Identifying and predicting the need for end-of-life care:
An agile review of the literature

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This agile review outlines findings of a search conducted by the Evidence Service to identify sources describing characteristics (personal and healthcare related) in relation to population need for end-of-life care or palliative care (PC). It covers several questions that emerged as we explored the evidence landscape. Initially, we identified models used to predict future population level need for PC, and then primary studies utilising these models to identify specific characteristics of people in need of this care. Finally, other primary studies were identified that described characteristics of people who received or were potentially in need of PC. This work will help to inform the development of an impact needs assessment for PC in Wales.

Review question	
What characteristics have previously been used as indicators to predict at a population level who might need end-of-life care?	
Sample	People who need end-of-life care (defined as those who are in their last 12 months of life)
Phenomenon of interest	Population level characteristics of people who need end-of-life-care
Design	Population needs assessments, modelling studies, evaluation studies
Evaluation	Population level end-of-life care personal and healthcare characteristics used as indicators
Research type	Quantitative, qualitative and mixed methods
Other Study Considerations	
No publication date limit	

What evidence did you identify that addressed your topic?

1. **Key messages**

- Several models were identified to answer the broad question of *how many people require PC at a population level?*
- Models predicting and identifying those in need of PC on an individual basis were not assessed
- All models looked at general PC need and five models incorporated the ability to calculate need based on different projection scenarios
- Five models included dementia and heart failure as those potentially in need of PC, but all included cancer
- Population models lack detail in terms of characteristics that may identify those in need of PC,
- Some models were validated, but we have not assessed the rigour of the validation process
- No population models looked at the type of individual care requirements or when it may be required. However, this information may be identified in tools that identify individual need for PC, but we did not assess these
- Primary studies identified the following characteristics to describe those who may need PC:
  - age
  - co-morbidity/multi-morbidity (sometimes described as only those associated with PC need)
  - disease group or disability burden
  - education level
  - ethnicity
  - gender or sex
  - geographical region
  - health and social care utilisation (GP visits, ED admissions, inpatient admissions, home health hours)
  - language preference
  - pain burden
  - place of residence (home, care facility)
  - socioeconomic status/social disadvantage (usually annual household income)

2. **Models to identify predicted population need for palliative care**

Seven models were identified to predict population level need for end-of-life and palliative care (PC), with the more recent models evolving from their chronological predecessors. The majority use a simple linear approach using mortality data and

disease-specific mortality data to project palliative care needs. The main differences between models is the criterion for age and disease or condition of people who may benefit from PC.

Higginson (1997) developed one of the earliest models. This was an adaptation of the Stevens and Raftery (1994) approach for epidemiologically based needs assessments. It considered effectiveness of services and existing models of care to triangulate need.

Rosenwax et al. (2005) further developed the method of using routine mortality statistics to estimate PC need in a population. They developed three estimates to determine who could benefit from PC: Minimal, mid-range and maximal estimate.

Gomez-Batiste et al. (2012) incorporated developments in PC practice and refined the use of data on the prevalence of those living with advanced chronic disease, older people with pluripathology, dementia and care home residence.

Murtaugh et al. (2014) refined previous methods (Higginson 1997, Rosenwax et al. 2005 and Gomez-Batiste et al. 2012) and based population PC estimates on the views of an expert panel. Utilising updated ICD-10 codes along with contributing cause of death for selected groups of conditions, they estimated potential PC need. Four estimates determined who could benefit from PC: minimal, lower mid-range, upper mid-range and maximal estimate.

Building on previous diagnosis-based approaches, theEtkind et al. (2017) model conducted two analyses utilising methodology developed by Gomez-Batiste et al. (2012) and followed a diagnosis-based approach developed by Murtaugh et al. (2014). Explicit assumptions about changes in disease prevalence over time were used and official mortality forecasts, to calculate age- and sex-specific proportions of deaths to estimate the prevalence of PC need in the population.

May et al. (2020) utilised all-cause mortality data along with the ICD-10 codes and groupings established by Etkind et al. (2017). The model used three estimates: total number of deaths from a disease associated with PC need; numbers of people aged 50+ living and dying with diseases indicating PC need by age and gender; and disability burden, pain prevalence and health care utilisation among people aged 50+ living and dying with diseases indicating PC need.

Finucane et al. (2021) estimated future PC needs using simple linear modelling to develop the method established by Etkind et al. (2017) by conducting additional analysis to estimate PC need by age group, underlying cause of death by disease group and proportion of people dying with multi-morbidity associated with advanced progressive diseases across different disease groups.

Most of the models utilise specific International Classification of Disease (ICD) system codes to identify disease groups. These are based on the tenth edition (ICD-10). Disease groups included are generally based on the ICD-10 codes outlined in the Rosenwax et al. (2005) model.

Subsequent models expanded and re-organised the list incorporating ICD-10 coding changes or including more people potentially in need PC:

- Organ failure (heart disease, heart failure, chronic lower respiratory disease, respiratory failure, reno-vascular disease, renal failure, liver disease)
- Dementia (Dementia, vascular dementia, Alzheimer's disease, senility)
- Other (Huntington's disease, motor neurone disease, Parkinson's disease, progressive supra-nuclear palsy, multiple sclerosis, multi-system atrophy, haemorrhagic, ischaemic and unspecified stroke, HIV)

3. Studies utilising models to estimate palliative care need among populations

We identified seven cohort or cross-sectional population studies using the aforementioned models to predict future population estimates of PC need. These are outlined in table 2 and were undertaken using data from Australia, Colombia, Germany, Ireland, and England. One study compared estimated need across 12 EU and non-EU countries.

Of the models identified, the Murtagh et al. (2014) model was most widely used (Westley-Wise, 2021; Calvache et al., 2020; and Kane et al., 2015). Three studies compared models to gauge the range of projected estimates using the same data set (Morin et al., 2017; Scholten et al., 2016; and Jeba et al., 2021). Two compared the Rosenwax et al. (2005) and Murtagh et al. (2014) models (Morin et al., 2017 and Scholten et al., 2016). In addition to these, Morin et al. (2017) also used a model develop by the French National Observatory on End-of-Life care (ONFV) to estimate PC need in 12 EU and non-EU countries. This model utilises a modified list of chronic conditions established by the Institut National de Santé Publique du Québec. Those identified as potentially in need of PC were categorised into three 'end-of-life trajectories', based on underlying cause of death and typology suggested by Murray and co-workers. We did not identify this model in our searches, but it is outlined in a French book, available online. Jeba et al. (2021) compared estimates projected by the Gomez, Etkind, and Murtagh models to estimate PC need in central Lancashire. The motive for using multiple models to estimate PC need was unclear.

All studies predicted increases in the number of people dying from disease(s) associated with PC need. A Scottish population study predicted increases of between 74% (2017) and 95% (2040) (Finucane et al., 2021). A Colombian population study (Calvache et al., 2020) also demonstrated a rise in absolute numbers of deaths between 2012 and 2016. Of these, those requiring PC (defined as malignant neoplasm, heart and cerebrovascular disease, renal disease, liver disease, respiratory disease, neurodegenerative disease, Alzheimer's, dementia and senility, and HIV/AIDS) increased 61.2%, with just over 31% of these being cancer related.

4. Characteristics that might help identify those who could benefit from palliative care

Our search also found observational studies describing individual characteristics of those in need of PC from population data, as outlined in table 3. Most studies identified used descriptive statistics to describe population characteristics of those potentially in need of PC. These included:

- age (broken down into different age groups)
- co-morbidity/multi-morbidity (sometimes described as only those associated with PC need)
- country of birth
- disease group or disability burden (different categories – usually identified from underlying cause of death)
- education level
- ethnicity
- gender or sex
- geographical region
- health and social care utilisation (GP visits, ED admissions, inpatient admissions, home help hours)
- language preference
- pain burden
- place of residence
- socioeconomic status/social disadvantage (usually annual household income)

Six primary studies used analytical statistics to investigate the population characteristics of those who accessed or needed PC. These are discussed in more detail below by characteristic. At the request of stakeholders, any characteristics relating specifically to dementia or heart failure are highlighted in bold.

4.1. Disease Group

Projected numbers of estimated death vary greatly by disease group. This is likely due to different disease categories being considered by authors and the models used, as well as the available data. However, Etkind et al. (2017) highlight that regular coding changes in mortality datasets, potential future changes in medical treatments or patient outcomes, make it difficult for these models to project disease-specific mortality. Despite these challenges, the following information around disease group and PC need and access are discussed.

The distribution of numbers of people within specific disease groups accounting for projected PC need varied across studies. Most agreed cancer would account for a large proportion of increased PC need (Etkind et al., 2017; Finucane et al., 2021; Scholten et al., 2016;). However, **heart disease** (between 8.4% and 30.8% increase using the Rosenwax and Murtagh methods respectively [Scholten et al., 2016]) and

dementia (185% rise. Finucane et al., 2021; Etkind et al., 2017) were also identified as an underlying cause for the potential growth in demand of PC.

All studies found people with cancer were most likely to access PC. Among those who investigated, people with **heart failure** (aOR 0.58; 95% CI 0.47–0.72: Westley-Wise et al., 2022) (Rosenwax et al., 2016) and **severe dementia** (Beernaert et al., 2013) were least likely to access PC compared to other disease groups, except for COPD in one study (Beernaert et al., 2013). However, there were often small numbers of patients with certain disease conditions (such as COPD and heart failure) (Beernaert et al., 2013).

