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Unrelieved Pain in Palliative Care in England



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Executive Summary

In England, an estimated 378,427 people receive palliative care each year in a range of specialised and generalised services. Overall, the quality of palliative care in England and the wider UK is widely regarded as excellent. However, despite the generally high level of care, many patients receiving palliative care die in pain every year. Yet, to date, there is little evidence of the scale of this problem.

This study estimates that currently there are approximately 125,971 end-of-life patients receiving, or in need of, palliative care suffering from unrelieved pain. Of these, an estimated 16,130 patients experience no relief from their pain at all in the last three months of life. Some of these patients suffer unnecessarily because of variations in the quality of care across care settings (e.g. hospice versus at home services).

However, even if unrelieved pain rates were the same as they are in hospices, where they are at their lowest since palliative care is excellent in hospices, there would still be 50,709 palliative care patients dying in some level of pain each year. Of these patients, 5,298 would still experience no pain relief at all in the last three months of life.

Our estimates include patients of all ages, including children (under 19) which only account for 0.83% of the registered deaths in England and Wales. This was dictated by the availability of evidence of the number of deaths by place of death, which does not differentiate by age. If we were to include only adults, the number of patients who experience no relief from their pain at all in the last three months of life would go from 16,130 to 15,996.

Overall, this study has adopted conservative assumptions that will provide the lowest possible estimate of the number of patients dying with unrelieved pain.

1 Background

The National Council for Palliative Care defines palliative care as: *"...the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is to achieve of the best quality of life for patients and their families."*¹

Palliative care in the UK may be delivered by specialist services such as hospital based palliative care teams and dedicated hospices, or through generalist services including general practitioners, care homes, district nurses, and domiciliary care.

There are ongoing campaigns to improve access to palliative care in the UK², and the Access to Palliative Care Bill 2017-19³ is currently in the House of Lords. The objective of this Bill is to require Clinical Commissioning Groups (CCGs) to ensure that local residents have access to specialist and generalist palliative care, and appropriate support services. However, generally, palliative care in the UK is excellent. In 2015, the UK was ranked first in the world in a comprehensive study on the quality and availability of palliative care (Economist Intelligence Unit, 2015).

Despite the excellent provision of palliative care in the UK, it is recognised that not all needs are met, especially within community palliative care (Dixon et al., 2015). Moreover, there is recognition that the application of current best practice protocols of palliative care, such as the WHO's cancer pain ladder for adults⁴ or the NICE guidelines (QS13, QS160), cannot alleviate pain for all end-of-life patients (O'Brien and Kane, 2014). Furthermore, there is limited referral of these cases of unrelieved pain to specialist pain clinics. A study of 160 UK pain consultants showed that referral rates from palliative medicine to pain clinics were low, with 53.85% receiving five or less referrals per year (Kay et al., 2007).

There is little evidence on the level of unrelieved pain in end-of-life patients, nor any understanding of the extent of this unmet need even if every patient received the very highest standards of care as currently delivered by hospices. The aim of this study is to assess the extent of this unmet need by presenting an estimate of the overall shortfall in numbers who would have their pain relieved if 'best practice' was adopted and some projection of how these numbers change over time. To arrive to this estimate, the study assesses first the current levels of unrelieved pain in different settings. The study focuses on England due to the limited availability of data for the entire UK. However, extrapolations are also provided that estimate the number of end-of-life patients with unrelieved pain in Scotland, Wales, and Northern Ireland assuming similar levels of unrelieved pain as reported in England.

The flow diagram (Figure 1) summarises the approach taken in this extrapolation study. The first stage of the analysis identifies the number of end-of-life patients in each palliative care setting in England. As there is some variation in the rates of unrelieved pain across the different palliative care services, the second stage applies the best estimate of the rates of unrelieved pain in each setting to estimate the total number of patients that die with unrelieved pain. Finally, these estimates of unrelieved pain by setting can be used to estimate the number of patients that would still die with unrelieved pain even if all end of life patients received pain relief as effective as received by patients in hospices.

