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Physical Symptoms at the Time of Dying Was Diagnosed: A Consecutive Cohort Study To Describe the Prevalence and Intensity of Problems Experienced by Imminently Dying Palliative Care Patients by Diagnosis and Place of Care

Katherine Clark, MBBS, MMed, FRACP,[1,2] Alanna Connolly, BE, MAppStat,[3] Sabina Clapham, BN, MN,[3] Karen Quinsey, BAppSc, MPA,[3] Kathy Eagar, MA, PhD,[3,4] and David C. Currow, BMed, MPH, PhD, FRACP, FAHMS[5]

Abstract

Objective: The aim of this work was to analyze routine assessments recorded, when a patient was documented as likely to die in hours to days, to determine the prevalence, intensity, and associations of physical symptoms.
Background: Although death inevitably occurs, very little prospective data describe at population level the physical symptoms confronting imminently dying people.
Methods: Using prospectively collected data from participating palliative care services in the Australian Palliative Care Outcomes Collaboration between July 1, 2013, and December 31, 2014, factors associated with worse symptom experiences were explored using logistic regression modeling.
Results: The experiences of 18,975 patients who died after being identified as imminently terminal were analyzed, with 75% ($n = 14{,}238$) of these being cancer deaths. Seventy percent ($n = 13{,}051$) occurred in a palliative care unit, 8.7% ($n = 1657$) in an acute hospital with palliative care support, and 22.5% ($n = 4266$) at home. More than half were assessed as experiencing acceptable symptom control especially those with nonmalignant disease. The notable exception was breathing problems, where compared to cancer patients, those with nonmalignant disease were 34% more likely to experience distressing breathlessness (odds ratio 1.34; 95% confidence interval 1.23–147). Regardless of the cause, deaths in a community setting were more likely to be complicated by more severe symptoms with the exception of breathlessness, where those dying in acute hospitals were most likely to be assessed as requiring further help.
Discussion: The terminal phase is perceived as a time where the majority will experience distressing symptoms, but this work suggests a contrary view. However, there did seem to be a detrimental effect depending on place of care with more significant problems recorded when people were dying at home. More work is needed to clarify this given the current push for more home deaths.

Introduction

Deaths secondary to chronic diseases are rising,[1] with many such deaths expected to be complicated by distressing symptoms.[2] Ensuring such symptoms are reliably addressed poses challenges due to both the limited availability of specialist palliative care services[3] and the observation that most other healthcare providers remain ill-equipped to provide such care.[4] Instead health professional's well-meaning preference is to persist with attempts to provide disease-modifying care.[5] The problem with this paradigm is that not all dying patients receive good palliation of physical and other symptoms.[6,7] This situation is likely contrary to the patient's wishes and a source of distress for patients and families,[8–10] potentially negatively impacting family's bereavement.[11,12]

[1]Department of Palliative Care, Calvary Mater Newcastle, Newcastle, Australia.
[2]School of Medicine and Public Health, University of Newcastle, Newcastle, Australia.
[3]Palliative Care Outcomes Collaboration, Australian Health Services Research Institute (AHSRI), University of Wollongong, Wollongong, Australia.
[4]Centre for Health Service Development, Australian Health Services Research Institute (AHSRI), University of Wollongong, Wollongong, Australia.
[5]Discipline, Palliative and Supportive Services, Flinders University, Adelaide, South Australia, Australia.
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A frequently suggested solution to address the variable quality of care received by people dying in hospitals is to increase the numbers who die at home.[13,14] While this may be a good option for some, for others, either through circumstances or personal choice, dying in hospital or hospice/palliative care unit is preferable.[15,16] Wherever people choose to die, there is a real need to ensure that there is readily available skilled workforce.

Upskilling health professionals includes enhancing their appreciation of the prevalence and intensity of problems likely to affect dying patients. Previously, Kehl et al.[17] undertook a systematic review that examined symptoms occurring in the final 24 hours to 2 weeks of life ($n = 2416$). They concluded that the time before death is frequently complicated by symptoms especially breathlessness and pain. However, seven of the 12 studies were retrospective chart reviews based on differing approaches to assessing and monitoring symptoms. Large, prospective, and observational studies of this population using standardized assessments are needed.