4.2. Multimorbidity

Estimates suggest multimorbidity's associated with PC need are also set to increase. A study estimating PC need in Scotland from 2017 to 2040, found, overall, 27.5% of all deaths in 2017 involved people with multimorbidity (defined as at least two diseases associated with palliative care need from different disease groups). The number of people dying with multimorbidity is projected to increase by 82% by 2040 in Scotland, accounting for 43.5% of all deaths or 45.6% of all PC deaths (Finucane et al., 2021). The proportion of those who die with multimorbidity is projected to increase by 60% (27.2% to 43.5%). The increases mainly occur among older age groups. If current trends continue, by 2040, Finucane et al. (2021) project 52% of people aged 85 to 99 will die from two or more diseases associated with PC need from different disease groups.

4.3. Gender

There appears to be a general consensus that females, particularly those with cancer are more likely to need, as well as access PC services when compared to males. A Belgium study (Beernaert et al., 2013) found female cancer patients were more likely to be referred to palliative care services than their male counterparts (OR 1.46, 95% CI 1.05 to 2.05). Similarly, Morin et al. (2017) identified men were less likely to have died from conditions indicative of PC need compared to women (ORs ranged from 0.86 to 0.94) in nine of the 12 countries estimated.

4.4. Age

Population age distribution and age of death trends appear to impact the number of people estimated to need PC in the future. However, different age group categories among the models and studies, make direct comparison difficult. Etkind et al., (2017) estimated future population needs in England and Wales by 2040. They showed those aged 85 and older in need of PC will almost double between 2014 and 2040, from 38.0% of overall PC need estimate to 56.0% of the need estimate respectively. This compares with the 0 to 44 and 45 to 64 year age groups where the estimated

number of people who die in need of PC will drop by 2040, when compared with 2014 data.

Age was found to be statistically significant factor in terms of access to PC. Access to PC was found to be lowest among those **aged <65 years (aOR 0.44; 95% CI 0.31 to 0.64)** among a population of Australian deceased people, or decedents (Westley-Wise et al., 2022).

Morin et al. (2017) estimated the proportion of decedents potentially in need of palliative care across 12 EU and non-EU states. When applying all three estimates, they found age was associated with increased odds of being in need of PC at the end of life. However, using Rosenwax's estimate, those dying at age ⩾90 years were less likely to have been potentially in need of PC compared with those doing so at age 18–49 years (OR 0.84, 95% CI 0.83 to 0.85).

4.5. Residence

Cross-sectional data found patients with **heart failure (OR 3.33, 95% CI 1.07 to 10.43) and dementia (OR 1.75, 95% CI 1.02 to 2.99)** were more likely to be referred when they lived in a nursing home than when they lived at home, while the opposite was found for cancer patients (Beernaert et al., 2013). Morin et al. (2017) compared three estimation methods and consistently identified those who died in a nursing home (OR ranged from 1.04 to 1.32) were more likely to be associated with PC need when compared to those who died at home. Those who died in hospital (OR ranged from 0.72 to 0.81) and other places (OR ranged from 0.57 to 0.84) were less likely to be associated with PC need than those who died at home. However, compared to people who died at a private residence, those who died at a residential aged care facility (aOR 0.3, 95% CI 0.2 to 0.3, p <0.001), non-aged care facility (aOR 0.3, 95% CI 0.2 to 0.5, p<0.001) and other or unknown residence (aOR 0.4, 95% CI 0.2 to 0.6, p <0.001) were less likely to access PC (Rosenwax et al., 2016).

Similarly, subgroup analysis restricted to non-cancer decedents identified those living in a care facility (OR 0.4; 95% CI 0.3 to 0.4; p <0.0010) compared to a private residence was associated with reduced access to specialist PC (Rosenwax et al., 2016).

Living in major cities was associated with increased odds of access to specialist PC care (Rosenwax et al., 2016).

4.6. Marital status

Most studies looked at marital status as a descriptive characteristic of those in need of PC, rather than terms of prediction of need or access. However, Rosenwax et al. (2016) found having a partner was associated with increased odds of access to specialist PC.

4.7. Socioeconomic status

Disregarding the cause of death, higher proportions of decedents accessed specialist PC if they lived in higher socioeconomic areas at time of death (Rosenwax et al., 2016). However, adjusting for social and demographic variables and accounting for underlying cause of death, lower socioeconomic status was no longer associated with reduced access to specialist palliative care (Rosenwax et al., 2016). Similarly, adjusted comparisons found no significant association between socioeconomic area status quintiles (Westley-Wise et al., 2021).

Our searches identified a systematic review investigating associations between measures of socioeconomic position and healthcare use in the last year of life, including specialist palliative care[2]. Meta-analyses of 112 high- to medium-quality observational studies found compared to people living in the least deprived neighbourhoods, people living in the most deprived neighbourhoods were least likely to receive specialist PC (OR 1.13, 95% CI 1.07–1.19, p < 0.001). For every quintile increase in area deprivation, not receiving specialist PC was more likely (OR 1.03, 95% CI 1.02–1.05, p < 0.001). Compared to the most educated (qualifications or years of education completed), the least educated people were more likely to not receive specialist PC (OR 1.26, 95% CI 1.07–1.49, p = 0.005).

4.8. Pain

Estimated increases in pain prevalence among people aged 50 and over in Ireland living and dying with a disease indicative of PC need, suggest pain burden is projected to increase to 68% between 2016 and 2046 (May et al., 2020).

Incorporating pain prevalence into projections of PC need was undertaken by Etkind et al., (2017). They identified that whilst raw numbers of people dying from dementia are projected to be higher than cancer by 2040, the number of people with cancer and pain (175,254) will be greater than the number of people with **dementia and pain** (131,645).

4.9. Other Characteristics

Other characteristics used to describe populations potentially in need of PC included disability burden, healthcare use (May et al., 2020), language preference and country of birth (Westley-Wise et al., 2021).

5. Timing of access to PC and duration

A recurring theme among studies was that those diagnosed with cancer accessed PC earlier and for longer than other conditions investigated. In a retrospective cohort study, among those who accessed PC, the number of days people received PC care within last year of life ranged between 5 and 25 days (Rosenwax et al., 2016). The

temporal distribution of the number of specialist PC days accessed in the last year life was skewed towards the weeks leading up to death. Over 60% of total days of hospital-based PC occurred in the four weeks before death, although this did vary by principal cause of death. Hospital-based PC started a median of 15 (IQR 6–44) days before death for decedents with cancer, 44 (IQR 8–149) days for motor neurone disease and 8 (IQR 4–22) days for decedents with liver failure. Decedents with other cause of death conditions started hospital-based PC a median of around 5–6 days before death (Rosenwax et al., 2016).

The same study examined the type of PC accessed. Community-based PC was accessed earlier in the last year of life with a median starting date of 62 (IQR 26–137) days before death for cancer, 192 (IQR 19–365) days for Huntington's disease and 86 (IQR 20–253) days for motor neurone disease. For the other conditions, the median starting dates ranged from 6 (IQR 3–54) days for Alzheimer's disease up to 43 (IQR 15–138) days for COPD (Rosenwax, et al., 2016).

A population-based study, using data from Belgium GP practices, described how patients with COPD, heart failure, dementia and cancer differ in frequency and timing of referral to palliative care services (Beernaert et al., 2013). Of 2,405 registered deaths the median days between referral and death was 10 (COPD), **12 (heart failure), 14 (Severe dementia)** and 20 (cancer) (Beernaert et al., 2013). No significant associations were found in the multivariate analyses for patients with COPD, nor between socio-demographic characteristics and the timing of onset of palliative care services for the four disease groups (Beernaert et al., 2013).

Similarly, a population-based cohort study from Ontario, Canada (Quinn, et al. 2021) found that patients dying of **dementia** had a lower odds of PC initiation at 91 days or more (aOR 0.42; 95% CI, 0.40 to 0.45) and between 31 and 90 days (aOR, 0.60; 95% CI, 0.57 to 0.62) relative to initiation at 30 days or less before death compared with patients with cancer.

6. Types of PC need in Dementia and Heart Disease

A separate search was conducted after stakeholders requested a focus on dementia and heart failure in terms of the types of PC need.

A paper by Crowther et al. (2013)[1] explored **PC in Dementia** and highlights findings from a large UK study of informal carers of people with dementia to explore what are determinants of care for people with dementia and their family carers. In-depth interviews with bereaved family carers of people with dementia identified death occurred in many different environments, e.g. district general hospitals, nursing and residential care homes and within the family home. There were only four referrals to specialist palliative and end-of-life care services amongst the sample (n=40) and these referrals were all made in those with a known and confirmed diagnosis of cancer. Patients with a dual cancer and dementia diagnosis were more likely to be referred to PC services; however, a dual diagnosis of dementia and another life-limiting chronic illness did not appear to trigger specialist PC services referral.

A population study using administrative data (Alqahtani et al., 2019) from USA found that of 939,680 patients admitted to hospitals with **acute Heart Failure,** 1.2% received PC during their hospitalisation. In a multivariate logistical regression analysis, the strongest predictors of referring to PC were older age (OR 14.17, 95% CI 9.53-21.09 for age > 85, and OR 6.18, 95% CI 4.18-9.15 for age 65-85 [reference age 18-40]), cardiogenic shock (OR 6.17, 95% CI 5.15-7.40), chronic renal failure (OR 4.19, 95% CI 3.75-4.68), and mechanical ventilation (OR 2.49, 95% CI 1.85-3.35). Racial minorities were less likely to receive PC than Caucasian patients, respectively: (OR 0.56, 95% CI 0.49-0.64) for African American vs Caucasian, and (OR 0.53, 95% CI 0.43-0.65) for Hispanic vs Caucasian. Geographic differences in PC utilisation were also observed with higher utilisation in hospitals located in the West (OR 1.59, 95% CI 1.38-1.83).

