

# Comfort in the last 2 weeks of life: relationship to accessing palliative care services

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## Abstract

**Introduction** Specialised palliative care services (SPCS) aim to address the needs of patients and caregivers confronting life-limiting illnesses but only half of the potential cohort are referred. Randomised controlled trials of SPCS provision can no longer be ethically justified so there is a need to develop new methods to evaluate the net impact of SPCS for the whole community, not just for those who access SPCS. The aim of this study was to assess whether perceived comfort in the last 2 weeks of life was associated with accessing SPCS. **Methods** This study utilised a whole-of-population random survey ( $n=4,366$ ) in South Australia. A total of 802 respondents had someone close to them die within the last 5 years due to a terminal illness, and they had the complete

data. A subsequent question was asked whether SPCS had been accessed. Perceived comfort levels for those who had used SPCS were compared with those who did not by using stereotype logistic regression, weighted to a standardised population.

**Results** Higher levels of comfort of the deceased having been assessed ‘very comfortable’ was associated with the use of SPCS ( $p=0.04$ ; odds ratio, 1.78; 95% confidence interval, 1.02–3.08). For people who accessed SPCS, 13.3% were reported as ‘very comfortable’ compared with 8.0% without SPCS. Almost one half of respondents (48.4%) reported that the deceased was considered ‘uncomfortable’ or ‘very uncomfortable’, irrespective of SPCS access.

**Discussion** While this study provides further incremental evidence of benefit from access to SPCS, there is much that still needs to be done to improve care for the whole community at the end of life.

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## Introduction

Patients and their family members identify comfort and good symptom control as essential components of good end-of-life care [21, 36, 47, 51, 53, 54]. Specialised palliative care services (SPCS) have developed to support a range of health professionals to address better the needs of patients and families confronting life-limiting illnesses. There is a need to understand all aspects of the benefits derived from SPCS access.

For patients, involvement of SPCS improve the “quality of dying” [55], pain assessment and management of people dying in nursing homes [43, 44] and symptomatic manage-

ment in people admitted to hospital [26] and meet needs [54] and satisfaction with care [9, 28, 30]. For caregivers, SPCS involvement has been found to improve satisfaction [28, 54] and reduce anxiety [30]. In health service delivery, SPCS involvement reduced inpatient bed days [9, 12] and decreased costs when compared to conventional care without shortening prognosis [9, 52].

Systematic reviews of the impact of SPCS have been conducted and concluded that, while a benefit is suggested, data quality limits any conclusions [17–20, 24, 25]. Generally, studies have not been able to assess people with a life-limiting illness who have not accessed SPCS. Reasons for not utilising a service include a service not being available, declining involvement having been referred or because a referral was not made for this person to a service. Given that access rates to SPCS for people with a life-limiting illness are approximately 50% in developed nations, understanding what is happening to the 50% who do not access SPCS is pivotal to understanding better the net benefits of involving SPCS for service planning [13, 38].

Ethical concerns make it hard to justify health service level randomised controlled trials of SPCS involvement [17–20, 24, 25]. It is therefore imperative that other methods are used to compare the health outcomes of those who have and have not received input from SPCS. Comparing the experiences of these two groups may help to define additional benefits, problems or limitations conferred by accessing SPCS.

The South Australian Health Omnibus Survey has been utilised as a novel method to assess the palliative care needs of the population of South Australia [49, 13]. The survey allows data to be collected from a cross-section of the South Australian population and, therefore, provides access to a systematically identified population of former caregivers of deceased individuals irrespective of SPCS involvement.

The aim of this study was to assess whether there was an association between levels of comfort in the terminal phase of a life-limiting illness and the use of SPCS. The null hypothesis was that there would be no difference in the proportion of people who were “very comfortable” in the last 2 weeks of life compared to those who had and had not accessed SPCS.

## Materials and methods

The South Australian Health Omnibus [49] is an annual, random, face-to-face, cross-sectional survey conducted within the state of South Australia. It is administered by a commercial research organisation with government support. There is a cost for each question included in the survey. Respondents were asked if someone close to them had died of a terminal illness in the last 5 years in South Australia

(Table 1). Pilot testing of the questionnaire with 50 members of the general public for comprehension and usability occurred prior to administration and no changes were made to the wording as a result of piloting.