¹ <https://www.ncpc.org.uk/palliative-care-explained>

² <http://endoflifecampaign.org/>

³ <https://services.parliament.uk/bills/2017-19/accesstopalliativecare.html>

⁴ Available at: <http://www.who.int/cancer/palliative/painladder/en/>

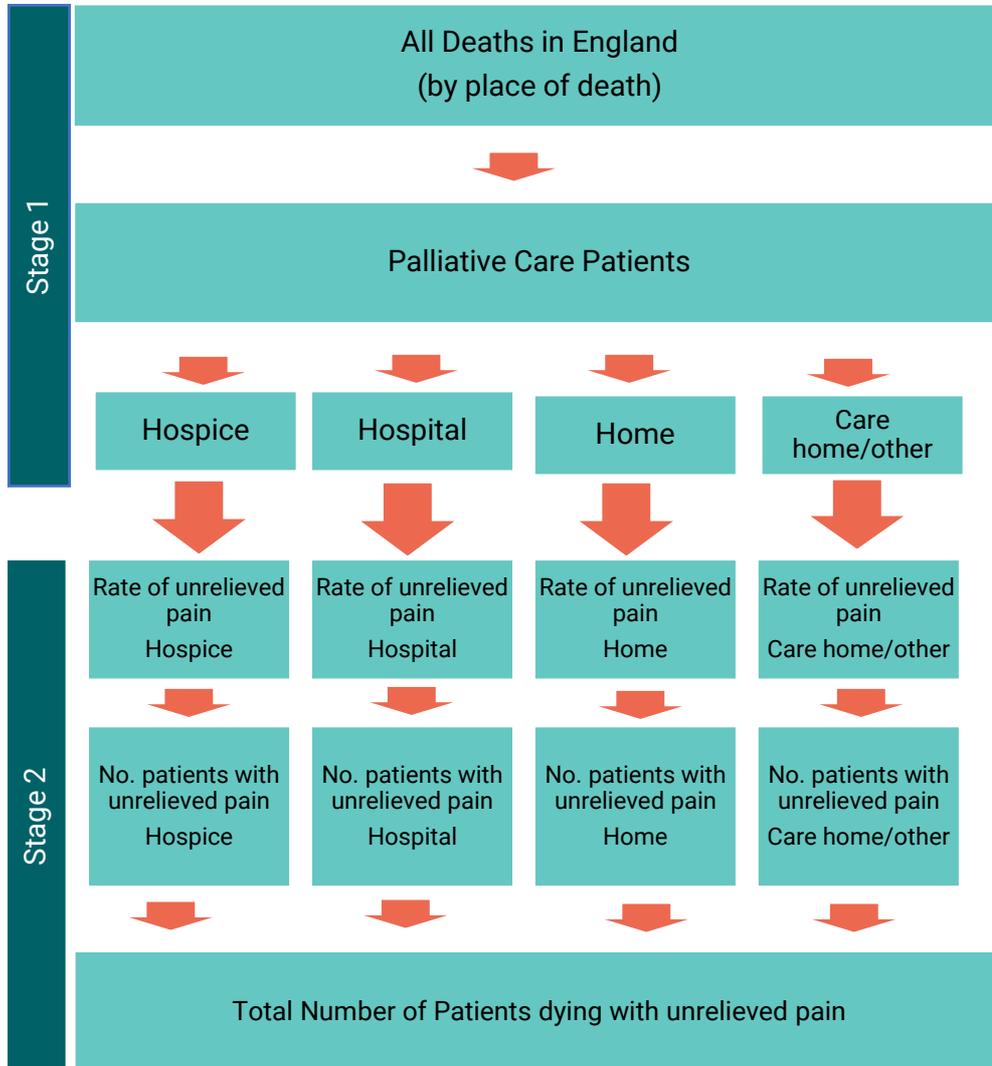


Figure 1. Extrapolation method

The rest of the report is organised as follows. Section 3 describes the literature and statistical sources used in this study, whilst the extrapolation model assumptions and the results are presented in Section 4. Section 5 concludes by discussing the results in the context of future trends for palliative care needs.