7. Identifying unmet need

Of the three studies that identified unmet need as part of their analyses, they did this by comparing numbers of people who died with conditions identified as needing PC and those who had accessed PC (Calvache et al., 2020 and Westley-Wise et al., 2022, Szekendi M et al. 2016).

The Australian study (Westley-Wise, 2022) identified an unmet PC need of 13.3% among those who died in hospital who needed PC in a region between 2016 and 2017. The highest proportions of 'unmet need' were in decedents with COPD (31.0%) and heart failure (26.3%). In contrast, a retrospective cohort study compared changes in PC service delivery relative to the number of patients who could benefit from such services between 2000-02 and 2009-10 (Rosenwax et al., 2016). Only 14 % (n = 729) of decedents with non-cancer conditions accessed specialist palliative care in the 2009-10 cohort. However, this represented a 6.1 % (95 % CI 4.9–7.3) increase on the specialist palliative care access reported for the same decedent group ten years earlier.

A multisite cross-sectional retrospective analysis from 33 hospitals in the USA (Szekendi M et al. 2016) found that 19% of inpatients on point-prevalence day were deemed appropriate for PC referral, but only approximately 39% of these received referral for PC services. Of patients appropriate for referral, almost 80% had either Medicare (57.3%) or commercial health care (22.2%) coverage. The proportion of patients receiving referrals was fairly consistent across age groups, with the exception of patients over the age of 84 year, who were referred more often. Referral practices varied by U.S. geographic region.

A third study from Colombia (Calvache et al., 2020) contrasted geographical areas where PC services are needed and actual PC services on offer and established a marked difference between them.

8. Variation of estimated need between models

A study comparing two models using German data identified large disparities in terms of the number of people who could benefit from PC (Scholten et al., 2016), with almost twice as many people identified in the Murtagh method (78.0% of all deaths) compared to the Rosenwax minimal estimate method (40.7% of all deaths). Studies suggest the wide range in estimated need between the models is most likely to reflect the model chosen and the types of conditions included in the estimated calculation. For example, the Rosenwax method excludes stroke, chronic ischaemic heart diseases, multiple sclerosis, non-Alzheimer dementia and diabetes and so is commonly reported to underestimate the actual PC need (Morin et al., 2017). In addition, population characteristics such as age and disease group distribution will impact projected estimates.

9. Limitations and considerations of the models

It is important to note that characteristics highlighted in this report have been identified from observational studies that describe populations who may benefit from PC. They utilise different population datasets and consider different disease groups as potentially needing PC, as well as varying age group categories. Therefore, direct comparisons cannot be made. Any proportions or statistical significance relate only to the population being studied and are unlikely to be generalisable to the Welsh population. However, they can be useful to highlight important characteristics of those who need PC, which will be useful to inform the development of an impact needs assessment for PC in Wales. It also highlights any characteristics that have not yet been examined among people who may need PC at a population level.

Most studies also warn of the potential of underestimating PC need when using death certificates. Many authors extracted only the underlying cause of death from the certificates, which prevents the ability to conduct multiple-cause of-death analyses, leading to an underestimation of the actual disease frequency and in turn of PC need. This can be overcome by using additional data sources (primary care databases and hospital records).

Another factor highlighted is that estimates refer to the overall need for PC, regardless of the level or setting of care. Models that incorporate a 'trajectory' may help to incorporate complex PC need and the differentiated needs of different groups of patients suffering chronic conditions at the end of life (Morin et al., 2017).

Please note, no quality appraisal has been undertaken so the Evidence Service cannot comment on the methodological quality of sources outlined in any of the tables. If any paper is to be used for policy considerations, please conduct a quality assessment and consider the generalisability of findings to your context.

- **Where did you search?**

Snowballing of identified secondary sources was undertaken in addition to the sources below.

Resource	Success or relevancy of the retrieval
Cochrane Library (basic search) https://www.cochranelibrary.com/cdsr/reviews	Searched, results found
NICE (basic search) https://www.nice.org.uk/guidance	Searched, results found
Medline (basic search) https://dialog.proquest.com/professional/medlineprof?accountid=16678	Searched, results found
Google Scholar (basic search) https://scholar.google.com/	Searched, results found
Scottish Intercollegiate Guidelines Network (SIGN) clinical guidelines (basic search) https://www.sign.ac.uk/our-guidelines	Searched, results found
Agency for Healthcare Research and Quality (AHRQ) (basic search) https://www.ahrq.gov/research/findings/evidence-based-reports/search.html	Searched, results found
Canadian Agency for Drugs and Technologies in Health (CADTH) (basic search) https://www.cadth.ca/	Searched, results found
US Department of Veteran Affairs (basic search) https://www.hsrd.research.va.gov/publications/esp/reports.cfm	Searched, results found
National Institute for Health Research (NIHR) Health Technology Assessment (HTA) Journal (basic search) https://www.journalslibrary.nihr.ac.uk/hta/#/	Searched, nothing found
National Institute for Health Research (NIHR) Public Health Research (basic search) https://www.journalslibrary.nihr.ac.uk/phr/#/	Searched, nothing found
Campbell Collaboration systematic reviews (basic search) https://www.campbellcollaboration.org/better-evidence.html	Searched, nothing found
The Community Guide (basic search) https://www.thecommunityguide.org/publications	Searched, nothing found
Evidence for Policy and Practice Information and Co-ordination Centre (basic search) http://eppi.ioe.ac.uk/cms/Default.aspx?tabid=62	Searched, results found
Joanna Briggs Institute (basic search) https://journals.lww.com/jbisrir/Pages/default.aspx	Searched, results found
What Works Centre for Wellbeing (basic search) https://whatworkswellbeing.org/resources/	Searched, nothing found

- **What terms did you use?**

An initial search was conducted using a combination of the following terms:

- Palliative care
- end of life care
- population needs assessment
- indicators

- **Data Extraction of identified literature**

Table 1: Models identified to estimate population level PC need

Higginson (1997). Health care needs assessment: palliative and terminal care. In: Stevens A, Raftery J, eds. Health care needs assessment: The epidemiologically based needs reviews. Oxford: Radcliffe Medical Press, 1997, pp. 1e45.

Available from: This paper is not available

Higginson (1997) developed one of the earliest models for population needs assessment for palliative care (PC). This model was adapted from the approach developed by Stevens and Raftery (1994) for epidemiologically based needs assessment.

Model outline: Using the number of people with selected causes of deaths (cancer and six selected non-cancer disease groups) multiplied by standard symptom prevalence (separately for cancer and non-cancer patients), this model triangulates three sources of information:
1. The size of the need i.e. the incidence and prevalence: For each of the subcategories, estimate incidence and prevalence figures and calculate likely need using data on death rates (number of patients at the end of life and number of families affected) and symptoms experienced (pain, breathlessness, depression). This can be made more detailed by using data on local populations (e.g., local death rates, standardized mortality ratios, deprivation index, ethnic composition, trends).
2. The services available locally, and
3. The effectiveness and cost-effectiveness of potential services

This model estimated PC need in the UK. It estimates that about 2,800 people per 1,000,000 population die from cancer each year in the UK; 25–65% of these will need help from a PC support team, and 15–25% will need inpatient hospice care. About 6,900 people per 1,000,000 population die from causes other than cancer each year, and although some of these people will die suddenly or with no identifiable terminal period, many will have circulatory, respiratory or neurological diseases with prevalence of symptoms comparable to that suffered by cancer patients.

Disease groups considered in need of PC: 1) All cancer deaths, and 2) Non-cancer deaths from diseases of: circulatory system, respiratory system, chronic liver and cirrhosis, nervous system and sense organs (including Parkinson's disease, multiple sclerosis and meningitis), senile and pre-senile conditions, and endocrine, nutritional, metabolic and immunity disease.

Data input into the model: 1) Disease-specific mortality, and 2) Standard symptom prevalence in relevant diseases (systematic review).

Characteristics that may identify those in need of PC: unable to access original paper

Considerations: The model uses prevalence of different symptoms (pain, breathlessness, depression) that overlap; therefore, it is difficult to get a precise number of PC need. Compared to its successors, it includes a limited number of non-cancer conditions requiring PC.

Rosenwax et al. (2005). Estimating the size of a potential palliative care population. Palliative Medicine. 19(7): pp.556-562.

Available from: https://pubmed.ncbi.nlm.nih.gov/16295289/

Rosenwax et al. (2005) developed a model that further developed the method of using routine mortality statistics to estimate the need for cancer and non-cancer PC in a population, using all deaths from any of 10 specific disease groups.

Model outline: This model produced three estimates to determine who could benefit from PC through focus groups, interviews and a literature review:
1. Minimal estimate: A conservative measure based on the number of deaths from 10 specific disease groups
2. Mid-range estimate: Included all deaths hospitalised with the same condition as certified on the death certificate sometime in the year before death, and
3. Maximal estimate: A broad measure that includes all deaths apart from poisoning, injury, and maternal, neonatal or perinatal deaths.