**Table 1** South Australian Health Omnibus Survey 2004—palliative care questions relevant to comfort in the last 2 weeks of life

### Palliative care questions

In the past 5 years, has anyone close to you in South Australia died of a terminal illness like cancer, motor neurone disease or emphysema? If yes, could you please say what their illness was? (Directions to interviewer—if more than one person has died, then ask about the person closest to the respondent)

- Cancer
- Motor neurone disease/multiple sclerosis
- Emphysema/other lung disease
- End-stage heart failure
- End-stage liver failure
- End-stage kidney failure
- HIV/AIDS
- Other (specify)
- Do not know illness

How long ago did this person die?

Where did this person die?

- Home
- Hospital
- Hospice
- Residential aged-care facility or nursing home
- Hostel
- Other
- Do not know

What was your relationship to this person?

- Spouse/partner
- Parent
- Child
- Sibling
- Other relative
- Friend
- Other (specify)

Consider the last 2 weeks of that person’s life, was he/she comfortable?

- Very comfortable
- Comfortable
- Somewhat comfortable
- Somewhat uncomfortable
- Very uncomfortable
- Do not know

Did this person who died of a terminal illness use a palliative care service? (Definition provided—palliative care aims to comfort, not to cure, to relieve pain and distress for people who are dying and to support patients, families and friends in approaching death and coping with grief)

- Yes
- No
- Do not know

## Sampling schema

From September to December 2004, 4,500 households were approached. In metropolitan areas, a starting point was randomly selected for each Australian Bureau of Statistics collector's district, and then ten dwellings were randomly selected using a skip pattern of every fourth household. In non-metropolitan areas, households were selected using 100 starting points statewide; all towns with a population greater than 10,000 were included and towns with a population above 1,000 were randomly included. A cluster size of ten was used at each of the non-metropolitan starting points. One interview per household was conducted with the person over the age of 15 who had most recently had a birthday. Interviews were conducted face to face by trained interviewers. Prompt cards were provided for selected answers to allow responses to be categorised. Data were anonymous and were double punched. Any missing responses were followed up by a telephone call. For quality assurance, 10% of each interviewer's respondents were randomly selected and re-contacted to confirm eligibility and responses. These processes are applied to the whole survey, are unchanged since the survey's inception in 1991 and could not be modified just for the questions relating to the end of life.

## Setting

South Australia has a population of 1.54 million people [8]. SPCS within South Australia span a range of different service delivery models, from large regional multi-disciplinary teams within Adelaide to single clinical nurses in small rural locations. Each service covers a geographic region encompassing public and private hospitals (tertiary, district and free-standing palliative care units, outpatient clinics) and a community care team working in conjunction with general practitioners and community nurses. Almost 60% of people with a life-limiting illness are referred to SPCS in the state [13]. Nationally, the average time from referral to death is 102 days, with 28.5% of people accessing SPCS for longer than 6 months [6]. In this setting, services provide care in parallel with disease-modifying therapies in line with World Health Organisation models [7].

## Statistical analysis

Data were weighted according to the age, gender, geographic profile and country of birth using the 2001 standardised population of South Australia [8]. Descriptive statistics were used for respondent and patient characteristics. In analyses focusing on level of comfort, "very comfortable" was used as the reference point for outcomes.

The categorical responses to level of comfort in the last 2 weeks of life (Table 2) were analysed by stereotype logistic regression for both univariate and multivariate analyses [5]. The multi-factor model sought to exclude any confounding factors using the collected demographic data to explore differences in respondents' perceptions of comfort at the end of life by SPCS access. Stata software version 9.2 (Stata Corporation, 2005, College Station, TX, USA) was used for statistical analysis. A sensitivity analysis using data with unweighted data assessed the direction and magnitude of findings.

## Ethics and consent

The Health Omnibus Survey received state ethics committee approval in 1991, and ethics review continues annually. Verbal consent was obtained from all participants (in South Australia, informed consent can be given by anyone over the age of 15).

## Results

### Description of respondents (unweighted)

A total of 4,500 households were approached to participate in the survey between September and December 2004. A participation rate of 76.0% was achieved (Fig. 1). There were a total of 1,465 male respondents (49.1%) and 1,520 female respondents (50.9%). Ages were evenly distributed. Three quarters (75.5%) of the sample were born in Australia and 62.9% were married or in a de facto relationship.