The Palliative Care Outcomes Collaboration (PCOC) is a national program funded by the Australian Government Department of Health (http://ahsri.uow.edu.au/pcoc), which aims to support improved outcomes for palliative care patients by the following:

1. Collecting clinically relevant measures at point-of-care using nationally consistent validated assessments.
2. Providing structured feedback to services.
3. Enabling services to benchmark with each other and with best practice to drive best practice.[18,19]

Routine assessments are based on key domains important to patients and their families,[20] including physical and psychological symptoms[21]; phase of illness[22]; and functional status and degree of dependency.[23] Combined, these assessments summarize patient and family needs with the aim of triggering timely responses. At a service level, participating units receive their collated performance data allowing progress to be tracked and inform quality improvement changes.[21] Participating palliative care services receive training to ensure good quality and reliable data.

Another important role of PCOC is to report this repository of prospectively collected, descriptive palliative care population data[24] with the aim of providing clinicians with quality information that summarizes patient's experiences. The study's aim was to collate and analyze data collected at the time a palliative care patient was assessed as imminently dying, to summarize point prevalence, intensity, and associations of their physical symptom scores. This included people dying of any cause across different care settings.

Methods

Study design and setting

A prospectively collected dataset from a consecutive cohort study was undertaken by analyzing routine point-of-care data collected by participating Australian specialist palliative care services for people identified as being in the terminal phase of their life-limiting illness.

Table 1. PCOC Phase Definitions at the Beginning and End of a Phase[43]

Phase	*Start phase*	*End phase*
Stable	Patient problems and symptoms are adequately controlled by established plan of care and: -Further interventions to maintain symptom control and quality of life have been planned and -Family/carer situation is relatively stable and no new issues are apparent.	The needs of the patient and/or family/carer increase, requiring changes to the existing plan of care.
Unstable	An urgent change in the plan of care or emergency treatment is required because -Patient experiences a new problem that was not anticipated in the existing plan of care; and/or -Patient experiences a rapid increase in the severity of a current problem; and/or -Family/carer circumstances change suddenly im pacting on patient care.	The new plan of care is in place, it has been reviewed, and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved, but there is a clear diagnosis and plan of care (i.e., patient is stable or deteriorating) and/or Death is likely within days (i.e., patient is now terminal).
Deteriorating	The care plan is addressing anticipated needs but requires periodic review because -Patients overall functional status is declining and -Patient experiences a gradual worsening of existing problem and/or -Patient experiences a new but anticipated problem and/or -Family/carer experience gradual worsening distress that impacts on the patient care.	-Patient condition plateaus (i.e., patient is now stable) or -An urgent change in the care plan or emergency treatment and/or -Family/carer experiences a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e., patient is now unstable) or -Death is likely within days (i.e., patient is now terminal).
Terminal	Death is likely within days.	-Patient dies or -Patient condition changes and death is no longer likely within days (i.e., patient is now stable or deteriorating).

PCOC, Palliative Care Outcomes Collaboration.

Table 2. Diagnosis Details by Setting

	Inpatient		*Consult*		*Community*	
	N	%	N	%	N	%
Malignant						
Lung	2317	17.8	127	7.7	602	14.1
Colorectal	1246	9.6	62	3.7	399	9.4
Other GIT	976	7.5	71	4.3	364	8.5
Breast	760	5.8	50	3	190	4.5
Pancreas	675	5.2	29	1.8	213	5
Hematological	619	4.8	119	7.2	181	4.2
Head and neck	599	4.6	32	1.9	148	3.5
Prostate	590	4.5	51	3.1	192	4.5
Gynecological	536	4.1	36	2.2	142	3.3
Other primary malignancies	471	3.6	26	1.6	80	1.9
Other urologicals	459	3.5	33	2	143	3.4
Skin	446	3.4	24	1.4	146	3.4
Unknown primary	320	2.5	43	2.6	82	1.9
CNS	215	1.7	11	0.7	93	2.2
Bone and soft tissue	163	1.3	1	0.1	35	0.8
Not defined	76	0.6	4	0.2	41	1
Nonmalignant						
Cardiovascular disease	528	4.1	143	8.6	191	4.5
Respiratory failure	354	2.7	168	10.1	128	3
Other nonmalignancies	320	2.5	143	8.6	276	6.5
End-stage kidney disease	291	2.2	62	3.7	116	2.7
Stroke	216	1.7	118	7.1	32	0.7
Other neurological disease	201	1.5	85	5.1	130	3
End-stage liver disease	135	1	29	1.8	24	0.6
Sepsis	107	0.8	50	3	13	0.3
Other dementia	77	0.6	30	1.8	154	3.6
Motor neuron disease	72	0.6	3	0.2	16	0.4
Multiple organ failure	72	0.6	64	3.9	12	0.3
Not defined	68	0.5	7	0.4	31	0.7
Alzheimer's dementia	56	0.4	24	1.4	67	1.6
Diabetes and complications	24	0.2	1	0.1	1	0
HIV/AIDS	8	0.1	3	0.2	2	0
Total	12,997	100	1657	100	4267	100