The three estimation models were applied to a cohort of people who died in Western Australia between 1 July 2000 and 31 December 2002 using disease specific mortality by linking death records with hospital morbidity data through the Western Australian Data Linkage System. The model demonstrated that between 0.28% and 0.50% of people in the Western Australian population in any one year could potentially benefit from a PC approach, some of whom would benefit from specialist PC services. The Minimal Estimate identified that 50.0% of all deaths in Western Australia in the 2.5-year period could have benefited from PC. While the Mid-range and Maximal Estimate identified 55.5% and 89.4% of all deaths could have benefited from PC. Most people in the PC constituency (irrespective of the estimate used) were aged 65 years and older (78.8%, 79.6% to 81.6%), non-Aboriginal (93.2%, 93.4% to 93.8%), married (48.8%, 48.0% to 43.4%) or widowed (33.2%, 34.1% to 38.0%), living in the major cities of Western Australia (71.0%, 70.6% to 71.7%) and about one third were socioeconomically disadvantaged.

Disease groups considered in need of PC:
1. For the Minimal and Mid-range Estimate: All cancer deaths (malignant and benign neoplasm), and Non cancer deaths including Heart failure, Renal failure, Liver failure, Chronic obstructive pulmonary disease, Motor Neuron Disease, Parkinson's disease, Huntington's disease, Alzheimer's disease and HIV/AIDS.
2. For the Maximal Estimate: All deaths (except deaths during pregnancy, childbirth, or puerperium; originating during the perinatal period; or resulting from injury, poisoning, and certain other external causes; or resulting from external causes of morbidity and mortality).

Data input into the model: 1) Mortality register and health service data using Western Australian Data Linkage System and 2) The Index of Socio-Economic Disadvantage (IRSD) derived from Census of Population and Housing and 3) the Accessibility Remoteness Index of Australia was attached to the database using the Australian Bureau of Statistics collector's district.

Characteristics that may identify those in need of PC: age groups (<65 years and 65 and over), ethnicity, marital status, place of residence, socioeconomical position – descriptive statistics only

Considerations: The Minimal Estimate is condition-based rather than needs-based and includes only a limited number of conditions as an indicator of PC need. The Mid-range and Maximal Estimate are partially needs-based. The Maximal Estimate could be regarded as the ideal state of affairs as it represents a world where PC is so ubiquitous and well understood by healthcare workers and the community alike that all patients have access to PC. However, in reality this might not occur for a variety of reasons: sociocultural factors, attitudes to death and dying, ignorance of PC, financial constraints and historical patterns of providing care. To address this, a more moderate, needs-based constituency was developed, the Mid-range Estimate, that represents the population who were hospitalised in the last 12 months of life for a condition from which they died. This includes patients who are already in contact with healthcare services and whose doctors are alerted to the possibility that their conditions are, at least potentially, life-threatening. PC should, therefore, be more readily accessible to these patients than those in the Maximal Estimate.

Gómez-Batiste et al. (2012). Identifying needs and improving palliative care of chronically ill patients: a community-oriented, population-based, public-health approach. Current opinion in supportive and palliative care. 6(3): pp.371-378.

This model was first published in a Portuguese paper in 2010. Unfortunately, we could not locate a translation of this and the majority of subsequent references to this model refer to the paper above from 2012.

Available from: https://pubmed.ncbi.nlm.nih.gov/22801465/

Model outline: To address limitations identified in previous models (Higginson;1997 and Rosenwax et al.;2005), this model incorporated developments in PC practice and refined the use of data on the prevalence of advanced chronic disease, older people with pluripathology, dementia and care home residence.

In a worked example in Catalonia, this model estimated that 75% of all deaths were from chronic progressive diseases while proposing consideration of prevalence of chronic diseases, dementia and nursing home patients to further refine this. In developed countries with ageing populations (15–20% >65 years of age) and annual mortality levels of 9 deaths per 1000, this model estimated 60–75% of the population will die as a result of a chronic advanced progressive illness that includes a period of terminal illness. The most frequent causes are: cancer (20– 25%), chronic organ failure (cardiac, pulmonary, hepatic and renal), neurological diseases, HIV/AIDS and other infectious conditions (35–45%)

Disease groups considered in need of PC:
1) All cause deaths
2) Patients living with advanced chronic disease and limited life prognosis
3) Elderly (≥ 65 years) with: pluripathology and dependency
4) Elderly (≥ 65 years) with dementia, and
5) Elderly (≥ 65 years) living in nursing homes or homes for the elderly

Data input into the model: 1) Total (all-cause) mortality and 2) Prevalence of disease, dependency, multiple pathology, symptom and housing data

Characteristics that may identify those in need of PC: unable to access original paper

Considerations: unable to access original paper

Murtagh et al. (2014). How many people need palliative care? A study developing and comparing methods for population-based estimates. Palliative Medicine. 28(1): pp.49-58.

Available from: https://pubmed.ncbi.nlm.nih.gov/23695827/

Model: This model was developed as a refinement to existing methods (Higginson 1997, Rosenwax et al. 2005 and Gomez-Batiste et al. 2012) incorporating the views of an expert panel. The expert panel review identified changing practice (e.g. extension of palliative care to more non-cancer conditions), changing patterns of hospital/home care and multiple, rather than single, causes of death as important. This led to updating the list of ICD-10 causes of death used to estimate need of PC. The model used the number of people with selected underlying cause of death (updated to current practice) plus contributing cause of death for selected groups of conditions to estimate co-morbidities. Four estimates were developed to determine who could benefit from PC:

1) Minimal Estimate: Based on the number of deaths from specific conditions.
2) Lower mid-range estimate: Extends the Low Estimate of Rosenwax to also include cases admitted to hospital in the year before death with the same condition as documented as 'cause of death', in addition to deaths where Alzheimer's, dementia, senility or chronic renal failure is recorded as a contributory cause (to further identify these specifically under-reported diseases),
3) Upper mid-range Estimate: Includes all deaths with any mention on the death certificate (underlying or contributory) of the disease categories used for the minimum estimate, and
4) Maximal Estimate: As per Rosenwax et al. (2005) Maximal Estimate.

Application of the four-estimation model to mortality data for England for the period of 2006 to 2008 estimated between 297,985 and 456,767 people needed PC annually during this period. This represents between 63.03% (95% CI 62.95% to 63.11%) using the Minimal Estimate and 96.61% (95% CI 96.58% to 96.64%) using the Maximal Estimate of all deaths during this period.

Disease groups considered in need of PC:
1) All cancer deaths- malignant neoplasms only included, and
2) Non cancer disease groups:
  (i)   Organ failure (heart disease, heart failure, chronic lower respiratory disease, respiratory failure, reno-vascular disease, renal failure, liver disease)
  (ii)   Dementia (Dementia, vascular dementia, Alzheimer's disease, senility) and
  (iii) Other (Huntington's disease, motor neurone disease, Parkinson's disease, progressive supra-nuclear palsy, multiple sclerosis, multi-system atrophy; haemorrhagic, ischaemic and unspecified stroke; HIV)

Data input into the model: 1) Office for National Statistics (ONS) mortality data, and 2) Linked hospital admissions data from Hospital Episode Statistics (HES).

Characteristics that may identify those in need of PC: Age

Consideration: Cause of death, while indicative of potential PC need, is not a precise indicator of PC or an accurate reflection of diagnosis as certain conditions can be under-recorded. The model allows for the latter by including both the contributory cause of death

and the underlying cause of death in the mid-range estimates. Estimating PC need through the number of deaths does not reflect the trajectory of those needs prior to death; this may be particularly relevant for children and young people, where the overall numbers of deaths were small but the trajectory of PC needs for some conditions may extend over several years. Subject to limitations caused by under-reporting on death certificates. All the refined estimates (minimal, mid-range and maximal) can be derived for local and regional populations, using readily available data, thus allowing commissioners to estimate how many people need palliative care in their Clinical Commissioning group area and commission accordingly.

Etkind et al. (2017). How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Medicine. 15(102).

Available from: https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2

Model outline: This model was developed to estimate future trends in PC need using routinely available national death registry data and mortality projections. Etkind et al. estimated and projected PC need using two analyses:

1. Based on the method used by Gomez-Batiste et al. (2012), assuming that 75% of people in high-income countries die with PC needs. Projected PC need therefore is calculated as 75% of projected deaths annually to a future date, assuming the proportion of deaths requiring palliative care would remain constant.
2. This method uses a diagnosis-based estimate and models two scenarios:
   a. Assuming proportion of PC need stays constant: Calculate the number and proportion of age and sex-specific deaths where an ICD-10 code associated with PC was recorded as the main underlying cause of death only, then apply this proportion to projected mortality forecasts for each year, with no adjustments.
   b. Assuming an annual change: Calculate the mean annual change in the proportion of deaths requiring PC in a given period, assuming the annual change would continue to occur in a linear fashion, and then apply this proportion to projected mortality forecasts.

To project PC need by age and disease-specific group, changes in PC need in specific age and disease groups are investigated by describing the number of people in each 5-year age group who are projected to need PC between the forecast timeframe, and then undertake disease group-specific projections.

This model was used to estimate future population PC needs in England and Wales by 2040. The model estimated that if the age- and sex-specific proportions with PC needs remain the same as in 2014, the number of people requiring PC will grow by 25.0% (from 375,398 to 469,305 people/year). However, if the upward trend observed from 2006 to 2014 continues, the increase will be 42.4%

(161,842 more people/year, total 537,240 people/year). Additionally, the disease-specific projections show that dementia and cancer will account for the predominant growth in PC need.

To assess the robustness of their methodology, the authors undertook sensitivity analyses. Firstly, they adjusted for the time period over which death registry and mortality projections data were collected and assessed the effect this had on their projections by comparing whether the PC estimate reached using 2014–2015 population data with 2014 death registry data, was the same estimate using 2013–2014 population data with 2014 death registry data. They found that using the later period reduced the PC need estimate by 0.5%. Secondly, they applied the Lee–Carter approach to mortality projections to produce an alternative projection and compared this to their main methodology and found that 551,146 people would need palliative care by 2040. This differs by 2.6% from their projection of 537,240 using method 2 (assuming annual change 2006–2014).