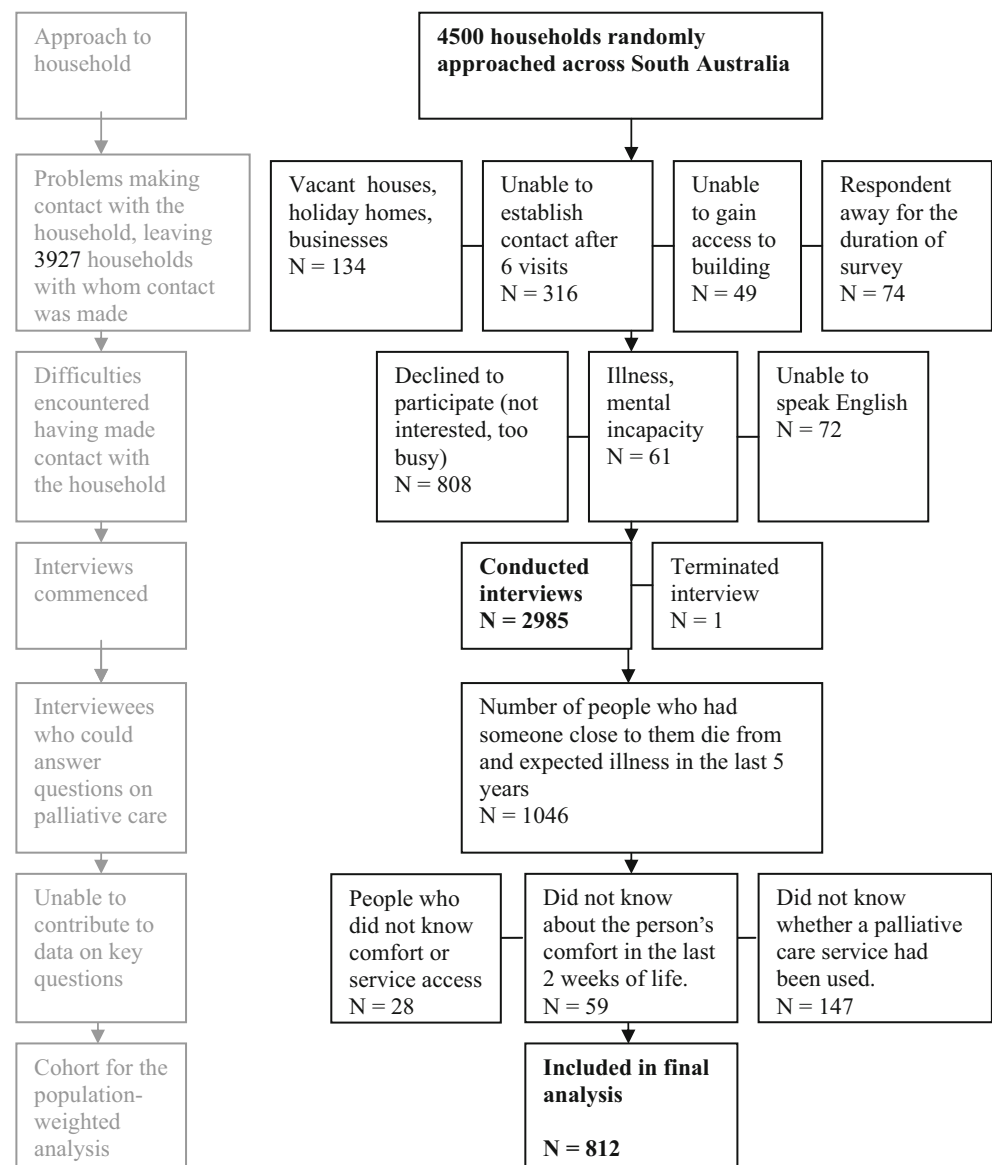
**Table 2** Reported level of comfort for individuals with a terminal illness in the last 2 weeks of life comparing by category of comfort for those who did and did not access a specialist palliative care service using data weighted to the standard population for key demographic characteristics

Comfort level	Total sample	SPCS used	SPCS not used
Very comfortable	92 (11.4%)	69 (13.3%)	23 (8.0%)
Comfortable	145 (18.0%)	94 (18.0%)	52 (17.9%)
Somewhat comfortable	179 (22.2%)	111 (21.3%)	69 (23.8%)
Somewhat uncomfortable	165 (20.4%)	106 (20.4%)	59 (20.3%)
Very uncomfortable	228 (28.1%)	141 (27.1%)	86 (30.0%)
Total <sup>a</sup>	809 (100%)	521 (100%)	289 (100%)

Respondents who did not know the person's level of comfort have been excluded ( $n=59$ ) and, additionally, those who did not know whether a palliative care service was used ( $n=147$ ). Twenty-eight people could not provide responses to either question.

