadequate

4 reimbursement, time limitations, long travel distances, and limited rights to visit patients at hospitals

5 were previously identified as barriers for GPs to provide many of these services, particularly those

6 based in rural and regional areas.[8 12] There are proposed reforms to rural care in Australia, such as

7 new training schemes for GPs to extend and upgrade skills, and greater incentives for GPs to provide

8 certain specialty services (e.g. palliative care) and after-hour care.[31]

9 Clear and timely information-exchange between GPs and external services is another important

10 indicator of good continuity of EoL care. Overall, GPs were satisfied with feedback from other services,

11 although satisfaction with feedback from palliative care services (including inpatient and community

12 services) exceeded those of other external services. This corresponds to the finding from our previous

13 study that GPs often reported their information-sharing with local palliative care teams being timely

14 and collegial.[8] Our study identified that around two-third of Australian GPs have difficulties in

15 obtaining admitting rights to a private or public hospital. In Australia, complex accreditation

16 procedures are required for GPs to be able to admit patients to a private or public hospital, which may

17 take several years to undergo.[32] These system-related barriers could impede information-exchange

18 between GPs and external services. Effective and consistent online communication systems could

19 further promote real-time sharing of key information regarding EoL care.[12] Such initiatives include My

20 Health Record[33] in Australia and Electronic Palliative Care Coordination Systems[34] in the United

21 Kingdom.

22 The retrospective case-finding approach used in the other two states raises concerns about data

23 quality, given the delays between patient death and time of reporting, although it accelerated the

24 data collection process. The prospective case-finding approach used in WA required longer follow-up

25 of a larger number of GPs and ongoing survey reminders, but promoted timely reporting and may help

26 to control recall issues. In this study, we identified some significant differences in some care activities

27 and outcomes between the prospective and retrospective cohorts (refer to supplementary tables 1-

28 5) despite the broadly comparable characteristics of GPs and patients involved in the two data

29 collection approaches. These discrepancies could suggest that prospective case-finding had alleviated

30 issues with recall because of its more timely data collection in comparison to retrospective case-

31 finding.

32 This study demonstrates both the feasibility and challenges of collecting clinical, population-based EoL

33 care data in general practice. Overall there are major challenges in engaging GPs in primary care

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1 research, [35-38] including the collection of clinical data in relation to palliative care and outcomes of

2 individual patients. A comparable Belgian palliative care research reported that only 65 (1.6%) of the

3 4065 invited GPs completed at least one report.[35] In our study, 63 of the more than 600 invited GPs

4 consented to participate and reported data for up to 12 months. The low response rate may have

5 potentially resulted in a lack of representativeness and selection bias if GPs who participated in the

6 study were more likely to have an interest or experience in palliative care compared to those who

7 refused. Therefore, larger-scale studies with random section of GPs and the data collection process

8 developed by our team are required to validate findings from the present study.

9 Our experiences indicated that key barriers for recruitment of GPs include time limitations, practice

10 managers' intentions to "protect" their GPs from external disruptions, lack of understanding of the

11 significance and benefits of GP-based research participation, and concerns about data safety and

12 privacy of their patients. Flexible recruitment strategies (e.g. in-person visits to general practice,

13 presentation of the project in GP and palliative care-related conferences and provision of appropriate

14 reimbursement), and strong support from professional communities (e.g. inclusion of GP and

15 palliative care specialist researchers in the research team) are required to address these challenges.

16 Clear messaging around the benefits and value that the study could bring to practitioners and their

17 patients, and timely sharing of study findings with participating GPs, would also motivate their

18 participation and retention in the study.[35]

19 An important strength of this study is the individual, patient-level clinical data which provides unique,

20 in-depth insights into real-world EoL care in Australian general practice. The relatively small sample

21 size of both GPs and reported patients may limit the generalizability of our findings that need to be

22 validated in larger-scale studies in the future. However, the distributions of age and gender of the

23 participating GPs are comparable to the national GP profile in Australia.[39] The median age and

24 proportion of cancer deaths of reported cases were slightly higher than Australian national statistics,

25 and this may have occurred because we excluded unexpected deaths from this report (e.g. deaths

26 arising from trauma).[40] In our study, 80.9% of all the reported deaths were classified as expected, a

27 figure that is comparable to the previous estimates in Australia[41] and the United Kingdom.[42]

Conclusions

29 Primary care practitioners play an essential role in EoL care of most patients and provide high quality,

30 compassionate care. However, EoL care for many patients could be improved with the successful

31 management of symptoms such as fatigue, loss of appetite and depression in the last stages of the

32 patient's life. These findings - in conjunction with low rates of palliative care training and a lack of

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1 confidence in some aspects of EoL care among GPs - suggest the need for applied training programs

2 in EoL at undergraduate and postgraduate levels of medical training. Reforms to support the extension

3 of GPs' skills, provision of specialty care and after-hour care in rural areas should also be considered.

4 Further, although there are considerable challenges, more extensive collection of clinical data from

5 GPs is required. This would allow further exploration of the findings from this study, provide additional

6 insights into the scope of primary care management of EoL patients, and help to support the

7 indispensable contribution of GPs to community-based EoL care.

8 **Acknowledgement**

13 **Contribution statement**

14 Study concept and design: Jinfeng Ding, Claire E Johnson, Angus Cook and Geoffrey Mitchell

15 Recruitment of GPs: Jinfeng Ding, Claire E Johnson, Angus Cook, David Chua and Sharon Licqurish

16 Data collection, cleaning and analysis: Jinfeng Ding and David Chua

17 Preparation of manuscript: Jinfeng Ding

18 Review of Manuscript: Claire E Johnson, Christobel Saunders, David Chua, Sharon Licqurish, Geoffrey

19 Mitchell and Angus Cook

20 **Data Sharing Statement**

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

23 **Funding**

30 **Patient and public involvement**

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1   Patients and/or the public were not involved in the design, conduct, reporting, interpretation or

2   dissemination of this research except that two patient representatives were invited the review the

3   questionnaires used in the study for validation purposes.

4   **Competing interests**

5   None declared.

6   **Ethics approval**

7   Conduct of the research in each of the participating states was approved by the ethics committees at

8   The University of Western Australia (RA/4/20/4232), The University of Queensland (2018000185) and

9   Monash University (# 15225), respectively.

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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)

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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		0.40		**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 <u>care in the 7 days immediately prior to their death?</u> *(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)	☐	☐	☐	☐	☐	☐	☐	☐	☐

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1 & 2
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4
Objectives	3	State specific objectives, including any prespecified hypotheses	4
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5 and 6
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	5 & 6
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5 & 6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5 & 6
Bias	9	Describe any efforts to address potential sources of bias	16
Study size	10	Explain how the study size was arrived at	Not applicable
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	6
		(*b*) Describe any methods used to examine subgroups and interactions	6
		(*c*) Explain how missing data were addressed	6
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	Not applicable
		(*e*) Describe any sensitivity analyses	Not applicable
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	5, 6 and 7
		(b) Give reasons for non-participation at each stage	Not applicable
		(c) Consider use of a flow diagram	Not applicable

Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	7
		(b) Indicate number of participants with missing data for each variable of interest	8, 9, 10, and 11
Outcome data	15*	Report numbers of outcome events or summary measures	8, 9, 10, and 11
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	Not applicable
		(*b*) Report category boundaries when continuous variables were categorized	6
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	Not applicable
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	17
Discussion			
Key results	18	Summarise key results with reference to study objectives	14
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	16 & 17
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	14, 15, 16 &17
Generalisability	21	Discuss the generalisability (external validity) of the study results	17
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	18

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.