Disease groups considered in need of PC:
1) All cancer deaths- malignant neoplasms only included, and 2) Non cancer disease groups:
   (i)   Organ failure (Heart disease, heart failure, chronic lower respiratory disease, respiratory failure, reno-vascular disease, renal failure, liver disease);
   (ii)   Dementia (Dementia, vascular dementia, Alzheimer's disease, senility); and
   (iii) Other (Huntington's disease, motor neurone disease, Parkinson's disease, progressive supra-nuclear palsy, multiple sclerosis, multi-system atrophy; haemorrhagic, ischaemic and unspecified stroke; HIV).

Data input into the model: Total (all-cause) mortality from ONS death registry data, population data from ONS using a mid-year estimate on June 30th.

Characteristics that may identify those in need of PC: age groups (0-44, 45-64, 65-74. 75-84, 85 years and over), sex, disease group (Cancer, organ failure, dementia, other deaths)

Considerations: The aggregate model uses recent trends to project future levels of need, because of this, it cannot account for potential future changes in medical treatments or patient outcomes. These estimates do not account for multi-morbidity as based on cause-of death. Use of death registry data means that this model can only estimate PC need at the end of life. Whilst the majority of PC needs do occur in the last months of life, PC needs are increasingly recognised earlier in the disease course, and such needs would not be captured by these estimates. This model used the methodology developed by Gomez-Batiste et al. (2012); therefore, it is subject to limitations inherent to the original model.

May et al. (2020). Population-based palliative care planning in Ireland: how many people will live and die with serious illness to 2046? HRB Open Research, 2.

Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7017420/

Model outline: This model was developed to extrapolate future trends in PC need using static modelling of routinely available national death registry data and mortality projections. May et al. estimated and projected PC need using three analyses:

1. This projection methodology models four scenarios:
   a. Based on the method used by Gomez-Batiste et al. (2012), assuming that 75% of people in high-income countries die with PC needs, projected PC need is calculated as 75% of projected deaths annually to a future date.
   b. Assuming proportion of PC need stays constant: Calculate the number and proportion of deaths for a year where an ICD-10 code associated with PC was recorded as the main underlying cause of death only, and then apply this proportion to mortality forecasts for each year up to a future date, with no adjustments.
   c. Assuming an annual change, prior 8 years: Calculate the mean annual change in the proportion of deaths requiring PC in an 8-year period, assuming the increases according to a compound interest rate, then applied this proportion to mortality forecasts up to a future date.
   d. Assuming an annual change, prior 3 years: Calculate the mean annual change in the proportion of deaths requiring PC in a 3-year period, assuming the increases according to a compound interest rate, then applied this proportion to mortality forecasts up to a future date.
   e. Assuming annual change, by age and gender: Calculate the number and proportion of age and gender-specific deaths in a year where an ICD-10 code associated with PC was recorded as the main underlying cause of death only. Assuming the increases according to a compound interest rate by gender for each five-year age band, then applied this proportion to mortality forecasts up to a future date.
2. This method estimated the number of people aged 50+ living and dying with diseases indicating PC need, by age and gender, for a future period. For each projected year, the number of people projected to live through the year was multiplied by the proportion of people living with a disease indicating PC need, as well as multiplying the number of people projected to die by the proportion of people dying with a disease indicating PC need.
3. This method estimated the disability burden, pain prevalence and health care utilisation among people aged 50+ living and dying with diseases indicating PC need for a future period. For each outcome of interest (disability burden, pain prevalence, utilisation categories), calculate the mean, adjusted for age, gender and PC disease, among people aged 50+. Combine these calculations with the population projections from Analysis 2. To quantify growth in disability and pain burden, and use of different health care services, in a single comprehensible index values were set in each outcome for the first year of the forecast to 100. Indices for the forecast period were then created with the set value as a base (e.g. a 50% increase in any outcome to 2046 gives a 2046 score of 150, etc.). Health service utilisation was based on current patterns, implicitly assuming no changes in policy or access during the projection period.

This model estimated PC need in the Republic of Ireland from 2016 to 2046. Using the assumption of constant need, it estimated a 68% increase in the total number of deaths from a disease associated with PC from 2016 to 2046. Using the changing needs methods, increase in absolute numbers of deaths from a disease associated with PC need between were estimated to be between 78% and 84%. The model projected an increase of 74% in number of people aged 50+ dying annually with a PC need and an increase of 89% in the number of people aged 50+ living through the year with a PC need. It also estimated increases in healthcare outcomes for older people living through the year with a disease indicating PC need between 2016 and 2046: 173% for disability burden, 83% for pain burden; and health care use: GP visits (101%), emergency department admissions (90%), inpatient hospital admissions (100%) and home health hours (106%). It estimated increases in outcomes for older people dying with a disease indicating PC need: 96% for disability burden, 68% for pain burden; and health care use: GP visits (74%), emergency department admissions (65%), inpatient hospital admissions (62%) and home health hours (107%).

Disease groups considered in need of PC:
1) All cancer deaths- malignant neoplasms only included, and 2) Non cancer disease groups:
   a. Organ failure (Heart disease, heart failure, chronic lower respiratory disease, respiratory failure, reno-vascular disease, renal failure, liver disease);
   b. Dementia (Dementia, vascular dementia, Alzheimer's disease, senility); and
   c. Other (Huntington's disease, motor neurone disease, Parkinson's disease, progressive supra-nuclear palsy, multiple sclerosis, multi-system atrophy; haemorrhagic, ischaemic and unspecified stroke; HIV).

Data input into the model: 1) Total (all-cause) mortality from Central Statistics Office (CSO) in Ireland; 2) mortality by age and gender from CSO in Ireland; and 3) data from The Irish Longitudinal study on Ageing (TILDA) for participants living with a disease indicating PC need.

Characteristics that may identify those in need of PC: Age group, gender, co-morbidities, disability burden, pain burden, health and social care utilisation (GP visits, ED admissions, inpatient admissions, home health hours)- descriptive stats only

Considerations: Static modelling assumes no change in disease profile by age and gender. This model assumed no exogenous changes in outcomes while making the projections. The healthcare use estimation is based on past use and not need, so unmet need may be uncounted while unnecessary use may be over-counted. Dynamic modelling that takes account of the interaction of different variables over time, as well as cross-validating predictive accuracy and quantifying the uncertainty associated with all stages of projections, would offer a more sophisticated picture of future population numbers and their associated outcomes. Use of death registry data relies on accurate completion of death certificates. Data used from TILDA is subject to self-report bias. TILDA does not specifically ask about all causes of deaths used in this model. Therefore, the authors reviewed the CSO cause-of-death data, counting only diseases recorded by

TILDA, and found a 1% discrepancy. This model used the methodology developed by Etkind et al. (2017); therefore, it is subject to limitations of the original model.

Finucane et al. (2021). How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery. BMJ open. 11(2): pp.e041317.

Available from: https://bmjopen.bmj.com/content/11/2/e041317

Model outline: This model was developed to provide a more comprehensive picture of future palliative care need than previous models, using simple linear modelling of routinely available national death registry data and mortality projections. Finucane et al. estimated and projected PC need using three approaches:

1. Based on the method used by Gomez-Batiste et al. (2012), assuming that 75% of people in high-income countries die with PC needs, projected PC need is calculated as 75% of projected deaths annually to a future date.
2. This estimation methods takes a diagnosis-based approach, replicating scenarios used by Etkind et al. (2017):
   a. Assuming proportion of PC needs constant: Calculate the number and proportion of age and gender-specific deaths at baseline where an ICD-10 code associated with PC was recorded as the main underlying cause of death only, and then apply this proportion to mortality forecasts for each year up to a future date, with no adjustments.
   b. Assuming an annual change: Calculate the mean annual change in the proportion of deaths requiring PC for a past period of time, assuming the mean annual change to be linear. Apply the resulting proportion to mortality forecasts up to a future date.
3. Builds on the diagnosis-based approach by using the number of people for whom a PC relevant disease was recorded as the main underlying cause as well as a contributory cause of death. Finucane et al. predict this to be the most accurate and comprehensive estimate of deaths in a calendar year. To project future need, calculate the number and proportion of age and gender-specific deaths where an ICD-10 code associated with PC care is recorded as either the main underlying or contributory cause of death. Assuming the mean annual change in the proportion of deaths associated with PC need over the baseline continues to occur in a linear fashion, apply the resulting mean annual change to mortality forecasts.

This model was applied to estimate PC need in Scotland from 2007 to 2017. During the 11-year period, registered deaths rose by 3.4% in Scotland. Using all methods to estimate population level palliative care need, estimations of the number of people who died with PC needs in Scotland in 2017 ranged from 43,403 (method 1) to 52,148 (method 3), an increase from 2007 irrespective of method used. Mortality projections to 2040 indicate a 13.6% increase of deaths in Scotland. Models estimated between 75% and 95% of those who die by 2040 might benefit from a PC approach. Authors also projected PC need by age group, underlying cause of death and multi-morbidity associated with advanced progressive disease up to 2040 using method 2B.