2 Death and palliative care statistics in England

The first stage of the analysis identifies the number of end-of-life patients in each palliative care setting in England. The number of deaths in England by place of death (home, hospital, hospice, care home and other communal establishment or elsewhere) are available from the end of life care profiles developed by Public Health England's National End of Life Care Intelligence Network.⁵ This dataset includes all causes of death (ICD-10 codes A00-Z99), except neonatal deaths. The latest available data reports 504,569 registered deaths for the year 2017/18 of which approximately 75% require palliative care (Etkind et al, 2017). Etkind et al. arrive at this estimate by excluding deaths with ICD-10 codes (O00-O99, P00-P96, Q00-Q99, R00-R99, U509, and V01-Y89) that the National Council for Palliative Care (2016) believe would not reasonably require palliative care. Taken together, these statistics indicate that 378,427 people died in 2017 with palliative care needs.

Not all patients receive palliative care (i.e. there is unmet need), and not all patients receive specialist palliative care. The Minimum Data Set (MDS) for Specialist Palliative Care Services (produced annually in partnership between Public Health England, the National Council for Palliative Care and Hospice UK - National Council for Palliative Care (2016)), helps identify the use of specialist palliative care services.

Specialist palliative care (SPC) consists of four services: inpatient beds, community, Hospital advisory teams, and outpatients & day therapy, as shown in Figure 2, where palliative care in hospices is considered as inpatient beds. The only available statistics on the provision of palliative care refer to specialist palliative care in England, Wales, and Northern Ireland: Minimum Data Set (MDS) for Specialist Palliative Care Services, produced annually in partnership between Public Health England, the National Council for Palliative Care and Hospice UK (National Council for Palliative Care, 2016). The MDS considers different services (e.g. inpatient and community services) which can potentially be received by the same patient. To avoid double counting patients receiving specialist care, several statistics have been presented. In 2012, it was estimated that up to 170,000 people received specialist palliative care across England (Association for Palliative Medicine of Great Britain and Ireland, 2012).

Unmet needs in palliative care are recognised and there are some available estimates for 2011 indicating that around 92,000 people per year have unmet palliative needs (Hughes-Hallett et al., 2011). Dixon et al. (2015) also consider this level of unmet need in palliative care for England (92,000), and present levels of unmet need in palliative care for the other three UK nations: 6,100 people a year in Wales, 3,000 people a year in Northern Ireland, and 10,600 people a year in Scotland.

⁵ Available at:

http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death

Rolling Annual death registrations by place of occurrence, England, [Q1 2015/16 - Q4 2015/16] to [Q1 2017/18 - Q4 2017/18]. Downloadable at: <http://www.endoflifecare-intelligence.org.uk/view?rid=203>