Study governance

The PCOC program was approved by the Human Research Ethics Committee of the University of Wollongong (approval ID: HE06/045). Only routinely collected, de-identified, aggregated clinical data were used in this work, thereby excluding the need for separate participant consents.

Study population

Between July 1, 2013, and December 31, 2014, 105 palliative care services across Australia contributed data for this work from a cohort of 18,975 patients identified by their palliative care team as entering the terminal phase. Only the data of those who died were included in the final analysis.

Data collection

Data included were as follows:

1. Demographic characteristics, including age, gender, date of death, place of care, and type of illness (malignant/nonmalignant).
2. Number of days that patients survived from the time they were identified as entering the terminal phase until their death. PCOC has defined four specific patient-relevant phases: stable, unstable, deteriorating, and terminal,[22] with this work's focus being the terminal phase, which means that death was expected within hours to days[21] (Table 1).
3. Patient's distress secondary to physical symptoms was summarized by the Symptom Assessment Scale (SAS). The SAS is an Australian validated numeric rating symptom score where 0 = ''no distress'' experienced from the problem and 10 = the ''worst imaginable distress experienced.''[23] Symptoms covered by the SAS include bowel problems, pain, difficulty sleeping, nausea, breathing problems, appetite problems, and fatigue. The SAS does not provide an in-depth assessment of individual symptoms but serves as a screening tool to summarize the amount of distress from a symptom that in turn dictates the urgency of conducting a comprehensive assessment. This is ideally self-reported but when this is not possible, the patient's family or, in the absence of, staff score this tool.
4. Performance status was measured by the 10-item, clinician-reported Australia-modified Karnofsky Performance Status (AKPS), where a higher score equates with a better level of function.[25]

5. People's actual capacity to undertake activities of self-care was measured by the Resource Utilization Groups Activities of Daily Scale (RUG-ADL).[25] The RUG-ADL scale summarizes people's capacity to move in bed, toilet, self-transfer, and feed their self. The total RUG-ADL score (the sum of the individual scale items) has a value between 4 and 18, with higher scores identifying greater care needs.[26]

Analysis

SAS/STAT software was used to conduct the analysis (Version 9.2 of the SAS System for Windows (64 bit). Copyright © 2002–2008; SAS Institute, Inc., Carey NC). Descriptive statistics summarized demographic details, length of the terminal phase, and clinical assessment tools (SAS, AKPS, and RUG-ADL).

Logistic regression models were produced for SAS domains. The symptom's intensity scores were categorically substratified: 0 (none); 1–3 (mild); 4–7 (moderate); and 8–10 (severe) and then dichotomized into absent/mild (SAS scores 0–3) and moderate/severe (SAS scores 4–10).[27] Categorical covariates included days from death, diagnosis, place of care, age, and gender. The predicted event was the odds of a patient reporting an SAS score ≥4 versus a patient not reporting an SAS score ≥4, reflecting the normal reporting of PCOC data to services. Records with missing items were excluded from the logistic regression and no imputation of missing data occurred.

Results

Descriptive details

Over 18 months, 21,284 patients were identified as in the being in the terminal phase with 2309 (10.8%) excluded from the analysis as the phase did not end in death. The symptom scores at the start of the remaining 18,975 terminal phases were considered.