Disease groups considered in need of PC:
1) All cancer deaths- malignant neoplasms only included, and 2) Non cancer disease groups:
   a. Organ failure (heart disease, heart failure, chronic lower respiratory disease, respiratory failure, reno-vascular disease, renal failure, liver disease)
   b. Dementia (Dementia, vascular dementia, Alzheimer's disease, senility) and
   c. Other (Huntington's disease, motor neurone disease, Parkinson's disease, progressive supra-nuclear palsy, multiple sclerosis, multi-system atrophy; haemorrhagic, ischaemic and unspecified stroke; HIV).

Data input into the model: 1) National death registry data from National Records of Scotland, and 2) Official mortality forecasts from Office for National Statistics and National Records of Scotland

Characteristics that may identify those in need of PC: age group (0-44, 45-64, 65-74, 75-85, 85-99, 100+), underlying cause of death (cancer, organ failure, dementia, neurological/stroke/HIV), multi-morbidity (diseases associated with PC need in the four categories) – descriptive statistics only

Considerations: Linear models presume projections will occur at the same rate as recent trends, and do not account for variability. Authors used a disease count approach to estimate multi-morbidity relevant to population palliative care need, as this is straightforward to estimate and replicate. Definition of multi-morbidity was relatively restrictive—decedents were required to have two major illnesses from different disease groups, both of which would individually confer PC need. These models draw on trends over an 11-year period, up to and including 2017, and project these trends forward. Similar to its predecessors, this model uses death registry data that relies on accurate completion of death certificates. Changes in how cause of death is recorded over time cannot be accounted for, though previous changes have had minor impact on population level coding. In addition, estimates make no adjustments for pandemic events, such as COVID-19 which have particularly affected people aged 75 and over. It is likely age-specific mortality rates are likely to change as a result of this. This model used the methodology developed by Etkind et al. (2017); therefore, it is subject to limitations of the original model.

Table 2: Studies that utilised the models identified in table 1

Westley-Wise et al. (2022) Who needs, receives and misses out on palliative and end-of-life care? A population-based study to identify needs and gaps in a regional health service. *Australian Health Review*.

Available from: https://www.publish.csiro.au/AH/AH21052

Model(s) tested: Murtagh et al. (2014)

Summary: This cross-sectional descriptive and analytical study aimed to assess the unmet need for palliative and end of life care, as well as sociodemographic and diagnostic factors associated with suboptimal access, among residents in an Australian region.

It estimated that from a population of 3175 patients aged 15+ who died in hospital in the region in 2016 and 2017, 74.8% needed palliative or end-of-life care in the year before death. Approximately 13.3% did not receive any. The highest proportions of 'unmet need' were in decedents with COPD (31.0%) and heart failure (26.3%).

Adjusting for sociodemographic and diagnostic factors, access was lowest among those aged <65 years (aOR 0.44; 95% CI 0.31–0.64) and those with heart failure (aOR 0.58; 95% CI 0.47–0.72).

Data collection: Data was collected from a databank established by the Centre for Health Research Illawarra Shoalhaven Population using six datasets; admitted patients (AP), sub- and non-acute in-patients (SNAP), emergency department (ED), non-admitted patients (NAP), death audit (DA)16 and regional Palliative Care Outcomes Collaboration (PCOC), Death data was coded according to ICD-10 codes and the Australian Modification (ICD-10-AM 9th edition) for AP data.

Characteristics that may identify those in need of PC: Sociodemographic characteristics input into the model included in the analyses included age at death, sex, ethnicity, socioeconomic status, language preference, rurality and residence in an aged care home and diagnosis of death.

Comments: Useful in that shows the estimated vs actual need of palliative care in the region during the study period.

Table 6 provides a useful comparison of population needs estimates from similar studies to this one with publication dates ranging from 2016 to 2020

Jeba et al. (2021) Projecting palliative and end-of-life care needs in Central Lancashire up to 2040: an integrated palliative care and public health approach. *Public Health*, *195*, pp.145-151.

Available from: https://pubmed.ncbi.nlm.nih.gov/34116382/

Model(s) tested: Gomez-Batiste et al. (2012), Murtagh et al. (2014), Etkind et al. (2017)

Summary: This population-based needs assessment involved secondary analysis of routinely available regional mortality and population data for Central Lancashire. Palliative care need was estimated using three recognised methods. Estimates were combined with routinely available population and mortality projections and observed trends in palliative care need to provide projections up to 2040.

Palliative care need in 2017 in Chorley & South Ribble and Greater Preston is estimated to be between 75% (1292) and 97% (1670), and 74.9% (1337) and 95.7% (1710) of all deaths, respectively. By 2040, the annual need is projected to increase compared with 2017 figures, by 24.2-55.9% (314-729 more deaths) in Chorley & South Ribble and by 13.4-41.4% (180-554 more deaths) in Greater Preston.

This needs assessment was used as the basis for a refreshed Local Palliative and End of Life Care strategy and used to articulate enhancement of 7-day specialist palliative care services across all settings.

Data collection: Data for 2012 to 2017 was obtained provided by Lancashire County Council Business Intelligence Team. Data from the Office for National Statistics was also collected

Characteristics that may identify those in need of PC: Age and cause of death

Comments: This is a more localised test of the models we identified. Authors noted the changes to ICD-10 coding system in 2022

Calvache et al. (2020) How many people need palliative care for cancer and non-cancer diseases in a middle-income country? Analysis of mortality data. *Colombian Journal of Anestesiology*, *48*(4).

Available from: http://www.scielo.org.co/pdf/rca/v48n4/2256-2087-rca-48-04-e201.pdf

Model(s) tested: Murtagh et al. (2014)

Summary: This cross-sectional study aimed to provide an estimate of the need for palliative care services in Colombia and compare these with the PC services currently available. Age and sex specific numbers of deaths and mortality rates for defined chronic illnesses between 2012-2016 were used to estimate the prevalence of palliative care need. The numbers of deaths requiring palliative care increased from 107,065 in 2012 to 128,670 in 2016 (61.2% of total deaths).

Data collection
The analyses are based on public and anonymized data from death certificates provided by National Administrative Department of Statistics of Colombia (DANE). Authors classified eight categories of conditions requiring palliative care (Malignant neoplasm, health and cerebrovascular disease, renal disease, liver disease, respiratory disease, neurodegenerative disease, Alzheimer's, dementia and senility, HIV/AIDS.

Characteristics that may identify those in need of PC:
Age, sex and underlying cause of death, geographical region.

Comments: This may not be generalisable as it's from Colombia. Figure 3A may be interesting, in that it contrasts the estimates of need for palliative care with the formal offer of services across different regions.

Morin et al. (2017) Estimating the need for palliative care at the population level: A cross-national study in 12 countries. *Palliative Medicine*. 31(6):526-536.

Available from: doi:10.1177/0269216316671280

Model(s) tested: Rosenwax et al. (2005), French National Observatory on End of Life Care, Murtagh et al. (2014)

Summary: This cross-sectional study using death certificate data aimed to estimate the proportion of decedents potentially in need of palliative care across 12 EU and non-EU states. Three population-based estimation methods were tested. They each utilised different

definitions of conditions indicating a need for palliative care. The French National Observatory and Murtagh methods of estimation used ICD-10 codes to categorise conditions, but Rosenwax included 10 specific diseases.

The proportion of individuals who died from diseases that indicate palliative care needs at the end of life ranged from 38% to 74%. The authors found important cross-country variation: the population potentially in need of palliative care was lower in Mexico (24%–58%) than in the United States (41%–76%) and varied from 31%–83% in Hungary to 42%–79% in Spain. Irrespective of the estimation methods, female sex and higher age were independently associated with the likelihood of being in need of palliative care near the end of life. Home and nursing home were the two places of deaths with the highest prevalence of palliative care needs.

Data collection:
Datasets used in the modelling was not provided in the paper.

Characteristics that may identify those in need of PC:
Characteristics used to determine the likelihood of being in need of palliative care included gender, age, marital status, and place of death.

Comments: Authors note it is important to acknowledge that while the study focused on the potential need for palliative care of patients at the end of life, they cannot tell for what period they would need this type of care.

Rosenwax et al. (2016) A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on?. *BMC Palliat Care* **15,** 46.

Available from: https://doi.org/10.1186/s12904-016-0119-2

Model(s) tested: Rosenwax et al. (2005)

Summary: Retrospective cohort study that aimed to document changes in PC service delivery relative to the number of patients who could benefit from such services. Using data on last year of life of persons with an underlying cause of death in 2009–10 from cancer, heart failure, renal failure, liver failure, chronic obstructive pulmonary disease, Alzheimer's disease, motor neurone disease, Parkinson's disease, Huntington's disease and/or HIV/AIDS (disease conditions considered as being amenable to receiving palliative care). The proportion of decedents receiving specialist palliative care was compared to a 2000–02 cohort.

The cohort included 12,817 deaths: 7166 (56 %) from cancer, 527 (4 %) from both cancer and non-cancer conditions and 5124 (40 %) from non-cancer conditions. Overall, 46.3 % of decedents received community and/or hospital-based specialist palliative care; a 3.5 % (95 % CI 2.3–4.7) increase on specialist palliative care access reported ten years earlier. The majority (69 %; $n = 4928$) of decedents with cancer accessed palliative care during the last year of life. Only 14 % ($n = 729$) of decedents with non-cancer conditions accessed specialist palliative care, however, this represented a 6.1 % (95 % CI 4.9–7.3) increase on the specialist palliative care access reported for the same decedent group ten years earlier. Compared to decedents with heart failure, increased odds of palliative care access was observed for decedents with cancer (OR 10.5; 95 % CI 9.1–12.2), renal failure (OR 1.5; 95 % CI 1.3–1.9), liver failure (OR 2.3; 95 % CI 1.7–3.3) or motor neurone disease (OR 4.5; 95 % CI 3.1–6.6).