<sup>a</sup>Numbers will not add up in rows or columns because population-weighted data have been used and rounded to the nearest integer for each cell.

**Fig. 1** The flowchart of engaging participants for the South Australian Health Omnibus 2004. Participation rate 76.0% (2,985/3,927)



One in three respondents ( $n=1,046$ ) indicated that someone close to them had died of a terminal illness within the last 5 years. When asked if SPCS had been involved in the care of the deceased individual, 52.5% answered 'yes', 28.9% declared 'no' and 17.8% stated that they did not know. SPCS involvement was significantly more likely if the deceased had a cancer diagnosis (66.3%) compared to other causes of expected death (54.0%;  $p=0.003$ ).

#### Analysis (weighted data)

All subsequent results use population-weighted data. Analysis excluded those who did not know the person's level of comfort ( $n=59$ ), those who did not know whether a palliative care service had been accessed ( $n=147$ ) and those who knew neither ( $n=28$ ). Data were available for 809 respondents (Table 2) with a further seven excluded from

multi-factor analyses because they did not know the person's place of death.

Two key characteristics are available for the deceased person—diagnosis and age. The life-limiting illness was cancer for 668 people (82.6%) and end-stage organ failure ( $n=116$ ), AIDS ( $n=1$ ) or motor neurone disease ( $n=24$ ) for others. The mean age of the deceased was 65.9 (range, 5–96; standard deviation (SD), 14.7).

The comfort level of the deceased in the last fortnight of life was rated as 'very comfortable' (11.4%), 'comfortable' (18.0%) or 'somewhat comfortable' (22.2%) (Table 3). A total of 48.4% reported the person was uncomfortable in the last 2 weeks of life (20.3% 'somewhat uncomfortable' and 28.1% 'very uncomfortable').

The association between the level of comfort and use of SPCS was examined in a multi-factor analysis by stereotype logistic regression having controlled for factors

**Table 3** Factors predictive of the deceased being ‘very comfortable’ in the last 2 weeks of life, as assessed by someone close to them up to 5 years after the death using population-weighted data and stereotype logistic regression ( $n=802$ )

	Factors included in analysis	<i>p</i> value	Odds ratio	95% confidence interval
Demographic characteristics of the respondent	Gender (male 359, female 438)	0.65	0.88	0.51–1.53
	Age (mean 48.3; SD 17.0) (15–29 (125), 30–44 (212), 45–59 (261), 60–75 (132), >75 (67))	0.87		
	Country of birth (English speaking 722, other 76)	0.43	1.41	0.60–3.31
	Highest level of education (school only 339, higher education 459)	0.76	0.92	0.55–1.55
	Most involved level of care (any care 227, none but still close to me 571)	0.29	1.40	0.75–2.61
Demographic characteristics of the respondent that may change as the result of someone close to them dying	Marital status (married/de facto 559, separated/divorced 70, widowed 54, never married 114)	0.23		
	Work status (working/student 515, not working 282)	0.26	1.53	0.73–3.21
	Income ( $\times$ ,000 per annum; <20 (142), 20–40 (149), 41–60 (135), >60 (294), not stated (77))	0.02		
Factors associated with the person that died and their care	Relationship to the deceased (spouse 32, other 765)	0.78	0.86	0.30–2.50
	Diagnosis (cancer 660, non-cancer 137)	0.50	1.32	0.59–2.93
	Months since death (mean 23.4; SD 18.2) (0–12 (340), 13–24 (175), 25–36 (119), >36 (164))	0.52		
	Use of palliative care service (yes 516, no 281)	0.04	1.78	1.02–3.08
	Place of death (community 199, inpatient 598)	1.11	0.90	0.61–2.01

relating to both the respondent and the deceased. The use of SPCS did not discriminate among the comfort levels of ‘comfortable’ to ‘very uncomfortable’. The probability of the person being ‘very comfortable’ was significantly greater if SPCS was used ( $p=0.04$ ; odds ratio, 1.78; 95% confidence interval, 1.02 to 3.08). The only other factor that was significant was that fewer respondents in the higher income brackets (6.2% in A\$40,000–60,000; 6.8% in >A\$60,000) reported the level of comfort as “very comfortable” compared to those in lower brackets (16.1% in <A\$20,000; 15.9% in A\$20,000–40,000).