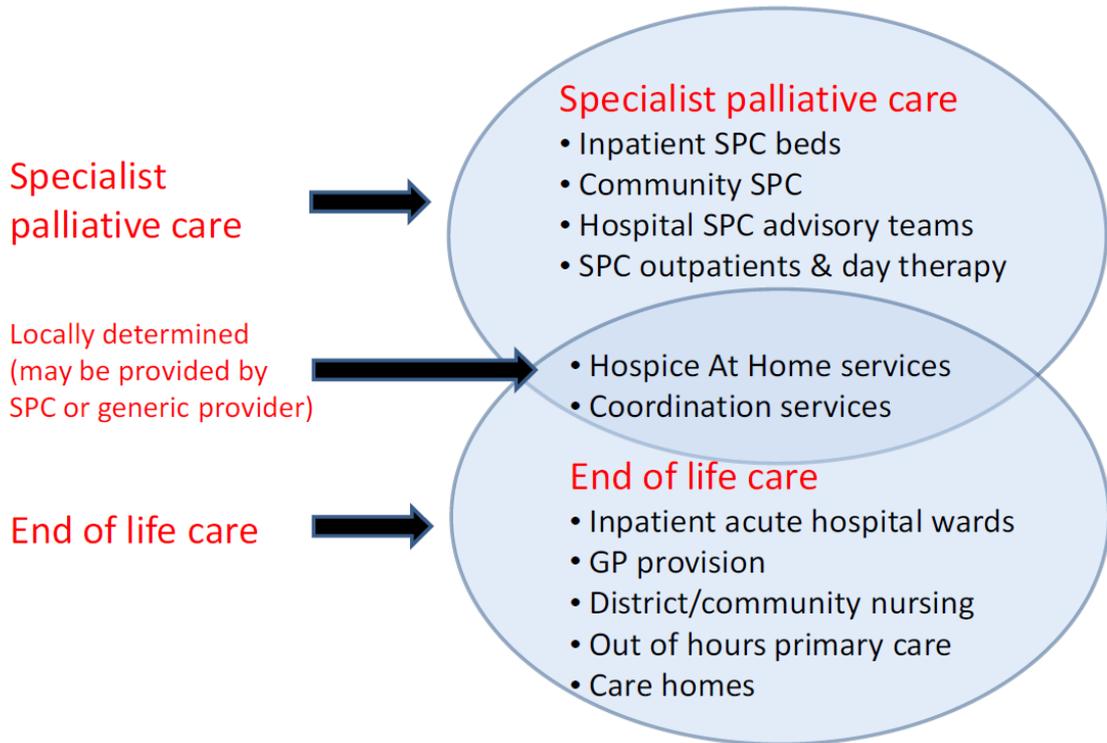


Figure 2. Different types of palliative care provision.

Acronyms: SPC (Specialist Palliative Care). Source: Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives, December 2012. Association for Palliative Medicine of Great Britain and Ireland.

To update the estimates of unmet need, we assume the current level of palliative care and then increase the number of patients with unmet needs provided by Hughes-Hallett et al. (2011) by the same proportion as the increase in the number of deaths in England and Wales between 2011 (484,367 persons) and 2017 (533,253 persons). That is a 10.09% increase. Therefore, we estimate that 101,283 people in England each year have unmet palliative care needs. These patients may be being treated by generalist/primary care palliative services, but the extent of the services available are more limited and are more focused on patients with cancer. According to Dixon et al. (2015), factors impeding good quality generalist care, in hospital or in the community, include reluctance to take responsibility for end-of-life care, lack of confidence or skills, lack of suitable care models for people with non-cancer conditions, time pressures, difficulties incorporating care into a generalist workload and resource pressures.

There is little available data on the extent and quality of end-of-life services provided through primary care, but there are clear indications of unmet needs. For example, the provision of end-of-life care should be included in the Sustainability and Transformation Plans - now Partnerships - (STPs) which were introduced in the NHS Shared Planning Guidance for 2016/17 – 2020/21 to support the delivery of the Five Year Forward View. However, the End-of-Life Care Coalition (2017) found that 18 out of 44 STPs have no mention of end-of-life care, or no details on how they plan to improve it. Also, the national primary care snapshot audit in End-of-Life Care 2015/16⁶ found that on average GPs utilised palliative care/support registers for just 39.6% of all deaths.

⁶ Available at: <http://www.endoflifecare-intelligence.org.uk/view?rid=1007>



Based upon the available evidence and data, the study makes the following assumptions about the size of the English palliative care population:

Assumption 1: Of the 504,569 deaths reported by ONS for 2017/18, 75% required palliative care – an estimated 378,427 people.

Assumption 2: Unmet needs in palliative care are estimated at 101,283 people.

Assumption 3: 55% of people who died in 2017/18 received specialist and/or generalist palliative care that met their needs – an estimated 277,144 people.