Of the 46 % of the cohort who did access specialist palliative care, the median number of days under specialist palliative care was 25 days (IQR 8–75 days), and the temporal distribution of specialist palliative care access days in the last year life was skewed towards the weeks leading up to death. Over 60 % of total days of hospital-based palliative care occurred in the four weeks before death, but this varied greatly by the principal cause of death condition. Community-based palliative care tended to be accessed earlier in the last year of life.

Living in major cities, being female, having a partner and living in a private residence was associated with increased odds of access to specialist palliative care. Subgroup analysis restricted to non-cancer decedents identified those living in a care facility compared to a private residence (OR 0.4; 95% CI: 0.3-0.4; p <0.0010) was the only social and demographic variable associated with reduced access to specialist palliative care.

Data Collection: A de-identified and linked extraction of death records, hospital morbidity records and community-based care records of persons who died in Western Australia (WA) from 1st January 2009 to 31st December 2010 was obtained from the Data Linkage Branch at the WA Department of Health.

Characteristics that may identify those in need of PC:
Social and demographic variables used for analyses included marital status at time of death, accessibility to services (geocoding of decedents address used, based on ARIA+ which considers road distance measurements to nearest service centre and population size), Index of Relative Social Disadvantage (geocoding) and residence at time of death. Logistic regression was used to examine these factors with access of palliative care. In the model accounting for all sociodemographic variables and the underlying cause of death condition living in areas of lower socioeconomic status was no longer associated with reduced access to specialist palliative care and the association of age at death was not as marked (when compared to not accounting for cause of death). **Decedents who were living in major cities, were female, had a partner and were living in a private residence at time of death still had increased odds of access to specialist palliative care after adjusting for the cause of death condition.**

Comments: Little information was available on the severity of the disease condition assigned as being amenable to palliative care or whether the death was truly expected or not. Thus, it may not have always been clinically appropriate for the decedent to be referred to palliative care. Secondly, authors did not have data to estimate how much of normal care provided by residential aged care facilities could be classified as being palliative in nature, and thus, may be underestimating the level of palliative care being delivered in these facilities. And lastly, authors acknowledge they are also likely to be underestimating the access to specialist palliative care in rural areas because they relied on community based palliative care data from a single provider that is focused in urban areas. Measurement of improvements in access for patients living in rural and remote areas will require additional data to be conclusive. They also acknowledge that life limiting conditions that may benefit palliative care are likely to change over time, for example, HIV/AIDS. These temporal changes need to be considered when interpreting findings.

Scholten et al. (2016) The size of the population potentially in need of palliative care in Germany - an estimation based on death registration data. *BMC Palliative Care*, 15:29. DOI 10.1186/s12904-016-0099-2

Available from: https://link.springer.com/article/10.1186/s12904-016-0099-2

Model(s) tested: Rosenwax et al. (2005) and Murtagh et al. (2014)

Summary: This study aimed to estimate the size of the German population that may benefit from palliative care using German death registration data from 2013. To give further insight into age-related differences regarding the demand for PC, authors performed an additional analysis accounting for the factor "age". They estimated the demand for palliative care within the different age groups with the Murtagh method and the maximal estimate (Rosenwax method).

According to the method Rosenwax defined, between 40.7 % (minimal estimate) and 96.1 % (maximal estimate) of death cases could benefit from palliative care. The estimation, based on Murtagh's refined method, results in 78.0 % of death cases potentially being eligible for palliative care. The percentage of potential palliative care candidates is conditioned by age. Based on the Murtagh Method, in the age category between 30 and 39 years, a potential demand for palliative care can be found for 40.4 % percent of all deaths occurring in this age category, with this number increasing to 80.3 % in the age bracket of 80 years and over. The Rosenwax method concluded similar need, but on a higher level. The increase of potential palliative care needs with older age is caused by a change of the cause of death from more external causes of death, like accidents, to more cases of death caused by diseases, potentially creating a need for palliative care (e.g. cancer and vascular diseases).

Data collection:
Number and causes of deaths were collected from The Federal Bureau of Statistics who hold a complete inventory count of all deaths in Germany. They also utilised the German Mortality Statistics from 2013. Authors reported as it was not possible to match mortality statistics with hospital admission data, this restricted the analyses they could undertake. It was also necessary to make some adaptions to convert the estimation methods to German data, particularly the defined codes to ICD-10-WHO year 2013 codes. This was necessary, as the ICD-Codes between countries and years can differ.

Characteristics that may identify those in need of PC:
Age, cause of death

Comments: Availability of data meant analyses was limited to age only. This study is based on a single year of data.

Kane et al. (2015) The need for palliative care in Ireland: a population-based estimate of palliative care using routine mortality data, inclusive of nonmalignant conditions. *Journal of pain and symptom management*, *49*(4), pp.726-733.

Available from: https://doi.org/10.1016/j.jpainsymman.2014.09.011

Model(s) tested: Murtagh et al. (2014) (minimal estimate only)

Summary: This study used routine mortality data (2007-2011) inclusive of non-malignant conditions to estimate the potential population with generalist and/or specialist palliative care needs in Ireland.

During the period 2007–2011, there were 141,807 deaths. Eighty percent were from conditions recognized as having associated palliative care needs, with 41,253 (30%) deaths from cancer and 71,226 (50%) deaths from noncancer conditions. The majority of deaths, 81% (91,914), were among those ≥65 years. There was a 13.9% (901) increase in deaths of those ≥85 years. Deaths from dementia increased by 51.3%, with an increase in deaths from neurodegenerative disease (42.8%) and cancer (9.5%).

This study seems to emphasise the necessity for routinely collected data at a patient, service, and population level to inform policy makers of the need for palliative care service delivery and use, which was lacking at the time.

Data collection:

Routine mortality data (2007-2011) from the Irish Central Statistics Office (CSO) to identify deaths from palliative care-relevant conditions. As there is no linkage of hospital data with mortality data in Ireland, this limited the data authors could collect.

Characteristics that may identify those in need of PC:
Age and cause of death

Comments: Because of data limitations, it was only possible to apply the minimal estimate method described by Murtagh et al. (2014)

Table 3: Primary studies looking at characteristics of those in need of PC

Quinn, K. L., et al. (2021). "Comparison of Palliative Care Delivery in the Last Year of Life Between Adults With Terminal Noncancer Illness or Cancer." JAMA network open **4**(3): e210677.

Available from: https://pubmed.ncbi.nlm.nih.gov/33662135/

Summary: This cohort study utilised the linked health administrative data of 145 709 adults who died of cancer or terminal noncancer illness and received palliative care in their last year of life in Ontario, Canada. Palliative care was initiated earlier (>90 days before death) in patients with cancer (32010 [28.9%]) than in those with organ failure (3349 [15.9%]; absolute difference, 13.0%) or dementia (2148 [15.3%]; absolute difference, 13.6%). A lower proportion of patients with cancer had palliative care initiated in the home (16088 [14.5%]) compared with patients with chronic organ failure (6904 [32.8%]; absolute difference, −18.3%) or dementia (3922 [27.9%]; absolute difference, −13.4%). Patients with cancer received palliative care across multiple care settings (92 107 [83.3%]) more often than patients with chronic organ failure (12061 [57.3%]; absolute difference, 26.0%) or dementia (7553 [53.8%]; absolute difference, 29.5%). Palliative care was more often delivered to patients with cancer (80615 [72.9%]) using a consultative or specialist instead of a generalist model compared with patients with chronic organ failure (9114 [43.3%]; absolute difference, 29.6%) or dementia (5634 [40.1%]; absolute difference, 32.8%). Patients with cancer (42 718 [38.6%]) received shared palliative care more often from general practitioners and physicians with subspecialty training, compared with patients with chronic organ failure (3599 [17.1%]; absolute difference, 21.5%) or dementia (1989 [14.2%]; absolute difference, 24.4%).

Characteristics of those in need of PC: disease group, age, sex, socioeconomic status, rural location of residence, comorbidities and chronic conditions, hospital fragility score

Limitations: The study did not measure delivery of palliative care by health care practitioners other than physicians, which may include nurse practitioners or social workers. The study intentionally used information on a patient's death certificate to define the cohort to maximize specificity because of the concern that other approaches may introduce too much heterogeneity and other sources of bias

Alqahtani, F., et al. (2019). "Utilization of palliative care in patients hospitalized with heart failure: A contemporary national perspective." Clinical cardiology **42**(1): 136-142.

Available from: https://onlinelibrary.wiley.com/doi/10.1002/clc.23119

Summary: This population study used administrative data from the USA to assess national trends in palliative care utilisation in patients admitted to hospital with acute heart failure. The study found that of 939,680 patients admitted to hospitals with acute heart failure, 1.2% received palliative care during their hospitalisation. Patients who received PC were older (79 ± 12 vs 69± 16 years, P < 0.001), Caucasians (73.4% vs 51.8%, P < 0.001), and had a higher prevalence of coronary artery disease (45.6% vs 39.3%, P < 0.001), chronic renal disease (79.3% vs 42.8%, P < 0.001), pulmonary hypertension (28.3% vs 15.1%, P < 0.001), and other key comorbidities compared with those who did not receive PC. In a multivariate logistical regression analysis, the strongest predictors of referring to PC were: older age (OR 14.17, 95% CI 9.53-21.09 for age > 85, and OR 6.18, 95% CI 4.18-9.15 for age 65-85 [reference age 18-40]), cardiogenic shock (OR 6.17, 95% CI 5.15-7.40), chronic renal failure (OR 4.19, 95% CI 3.75-4.68), and mechanical ventilation (OR 2.49, 95% CI 1.85-3.35). Racial minorities were less likely to receive PC than Caucasian patients, respectively: (OR 0.56, 95% CI 0.49-0.64) for African-American vs Caucasian, and (OR 0.53, 95% CI 0.43-0.65) for Hispanic vs Caucasian. Geographic differences in PC utilization were also observed with higher utilization in hospitals located in the West (OR 1.59, 95% CI 1.38-1.83).