Approximately 75% ($n = 14{,}238$) of patients had cancer (Table 2) with 77.5% ($n = 14{,}708$) dying in an inpatient setting either under the care of a palliative care service or when a palliative care service was providing consultative advice; 76.2% ($n = 14{,}462$) were 65 years of age or older, and 52.7% ($n = 10{,}001$) were male (Table 3).

Of the 13,051 patients admitted directly under palliative care services, 80.2% ($n = 10{,}468$) died due to cancer with 71.5% of the 4266 who died at home also dying of cancer. In contrast, of the 1657 people who entered the terminal phase while palliative care services were providing consult support, only 43.4% ($n = 719$) had cancer (Table 2).

Functional status and level of dependency

When people were identified as entering the terminal phase, 91.0% ($n = 16{,}457$) scored an AKPS of either 10 (comatose or barely rousable) or 20 (totally bedfast and requiring extensive nursing care by professionals and/or family). Most were fully dependant in all care, with 85.2% ($n = 15{,}320$) of all patients having the highest RUG-ADL score (Table 3).

Duration of the terminal phase

The terminal phase was mostly no longer than two days (73.6%; $n = 13{,}965$), with 23.2% ($n = 4393$) of patients identified in the terminal phase on the actual day of death (Table 3).

Symptoms at the beginning of the terminal phase

More than half of this cohort did not experience symptoms that were sufficiently distressing to require further assessment (Table 4). Of those with symptoms that required attention, 28.7% ($n = 5095$) were moderately to severely distressed by fatigue, 22.2% ($n = 3978$) by pain, and 22.1% ($n = 3935$) by breathing problems. Appetite problems were moderately to severely distressing for 11.5% ($n = 2017$), 8.9% ($n = 1592$) by bowel problems, 6.8% ($n = 1196$) by difficulty sleeping, and 3.9% ($n = 690$) by nausea.

Predictors of poor symptom control

The odds ratio (OR) of people experiencing moderate to severe symptoms (SAS ≥4) when controlled for selected covariates

TABLE 3. PARTICIPANT'S CHARACTERISTICS

	N	%
Broad diagnosis		
Malignant	14,238	75.0
Nonmalignant	4652	24.5
Unknown	85	0.5
Setting of care		
Inpatient	13,051	68.8
Consult	1657	8.7
Community	4266	22.5
Age		
<15	28	0.1
15–24	44	0.2
25–34	130	0.7
35–44	376	2.0
45–54	1193	6.3
55–64	2742	14.5
65–74	4490	23.7
75–84	5582	29.4
85+	4390	23.1
Gender		
Male	10,001	52.7
Female	8973	47.3
Indeterminate	1	0.0
AKPS at the beginning of the terminal phase		
10	9050	50.1
20	7407	41.0
30	1095	6.1
40	354	2.0
50	127	0.7
60+	43	0.2
Total RUG-ADL at the beginning of the terminal phase		
4–5	54	0.3
6–13	695	3.9
14–17	1920	10.7
18	15,320	85.2
Length of terminal phase		
Same day	4393	23.2
1 day	6316	33.3
2 days	3256	17.2
3 days	1836	9.7
4 days	1120	5.9
5 days	694	3.7
6–7 days	683	3.6
8–14 days	527	2.8
15+ days	150	0.8

Table 4. SAS Scores at the Beginning of the Terminal Phase

	Pain		*Fatigue*		*Breathing problems*		*Bowel problems*		*Nausea*		*Appetite problems*		*Difficulty sleeping*	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
0	9434	52.7	11,843	66.8	11,263	63.1	14,318	81.0	16,205	90.9	14,761	84.0	15,246	86.3
1	1152	6.4	190	1.1	542	3.0	433	2.4	284	1.6	213	1.2	328	1.9
2	2024	11.3	330	1.9	1167	6.5	759	4.3	398	2.2	337	1.9	502	2.8
3	1315	7.3	280	1.6	930	5.2	576	3.3	242	1.4	245	1.4	389	2.2
4	1117	6.2	331	1.9	866	4.9	433	2.4	183	1.0	223	1.3	314	1.8
5	1167	6.5	673	3.8	873	4.9	455	2.6	198	1.1	360	2.0	351	2.0
6	617	3.4	575	3.2	578	3.2	227	1.3	84	0.5	232	1.3	188	1.1
7	323	1.8	503	2.8	326	1.8	110	0.6	57	0.3	164	0.9	89	0.5
8	494	2.8	1541	8.7	747	4.2	180	1.0	93	0.5	412	2.3	155	0.9
9	148	0.8	885	5.0	305	1.7	90	0.5	47	0.3	274	1.6	60	0.3
10	112	0.6	587	3.3	240	1.3	97	0.5	28	0.2	352	2.0	39	0.2
Total	17,903	100	17,738	100	17,837	100	17,678	100	17,819	100	17,573	100	17,661	100