3 Estimating unrelieved pain in palliative care

The first step in estimating the level of unrelieved pain is to identify the level of pain in the palliative care population. Not all patients approaching the end of life experience pain. The prevalence of pain has been reported within the clinical literature primarily for cancer patients, where 80–90% of patients with advanced cancer are estimated to experience pain (O'Brien and Kane, 2014). The published literature indicates that an acceptable level of pain relief is achievable using well-publicised protocols in 85-90% of cancer patients (O'Brien and Kane, 2014). Studies based upon self-reported pain find lower levels of pain control for cancer patients, with an average of 70% achieving acceptable pain relief. (Valeberg et al., 2008).

Etkind et al. (2017) identified several studies reporting pain prevalence in patients with cancer, organ failure, dementia, and neurological conditions. There is a clear variation in pain prevalence by condition. Based upon pain prevalence data in the literature (84% in cancer, 67% in organ failure, and 60% in dementia and other conditions) and on the ICD-based registered deaths, Etkind et al. estimated that on average 70% of people within the palliative care setting will experience pain. There is no reason to believe that the prevalence of pain would further vary by country or care setting, although the degree of pain relief experienced by patients may vary based upon local guidelines, availability of effective analgesics and the quality of care.

The reported rate of unrelieved pain is highly variable as documented in Table 1. There are numerous reasons why experience of pain and pain relief may vary. Pain can vary by condition and severity of condition (e.g. review by Etkind 2017 reports prevalence of pain for cancer, organ failure, dementia, and neurological conditions) and is subjective (e.g. reported pain by family and carers, patients, or health care professionals). The effectiveness of pain relief will depend upon the agent used, condition, patient and application.

Pain relief can also vary in effectiveness overall and temporally. For example, one patient may find that analgesics reduce their pain partially but never completely. Another patient may find that sometimes their pain is reduced completely (e.g. background pain), but that sometimes analgesics are not completely effective (e.g. breakthrough pain).

Among cancer patients, O'Brien and Kane (2014) cite rates of refractory pain (pain that cannot be adequately relieved despite optimised use of systematic analgesics) in 10-15% of patients in the clinical literature, whilst as many as 30% of patients self-report unrelieved pain. If 84% of cancer patients experience pain, then between 8-13% (clinical judgement) and 25% (self-reported) of cancer patients may suffer unrelieved pain. However, given that cancer patients have the highest prevalence of pain, and that cancer pain may be particularly complex and involve different pains in the later stages of life (Twycross and Fairfield, 1982), using cancer-related statistics may inflate estimates of unrelieved pain for the wider palliative care population. Further, these studies do not present results for different care settings, mostly focusing on either outpatient or inpatient settings.

An alternative measure of unrelieved pain is provided in the National Survey of Bereaved People (VOICES) conducted in 2015 (Office of National Statistics, 2016b). The VOICES survey collected information on bereaved people's views on the quality of care provided to a friend or relative in the last three months of life and in the last two days of life, for England. The results on pain experienced during the last three months of life are broken down by setting and by level of pain relief (e.g. no pain relief at all, partial pain relief, etc). Data from the VOICES survey has been used to estimate levels of

unrelieved pain. According to Macmillan Cancer Support’s analysis of the latest results, over 12,000 cancer patients who die in England each year spend the last two days of their lives without adequate pain relief (Macmillan, 2017). Winyard and Macdonald (2014) used the data to approximate the number of people who would die with unrelieved pain each year even with access to specialist palliative care, using the ‘not at all’ to pain relief in a hospice setting.

Limitations of the survey are that the data are reported by third party observers (family, friends and carers) who may be particularly attuned to the suffering of patients, and that it only covers England. That said, the VOICES study provides a more nuanced understanding of unrelieved pain in the last three months of life across English palliative care and will therefore be used in this study.