Characteristics of those in need of PC: Age, ethnicity, disease group, co-morbidities, geography.

Limitations: Authors appear to have an NIS administrative database used for billing purposes to gather data, which is limited by erroneous coding.

Szekendi, M. K., et al. (2016). "The Prevalence of Inpatients at 33 U.S. Hospitals Appropriate for and Receiving Referral to Palliative Care." Journal of palliative medicine **19**(4): 360-372.

Available from: https://www.liebertpub.com/doi/10.1089/jpm.2015.0236

Summary: A multisite cross-sectional, retrospective point prevalence analysis to determine the size and characteristics of the population of inpatients at 33 U.S. Authors also conducted a qualitative assessment of barriers and facilitators to referral, focusing on organizational characteristics that might influence palliative care referral practices. A total of 2,618 in-patients met the study criteria for inclusion. Among those appropriate for referral, 29.8% received a referral and 31.6% received palliative care services, although in some cases these services (such as physical therapy or psychological counselling) were provided without a referral to or consultation with the palliative care team. Patients with two or more conditions were most likely to receive a palliative care referral (40.5% versus 35.8% for patients with poor-prognosis cancer only, 26.1% for patients with advanced COPD only, and 21.6% for patients with advanced CHF only). The proportion of patients receiving referrals was fairly consistent across age groups, with the exception of patients over the age of 84 year, who were referred more often. Referral practices varied by U.S. geographic region. We found that 36.4% of patients appropriate for referral received a referral at hospitals located in the Northeast, compared with 31.9% at hospitals in the West, 25.8% in the South, and 25.3% in the Midwest (p < 0.05 comparing Northeast and South and comparing Northeast and Midwest).

Of patients appropriate for referral, almost 80% had either Medicare (57.3%) or commercial health care (22.2%) coverage.

Characteristics of those in need of PC: Age, disease group, multi-morbidities

Limitations: Authors note that their estimated prevalence is a conservative figure and may underestimate the unmet need to palliative care. In addition, findings reflect bias related to differences among hospitals in charting and coding practices. Palliative care service offerings (e.g., inpatient beds, ambulatory services) differed among participating hospitals.

Beernaert et al. (2013) Referral to palliative care in COPD and other chronic diseases: a population-based study. Respiratory Medicine. **107**;11 1731-1739

Available from: https://doi.org/10.1016/j.rmed.2013.06.003

Summary: This population-based study utilised data from Belgium GP practices to describe how patients with COPD, heart failure, dementia and cancer differ in frequency and timing of referral to palliative care services. Of 2405 registered deaths respectively 5%, 4% and 28% were identified as from COPD, heart failure or cancer and 14% were diagnosed with severe dementia. Patients with COPD

(20%) were less likely than those with heart failure (34%), severe dementia (37%) or cancer (60%) to be referred to palliative care services (p < 0.001). The median days between referral and death was respectively 10, 12, 14 and 20.

Female cancer patients were more likely to be referred to palliative care services than their male counterparts (OR 1.46, 95% CI 1.05 to 2.05). Patients with heart failure (OR 3.33, 95% CI 1.07 to 10.43) and dementia (OR 1.75, 95% CI 1.02 to 2.99) were more likely to be referred when they lived in a nursing home than when they lived at home, while the opposite was found for cancer patients. No significant associations were found in the multivariate analyses for patients with COPD (Table 3). There were no significant associations between socio-demographic characteristics and the timing of onset of palliative care services for the four disease groups (not in table).

Characteristics of those in need of PC: diagnosis, main residence last year of life, age, sex,

Limitations: With a low number of patients with COPD and heart failure referred statistical power for sub analyses for those patients (e.g. timing of referral) was low.

Currow et al. (2008) Populations who die without specialist palliative care: does lower uptake equate with unmet need? Palliative Medicine. 22(1):43-50. doi:10.1177/0269216307085182

Available from: https://journals.sagepub.com/doi/pdf/10.1177/0269216307085182

Summary: The aim of this study was to understand, at a population level, the perceived unmet needs in four key subpopulations who have been reported to have less access to SPCS: 1) those with non-cancer diagnoses (analysis of cancer versus noncancer); 2) those of substantially older age (analysis of individuals 75 years and older, versus younger); 3) those with lower household incomes (analysis of less than AU$60 000, versus more); and 4) those of non-English speaking backgrounds (analysis by country of birth, English versus non-English speaking). The null hypothesis was that there would be no differences observed in unmet needs in people who did and did not access specialized palliative care services.

As part of a broader state-wide randomized face-to-face population health survey over six years (18 224 interviews, 71% response), questions were asked of people bereaved in the previous five years when someone close to them died an `expected' death (39% of respondents). Questions included respondent demographics, the diagnosis of the deceased and, for one year, whether SPCS was of benefit (if used) or needed (if not used). Differential uptake rates were calculated for diagnosis, income, country of birth and age and 2

× 2 tables reflecting the accuracy of match of service with caregiver needs were generated for each group (accuracy = true positives + true negatives/total).

Uptake of SPCS was significantly lower in people with a non-cancer diagnosis (40% versus 62%; P < 0.0001), lower income (56% versus 61%; P = 0.0006) and people born where English was not the first language (52% versus 58%; P = 0.0096). The only subgroup where the accuracy of matching between palliative care service uptake and identified needs was lower than the overall average (83%) was where cancer was not the life-limiting illness (69%; cancer 86%).

Characteristics of those in need of PC: Disease diagnosis of decedent, age, first language, household income of respondent

Limitations: Utilising proxy data to gather information about those accessing PC does not identify those with a caregiver.

Currow et al. (2004) Specialist palliative care needs of whole populations: a feasibility study using a novel approach. Palliat Med. 18(3):239-47. doi: 10.1191/0269216304pm873oa. PMID: 15198137

Available from: https://pubmed.ncbi.nlm.nih.gov/15198137/

Summary: This cross-sectional study sought to determine the feasibility of a novel whole-population method for determining specialist palliative care services (SPCS) uptake and need. The hypothesis was that the whole community could provide population-based reports about deceased individuals to help in service evaluation and planning. An annual survey of 4400 people, which has been conducted since 1991 - the South Australian Health Omnibus survey included four questions on palliative care (year 2000 survey). The study provides an initial step in the process of evaluating a novel way of defining the denominator for a whole-of population approach to people with a life-limiting illness who may need access to SPCS.

Of the respondents who indicated that a person 'close to them' had died, 507 (47%) indicated that the person was followed by a SPCS (Table 1). Excluding 'don't know' as a response, 55.2% indicated that a SPCS was involved. People who died of cancer more frequently accessed palliative care than those with nonmalignant life-limiting illnesses (cancer 61% versus noncancer 36%, P<0.001, Table 2). If a proxy relationship between the respondent's and the deceased's characteristics is assumed, rates of access to SPCS were similar regardless of country of birth, educational level, or residential region (metropolitan 55% versus regional rural 57%, P0.659, Table 2). Respondents whose income was more than AU$60 000 per year were more likely to report the use of palliative care services

(>$60 000 62% versus <$60 000 52%, P 0.010, Table 2) and less likely to report that family and friends took the caring role as a reason for not using a SPCS (>$60 000 55% versus <$60 000 67%, P for trend across all answers to question 4 = 0.050, table 3).

Where there was an identified death, 404 respondents (38%) definitely indicated that a palliative service had not been used by the PLLI (Table 1). Reasons cited included: family and friends provided the care (137, 34%), the service was not wanted (86, 21%), and other (107, 27%). In the 'other' category, frequently identified themes were that the person was an inpatient at the time of death, that the time between diagnosis and death was short, or that the person died 'suddenly' or 'unexpectedly.'

People with a non-English speaking background more commonly indicated that SPCS were not wanted because family and friends looked after the deceased person (non-English speaking background 76% versus English-speaking background 63%, P for trend across all answers to question 4 = 0.114, Table 3). People who died of cancer and did not access SPCS were more commonly cared for by family and friends than people with a noncancer illness (cancer 43% versus noncancer 31%, P for trend across all answers to question 4 = 0.034, Table 3)

If successful, such a tool can help service planning for all PLLI and their carers, compare outcomes (including bereavement follow-up) for those who do and do not use SPCS, and track trends over time.

Characteristics of those in need of PC (Statistically significant in bold): cancer or non-cancer diagnosis of decedent,
Country of birth, educational level, residential region, annual household income, native language of respondent (all non-significant)

Limitations: This was a proxy survey design and questions asked were limited in the information they gathered. Fifty-six of the original 4400 people contact declined to contribute to the survey because of language barriers. Any interpretation of the data around people for whom English was not their first language is limited.

References

1. Crowther et al. (2013) Palliative care for dementia – time to think again? Q J Med; 106:491–494 doi:10.1093/qjmed/hct078. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3665910/pdf/hct078.pdf

2. Davies et al. (2019) Socioeconomic position and use of healthcare in the last year of life: a systematic review and meta-analysis. PLOS Medicine. 16 (4). https://doi.org/10.1371/journal.pmed.1002782