#### Sensitivity analysis

The raw survey data without population weightings were then completely re-analysed, confirming the direction and magnitude of each of these findings.

## Discussion

#### What is new?

According to respondents, the use of SPCS was associated with higher levels of comfort during the last 2 weeks of life. This is the first study to assess the impact of SPCS on

comfort in the last fortnight of life in a whole population using a random population survey method. Although the finding may seem intuitive, documenting this finding with the denominator as the community at large is new and crucial for service planning, contrasting with previous methodologies that have used mortality follow-back methods, contacted only caregivers known to a particular SPCS or employed secondary analyses to calculate “quality of death” scores [21, 36, 47, 51, 53–55]. After death, surveys can collect information on a representative sample of deaths rather than on just people who are able and willing to talk about their experiences [2] as was used in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment [36].

It is an overwhelming concern that one in two respondents indicated that someone close to them was ‘uncomfortable’ or ‘very uncomfortable’ in the terminal stage of life irrespective of whether SPCS was used or not. The nature of this lack of comfort is being explored in subsequent surveys to determine if it relates to physical or emotional symptoms, or both. Such a level of discomfort demands an urgent response by all service providers.

Are these statistically significant results also significant in clinical practice and health service planning given the proximity of the lower confidence interval to one? People with more complex symptoms are more likely to be referred

to SPCS [14]. These are the same people who, in this study as they enter the terminal phase of their care, are ultimately reported to be more comfortable than people whose complexity of needs has not triggered a referral to SPCS. The net benefit of SPCS in contributing to comfort is therefore under-estimated in the statistical results. The modest magnitude of benefit seen in this study should be considered as an addition to the already existing evidence base for people who have accessed SPCS [15, 17–20, 24, 25]. The current study reflects only one time-limited facet of the overall contribution of SPCS to care—the terminal phase—and it is likely that the total benefit of accessing SPCS is the sum of benefits achieved by SPCS for patients, caregivers and health professionals over the entire period of contact.

Has perceived comfort differing across socio-economic strata been reported before? Although there are data that support differential access of SPCS by people from higher socio-economic strata [1, 3, 13, 23], this has not been linked to measured outcomes. The reason for such an association is not clear from the data currently available.

What are the strengths of the study?

This current study employs a new method to explore the impact of SPCS at a whole population level on a question central to continued funding of SPCS—do services make a difference to comfort at the end of life? The sampling process employed by the Health Omnibus allows a truly representative sample with the denominator being the whole population. Rather than using SPCS staff to survey perceptions of care and comfort, the use of independent interviewers reduced the likelihood of a biased positive appraisal.

Another strength of the study is the analysis tool. Initial analyses revealed that the assumptions underlying the proportional odds model were not met for level of comfort; hence, the less restrictive stereotype model was chosen. Reflecting the basic premise originally proposed by Anderson for stereotype logistic regression, the more commonly used proportional odds logistic regression was inappropriate to use in this study as the levels of comfort were not grouping an underlying continuous variable [5]. By contrast, stereotype logistic model should be used in cases in which respondents must choose between a number of ordered responses especially in a situation in which a predictor may discriminate between some but not all of the outcome categories.