were examined (Table 5). Those with nonmalignant disease are less likely to experience moderate to severe symptoms compared to those with malignant disease. The one notable exception to this was breathing problems, where those with nonmalignant disease 34% more likely to experience moderate or severe breathlessness compared to those with malignant disease (OR 1.34; 95% confidence interval [CI] 1.23–1.47).

A shorter terminal phase increased odds of having moderate or severe breathing problems and decreased the odds of moderate to severe symptoms of fatigue, bowel problems, and appetite problems. Pain, nausea, and difficulty sleeping mostly did not show any significant change in the odds of encountering moderate to severe symptoms when time from death was considered. The one exception is that people who were diagnosed as dying more than eight days before death were more likely to experience moderate to severe nausea.

With the exception of bowel problems, patients in the community are more likely to have moderate to severe symptoms then patients in a dedicated inpatient unit. In the acute setting, patients are more likely to experience moderate to severe breathing problems and difficulty sleeping, and less likely to experience pain and bowel problems when compared with the inpatient setting.

Women are less likely to experience breathing problems (OR 0.87, 95% CI 0.81–0.93) than men and are more likely to experience moderate to severe nausea (OR 1.47, 95% CI 1.26–1.72) than men. Patients of 65 years of age or older are more likely to experience moderate to severe symptoms of pain, fatigue, and difficulty sleeping.

Discussion

This study describes the symptom experiences of a large, national consecutive cohort of people at the time they were identified imminently dying. This is an important study being one of the largest ever descriptive studies of dying people's experiences. This work summarizes not only symptom prevalence but also the symptom intensity based on the perceived degree of distress it caused.

One of the major concerns expressed by patients and families facing the end of life is that the dying process will be complicated by distressing, intractable symptoms especially pain and breathlessness.[28] Although it is impossible to understand from this work whether or not people were already medicated, it is possible to conclude that the majority were either not highly symptomatic at the time that they were assessed as dying or were well palliated or both. Only 4.2% were documented as experiencing severe pain that urgently required attention. This is not suggesting that this low figure is acceptable. However, these data do provide clinicians with sufficient confidence to honestly reassure people that for the majority, the final stages of life are not likely to be complicated by unbearable or unmanageable pain. The most distressing problem at this time was actually fatigue with nearly one-third described as experiencing moderate to severe distress as a result. It is not possible to understand whether the distress was due to the fact that families may have perceived this to be iatrogenic or secondary to disease progression. The shorter the duration of the dying phase, the less this was perceived as problematic.

The most significant issue raised here is the observation that all symptoms were rated as more distressing when people were dying in the community compared with the inpatient setting, with the expectation of bowel problems. An enormous policy push exists to support people to die at home, with the aim of reducing the burden on the health system. Instead, care is moved to (with the attendant responsibilities) to patients' families and community services. It is commonly stated that people want to die at home, but achieving this requires families and friends to be willing caregivers able to mobilize sufficient support of health professionals, including a family physician.[29,30] As death approaches, some will change their minds regarding the place of care, preferring to move from a community setting to an inpatient setting.[16,31] The results presented here seriously question for the first time whether the same level of comfort can be achieved in the community setting, and whether poorer symptom control is a price that people are prepared to pay to die at home. Much more detail is required to explore this observation.