Table 1. Unrelieved pain statistics for cancer patients

Source	Estimates of unrelieved pain
Clinical literature (1)	10-15%
Self-reported (2)	30%
Reported by family and carers-not at all relieved (3)	0.7% at hospice – 7.4% at home
Reported by family and carers-partially relieved (3)	10% at hospice - 37.2% at home
Reported by family and carers-unrelieved pain (including both ‘not at all relieved’ and ‘partially relieved’) (3)	10.7% at hospice – 44.6% at home

Sources: (1) O’Brien and Kane (2014), (2) Valeberg et al. (2008), (3) Office of National Statistics (2016b) VOICES reports unrelieved pain separately for three disease categories: cancer, cardiovascular, and other. The percentages in this table refer to cancer patients.

The unrelieved pain (that is pain that is not relieved at all and only partially relieved) statistics for cancer show that findings in clinical studies are close to pain levels reported in the VOICES study by family and carers of cancer patients dying in hospices. Specialist palliative care delivered in hospices can be considered the most effective at relieving pain.

The levels of unrelieved pain in hospices are lower for cancer (10.7%) than for cardiovascular diseases (21%) and ‘other’ conditions (23%), resulting in an average 13.4% level of unrelieved pain in hospices (1.4% not at all relieved, and 12% partially relieved). In contrast, pain is more uniformly relieved across diseases at hospitals, where approximately 4% of patients find that their pain is not relieved at all, and around 28% of patients had their pain partially relieved.

Whilst unrelieved pain reported in VOICES includes partially relieved and not at all relieved pain, it does not include patients whose pain is totally controlled intermittently, which would be captured by the response ‘Completely, some of the time’.

The rates of unrelieved pain by care setting reported in VOICES are presented in Table 2, corresponding to the overall level which is a weighted average across disease categories. These are responses to the question “Q31. During the last three months of his/her life, while he/she was in the [setting], how well was his/her pain relieved?”.

Table 2. Current levels of unrelieved pain in the last 3-months of life (VOICES-2015)

Place of death	% Pain not at all relieved			% Pain partially relieved		
	LCL	Central	UCL	LCL	Central	UCL
Home	7.6	8.2	8.8	42.6	43.6	44.6
Hospital	3.6	4.0	4.4	26.7	27.6	28.5
Hospice	0.8	1.4	2.0	10.4	12.0	13.5
Care home/other	1.8	2.2	2.6	23.0	24.2	25.4
Total	3.8	4.3	4.7	28.0	29.0	30.1

The levels of unrelieved pain presented in Table 2 can be used to estimate the number of patients dying with unrelieved pain at present by applying these to the estimated number of palliative care patients. This study therefore assumes the following:

Assumption 4: The mean VOICES study of carer reported pain levels represent the real experiences of palliative care patients in England – indicated in Table 2.

Assumption 5: The most relevant measure of unrelieved pain is for patients where their pain is not relieved at all – indicated in Table 2.

The figures used are highlighted in the red box in Table 2. However, to make the sensitivity of the findings to these assumptions clear, the upper and lower confidence levels of the VOICES study are also used, and figures for both completely unrelieved and partially relieved pain are presented in the results section.

This extrapolation can be taken one step further by estimating the number of patients who would still be left with unrelieved pain even if everybody with palliative care needs received the same level of pain relief as experienced by patients in a hospice setting. This analysis requires additional assumptions:

Assumption 6: All patients receiving palliative care could be treated to the same level as those currently treated in a hospice setting – indicated in Table 3.

Assumption 7: It is possible to eradicate all unmet need.

Again, the results sections demonstrate the sensitivity of the results to these assumptions. Overall, this study has adopted conservative assumptions that will provide the lowest possible estimate of the number of patients dying with unrelieved pain.

Table 3. Assumed levels of unrelieved pain

Unrelieved pain in the last 3-months of life		
Hospice standard level of unrelieved pain		
Pain not at all relieved	1.4%	95% CI (0.8% - 2%)
Pain partially relieved	12.0%	95% CI (10.4% - 13.5%)

4 Results

The results are presented disaggregated by place of death. Deaths by place of death (home, hospital, hospice, care home and other communal establishment or elsewhere) are based on all causes of death (ICD-10 codes A00-Z99) and exclude neonatal deaths. There are 504,569 registered deaths, with 45.9% in hospital, 23.5% at home, 22.6% in care homes, 5.8% in hospices, and 2.2% in other places (National End of Life Care Intelligence Network, 2018).