Limitations—methods

This study used the reports of proxies to investigate the impact of SPCS on comfort at the end of life. Proxy reports

are frequently used in palliative care research due to the difficulties encountered in research engaging people with a life-limiting illness [2, 4, 11, 31, 33]. Studies have examined the accuracy of retrospective reports by proxies, comparing reports of patients prior to death with those of their relatives after death [4, 10, 22, 27, 31, 33]. In studies comparing concurrent prospective (pre-death) reports by patients and their relatives, family caregivers' overall symptom distress scores have been highly correlated with patients' overall scores [32, 35]. Families tend to rate symptoms more severely than patients [34, 37, 47] and under-report psychological distress [16, 34, 45]. Overall comfort is something that relatives can assess using several factors to reach their conclusions: levels of comfort stated by the patient [48, 50], behaviours, activity levels, analgesic use and facial expressions [40, 41]. All of these factors, potentially in a composite measure, should be included in future work seeking to understand levels of comfort at the end of life. Congruence between proxies and patients is greater for issues where there is an observable consequence [16], such as service utilisation, functional ability or preferred place of care [16, 22, 27, 31, 45]. Proxies living with patients have been found to have a higher level of agreement [39] but caregiver strain, unrealised expectations and poor caregiver coping may be associated with some incongruent reports [39, 42, 47] including reporting caregiver distress as patients' physical pain [47].

The current study is an important reflection of the people's perceptions of end-of-life care and is likely to relate to the deceased's experience. By the terminal phase of a life-limiting illness, individuals are often too unwell to participate even in initiatives designed to improve the quality of care. In this setting, proxies become an invaluable source of information about the quality and outcomes of the care given. Even if there are limitations in proxy reporting, family members' own perceptions demand attention [36]. Perspectives from all involved parties (patients, family, caregivers, clinical staff) should be sought in evaluating end-of-life care [33].

Counter-intuitively, even patients may not be "gold standard" reporters of discomfort as they may downplay or emphasise certain symptoms, not want to complain or seek to provide the answers they think are expected [2, 35, 39]. The "gold standard" of comfort is an amalgam from a number of key sources including patients and people close to them.

The timing of the interview and the way that questions are framed may have an impact on a bereaved person's proxy response about the deceased [39]. Concerns have been raised about the validity of retrospective proxy reports because respondents may be affected by grief or difficulties in recall. Many factors may influence the response to the question about the comfort of someone close who died

including recall biases, positive reappraisal as a coping strategy and the net emotional effects of grief which may, at the time of answering, be positive or negative. The current study deliberately covers a large population and a 5-year period to account for some of the variations that may be encountered over time in reporting the comfort level of the deceased. To ensure that the net impact of time since death is taken into account when evaluating comfort in the last 2 weeks of life, time since death was included as a variable in the multi-factor analysis.

#### Limitations—sample

It is likely that certain groups including people whose first language was not English were under-represented in the raw data. Lower participation rates from identifiable sub-populations within the community are dealt with by using population-standardised weightings for all analyses. The study design meant that individuals in remote locations and patients without caregivers could not have their experiences reflected in the data.

Nearly a third of respondents who had experienced a death within 5 years reported the bereavement occurred within the last 12 months. In a population survey of this nature, deaths theoretically should be evenly distributed in each of the years across the 5-year period. This apparent anomaly may be due to recall error given that life-changing or highly emotional life events may feel more recent than they actually were [2, 11].

#### Generalisability

This report deals with responses from a single state, in a health system that has relatively high rates of access to SPCS. The models of care and care offered differ in health settings around the world and may therefore limit generalisability to health systems that are markedly different.

#### What are the implications for future research?

Future research in this area needs to validate these findings in different health systems. Rather than face-to-face interviews, computer-assisted telephone techniques could be used at a population level to replicate this study in other health systems. Given the annual nature of the Health Omnibus, the questions used in 2004 have been modified to allow assessment of physical comfort and distress separately in subsequent surveys [29, 46]. Further research is also required to better understand the factors that influence proxy reports during bereavement. In any prospective research on comfort at the end of life, patient, caregiver and staff input will be required. Definitions of comfort (physical, emotional, social) will need to be explored.

## Conclusions

For practice and for service planning, this study supports a measurable benefit from SPCS involvement at a population level with higher levels of comfort in the last 2 weeks of life in people who accessed services. However, the challenge is to ensure that people who are perceived to be ‘uncomfortable’ and ‘very uncomfortable’ have systematic attempts to improve the quality of their care given the high prevalence of discomfort irrespective of SPCS utilisation. This requires all clinicians involved in end-of-life care to continue to explore ways to adequately identify that a person is dying and providing attention to optimising comfort until death. Such findings also require health service planners to improve ways of delivering care to all people with complex needs facing a life-limiting illness.

**Competing interests** The authors declare no competing interests.

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