The majority were correctly recognized as dying, but 10.8% ($n = 2309$) did not progress from the terminal phase to death. Rather, these patients either stabilized or improved leading to a phase change. This highlights that even in a palliative care setting, confirming the correct diagnosis of dying with absolute certainty remains a clinically challenging exercise.[32] This also reinforces the importance of tailoring care to individual's assessed needs rather than treating pre-emptively on the presumption that problems will occur.[33] An approach that considers each patient's specific and sometimes changing needs is far preferable with this individualized approach

Table 5. OR of Having an SAS Score of Moderate or Severe (SAS ≥4)

Covariate	*Pain, OR (95% CI)*	*Fatigue, OR (95% CI)*	*Breathing problems, OR (95% CI)*	*Bowel problems, OR (95% CI)*	*Nausea, OR (95% CI)*	*Appetite problems, OR (95% CI)*	*Difficulty sleeping, OR (95% CI)*
N[a]	17,036	16,875	16,972	16,819	16,957	16,714	16,799
Days from death							
0–1				Ref.			
2–3	1.05 (0.97–1.14)	1.12 (1.03–1.21)	0.72 (0.66–0.78)	1.21 (1.07–1.37)	0.92 (0.76–1.11)	1.12 (1–1.26)	1.07 (0.93–1.23)
4–5	1.05 (0.92–1.19)	1.30 (1.16–1.46)	0.57 (0.49–0.65)	1.29 (1.08–1.53)	0.82 (0.62–1.09)	1.16 (0.98–1.36)	1.01 (0.83–1.25)
6–7	0.80 (0.65–0.99)	1.54 (1.3–1.83)	0.46 (0.36–0.58)	1.40 (1.07–1.83)	1.19 (0.82–1.74)	1.44 (1.14–1.81)	0.61 (0.41–0.89)
8+	1.11 (0.91–1.34)	1.72 (1.45–2.03)	0.47 (0.37–0.59)	2.00 (1.58–2.54)	1.65 (1.19–2.3)	1.80 (1.45–2.23)	1.21 (0.91–1.61)
Broad diagnosis							
Malignant				Ref.			
Nonmalignant	0.77 (0.7–0.85)	0.64 (0.59–0.7)	1.34 (1.23–1.47)	0.70 (0.6–0.81)	0.58 (0.46–0.73)	0.70 (0.62–0.8)	0.75 (0.63–0.88)
Episode setting							
Inpatient				Ref.			
Consult	0.73 (0.61–0.86)	0.99 (0.85–1.15)	1.44 (1.25–1.67)	0.54 (0.4–0.73)	0.91 (0.61–1.35)	0.80 (0.63–1.02)	1.41 (1.09–1.84)
Community	1.15 (1.06–1.26)	1.79 (1.66–1.94)	1.24 (1.14–1.36)	1.03 (0.9–1.16)	1.42 (1.19–1.69)	1.84 (1.66–2.05)	2.41 (2.12–2.75)
Age							
<24	0.58 (0.3–1.13)	0.99 (0.57–1.72)	1.79 (1.05–3.05)	0.75 (0.3–1.91)	1.50 (0.58–3.84)	0.57 (0.24–1.36)	0.87 (0.39–1.95)
25–34	1.37 (0.92–2.04)	1.22 (0.82–1.81)	1.01 (0.65–1.57)	1.22 (0.69–2.17)	1.38 (0.66–2.91)	1.04 (0.59–1.82)	1.41 (0.79–2.53)
35–44	1.15 (0.89–1.47)	0.99 (0.77–1.26)	0.77 (0.58–1.03)	1.14 (0.8–1.63)	1.42 (0.91–2.23)	0.90 (0.63–1.28)	1.07 (0.73–1.57)
45–54	1.04 (0.89–1.23)	0.95 (0.81–1.11)	0.94 (0.79–1.11)	0.88 (0.69–1.13)	1.17 (0.85–1.6)	0.90 (0.72–1.12)	0.98 (0.76–1.26)
55–64				Ref.			
65–74	0.83 (0.74–0.93)	0.87 (0.78–0.97)	0.97 (0.87–1.1)	0.85 (0.72–1.01)	0.87 (0.68–1.1)	0.86 (0.74–1.01)	0.71 (0.59–0.86)
75–84	0.77 (0.69–0.86)	0.84 (0.76–0.94)	0.90 (0.8–1)	0.88 (0.75–1.04)	0.68 (0.53–0.86)	0.84 (0.72–0.98)	0.65 (0.54–0.77)
>84	0.79 (0.7–0.9)	0.81 (0.73–0.91)	0.68 (0.6–0.77)	0.88 (0.74–1.05)	0.65 (0.49–0.85)	0.90 (0.77–1.05)	0.61 (0.5–0.75)
Gender							
Male				Ref.			
Female	1.01 (0.94–1.09)	0.98 (0.92–1.05)	0.87 (0.81–0.93)	1.07 (0.96–1.19)	1.47 (1.26–1.72)	0.92 (0.84–1.02)	0.80 (0.71–0.91)