Table 4 presents estimates for the current level of unrelieved pain in palliative care patients for 2017/18. Using assumptions 1, 4, and 5, an estimated 16,130 (range: 14,395 to 17,865) patients died in England in completely unrelieved pain. An additional 109,841 patients (range: 105,869 to 113,783) died in some pain. Relaxing assumption 5 completely would increase the estimated number of patients dying in unrelieved pain to 125,971 (range: 120,265 to 131,648).

Table 4. Current levels of unrelieved pain. Number of patients

Place of Death	No. Palliative Care Deaths (1)	Pain not at all relieved			Pain partially relieved			All Unrelieved pain		
		LCL	Central Est.	UCL	LCL	Central Est.	UCL	LCL	Central Est.	UCL
Home	81,793	6,216	6,707	7,198	34,844	35,662	36,480	41,060	42,369	43,678
Hospital	173,763	6,255	6,951	7,646	46,395	47,959	49,522	52,650	54,909	57,168
Hospice	28,807	230	403	576	2,996	3,457	3,889	3,226	3,860	4,465
Care home	85,692	1,542	1,885	2,228	19,709	20,737	21,766	21,252	22,623	23,994
Other	8,372	151	184	218	1,925	2,026	2,126	2,076	2,210	2,344
Total	378,427	14,395	16,130	17,865	105,869	109,841	113,783	120,265	125,971	131,648

Notes:

1. Deaths under 19 years old represent a 0.83% of deaths registered in England and Wales (ONS, 2017). Therefore, if we were to consider only adults, the number of patients who experience no relief from their pain at all in the last three months of life would go from 16,130 to 15,996.

The aim of the study is to assess unmet needs which is done by applying assumptions 6 and 7. This provides an estimate of the number of patients who would still die with unrelieved pain even if every palliative care patient experienced the same level of pain as those currently in hospice care. Table 5 presents the results and indicates that 5,298 patients (range: 3,027 to 7,569) would still have completely unrelieved pain, although this is 67 percent reduction. Again, if assumption 5 is relaxed this number increases to 50,709 (range: 42,384 to 58,656).

Table 5. Projected number of palliative care patients dying with unrelieved pain

Place of Death	No. Palliative Care Deaths (1)	Pain not at all relieved			Pain partially relieved			Total unrelieved pain		
		LCL	Central Est.	UCL	LCL	Central Est.	UCL	LCL	Central Est.	UCL
Home	81,793	654	1,145	1,636	8,506	9,815	11,042	9,161	10,960	12,678
Hospital	173,763	1,390	2,433	3,475	18,071	20,852	23,458	19,461	23,284	26,933
Hospice	28,807	230	403	576	2,996	3,457	3,889	3,226	3,860	4,465
Care home	85,692	686	1,200	1,714	8,912	10,283	11,568	9,598	11,483	13,282
Other	8,372	67	117	167	871	1,005	1,130	938	1,122	1,298
Total	378,427	3,027	5,298	7,569	39,356	45,411	51,088	42,384	50,709	58,656

Notes:

1. Deaths under 19 years old represent a 0.83% of deaths registered in England and Wales (ONS, 2017). Therefore, if we were to consider only adults, the projected number of patients who experience no relief from their pain at all in the last three months of life would go from 5,298 to 5,254.

Tables 6 and 7 present an approximation of the number of patients dying with unrelieved pain (current levels of pain in Table 6 and assumed hospice standard pain relief in Table 7) in the other three UK nations, on the basis of latest ONS statistics (Office of National Statistics, 2016a) on the number of deaths in the usual place of residence, without distinction of place of death as presented for England. The number of registered deaths considered by UK nations excludes neonatal deaths. Assumption 1 is applied (75% required palliative care) to estimate the number of palliative care deaths. Finally, the assumed levels of unrelieved pain in England presented for current pain levels in Table 2 and for hospice standard in Table 3 are applied.