[a]Numbers of observations used in the logistic regression.
95% CI, 95% confidence interval; OR, odds ratio; Ref., reference category.

recommended in the recent United Kingdom's National Institute for Health and Care Excellence's (NICE) guidelines for dying adults in the last days of life.[34]

Approximately 97% of this cohort died within seven days of being identified as imminently dying. However, there were outliers with a small minority whose life was much longer. Despite this, their illness phase was not modified, suggesting their care team continued to consider this to be the correct clinical situation. Although it is possible that for some of these people with a prolonged phase of dying there may have been errors of clinical judgment, it is more likely that for most people in this category, the dying phase was a slow and prolonged process reflecting the natural history of each person's particular illness.[35]

This work reinforces that breathlessness commonly complicates the end of life even more so for those dying with nonmalignant disease. It is not clear as to whether this is because of differing disease processes or less optimal palliation of those without cancer, with both possibilities raised previously. These suggestions continue to require attention, given that the real advances that have been made to better understand the mechanism of the problem and ways to optimally palliate it.[36,37]

The majority of patients at the time they were identified as dying were fully dependant and barely able to be roused reinforcing their very poor performance status with this a reliable prognostic indicator for patients with cancer.[38] There was, however, a very small group of people who were allocated a much higher level of function. From the extracted data, it is not possible to understand the context in which the scores were allocated or, in fact, if these were erroneously applied. There is a cohort of people with life-limiting illnesses who experience sudden death, but that cohort should not be reflected in these data.[39,40] However, these patients were not removed from the dataset as they do constitute part of the whole, with the small numbers observed as having reasonable performance status not affecting the overall models.

Strengths of this work

This large, national, descriptive consecutive cohort study is based on prospectively, routinely collected data at point-of-care across a range of care locations. Furthermore, these data were collected in a manner that allows them to be standardized according the terminal phase with this definition based on nationally agreed and validated criteria.[17]

Limitations of the work

There are limitations to this work. While the details of the actual diagnoses of all the participants were included, a regression analysis to further explore the impact of specific disease groupings on symptoms was not undertaken. More work is required to understand the experiences of the subgroups to define their characteristics and how they should be best managed. Another limitation is that only people included in this study had been referred to specialist palliative care services in a country with universal health coverage. What happens to the people not referred to specialist palliative care services and cannot be inferred from these data, especially given the evidence that people referred to specialist palliative care services are perceived by their relatives to be more comfortable at the end of life than those who are not.[41] The referral patterns in countries with predominantly fee-for-service care also cannot be inferred. This was a high-level study and, as such, provides an overview only making it impossible to understand how people were actually managed and whether there were other factors likely to have been contributing to symptoms. This was a point prevalence study only and changes over time were not included. Even while this study is based on a validated symptom tool assessment, there are no details to record who rates the SAS scores—patients, families, or staff. This is an issue that has been acknowledged by PCOC with plans already in place to include documentation as to who rated the SAS. However, for other PCOC tools, a proxy rating is highly valid.[42] Finally, the SAS does not provide assessments of other problems that might be bothersome at the end of life, including anxiety or depression.

Future research

The most urgent work identified by this study is the need to better understand the differences between distressing symptom reports in the community and other inpatient settings. The discrepancies are large, and patients together with their families need to be aware of any limitations in delivering symptom control if these findings truly reflect people's experiences. This population study provides robust data to expand clinician's understandings of the experiences of people in the very final stages of life. However, more detail is needed to understand at a population level if, when the data are collected prospectively, the experiences of people when not referred to palliative care are different to those highlighted here. Such work needs to be complemented with data from caregivers about their perceived experience of the comfort of people they love and care for at the end of life.

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Address correspondence to:
Katherine Clark, MBBS, MMed, FRACP
Department of Palliative Care
Calvary Mater Newcastle
Edith Street, Waratah
Newcastle 2291
Australia

E-mail: katherine.clark@calvarymater.org.au