Table 6. Current levels of unrelieved pain. Number of patients in other UK nations

	No. of Palliative care deaths	Pain not at all relieved			Pain partially relieved			Total unrelieved pain		
		LCL	Central Est.	UCL	LCL	Central Est.	UCL	LCL	Central Est.	UCL
Scotland	42,211	1,606	1,799	1,993	11,809	12,252	12,692	13,415	14,051	14,684
Wales	24,587	935	1,048	1,161	6,879	7,137	7,393	7,814	8,185	8,554
Northern Ireland	11,508	438	491	543	3,219	3,340	3,460	3,657	3,831	4,003

Table 7. Projected number of palliative care patients dying with unrelieved pain in other UK nations

	No. of Palliative care deaths	Pain not at all relieved			Pain partially relieved			Total unrelieved pain		
		LCL	Central Est.	UCL	LCL	Central	UCL	LCL	Central Est.	UCL
Scotland	42,211	338	591	844	4,390	5,065	5,698	4,728	5,656	6,543
Wales	24,587	197	344	492	2,557	2,950	3,319	2,754	3,295	3,811
Northern Ireland	11,508	92	161	230	1,197	1,381	1,554	1,289	1,542	1,784

5 Discussion

Existing estimates of the number of patients dying without any pain relief in England are approximately 6,000 per annum (Winyard and Macdonald, 2014). Our results indicate that this is a conservative estimate. Our closest estimate of unmet need is 5,298 patients per annum who would die without any pain relief represents an aspirational, best-case possible scenario where every patient receives the very highest standard of care. At present, the level of unmet need is larger: an estimated 16,130 patients are dying in pain, that is, pain not at all relieved.

It is important to qualify why this central estimate of unmet need for pain relief in palliative care (5,298 patients) is a conservative estimate. Firstly, the estimate is based on levels of unrelieved pain reported by family and carers for the “not at all” category in the VOICES question relative to unrelieved pain in hospices which are lower than those reported by the clinical literature. To match unrelieved pain levels reported in VOICES with those from the clinical literature, the VOICES levels would need to consider ‘not at all’ and ‘partial pain relief’ responses combined. In this case, the number of patients dying in pain could be 50,709 (95% CI: 42,384 - 58,656). Therefore, the definition of unrelieved pain has a significant impact on the central estimate on its variation given the much larger levels and response variation for pain partially relieved than for pain not at all relieved in hospices.

Then, is there a preferred definition? Our understanding is that a general assessment of unmet needs aligning with the clinical literature should add patients dying in pain partially or not at all relieved. However, the conservative central estimate of 5,298 patients, which is based on 1.4% patients dying in hospices with pain not at all relieved, represents a lower bound which informs on unmet needs for those patients with refractory pain.

A simple extrapolation from England to the other UK nations is presented. This extrapolation is based upon the 2016 mortality statistics for the UK and assumes both similar levels of palliative care need, and similar levels of unrelieved pain in the rest of the UK as is reported in England. According to this extrapolation, an estimate of the current number of people dying UK-wide with unrelieved pain would be between 19,468 (no relief at all) and 152,038 (partial or no pain relief). Applying this same approach to the number of patients who would still experience unrelieved pain even if they received hospice level care, estimates of the UK figures would be 6,394 people (no pain relief at all) and 61,202 (partial or no pain relief).

There is extensive evidence on the difficulty of controlling pain for patients in palliative care. One of the most recent pieces of evidence for England (Royal College of Physicians, 2016) reports that 73% of case records showed that after a case review pain was controlled in 79% of cases: 21% of palliative care patients dying in hospitals had unrelieved pain. This level of unrelieved pain can be compared to that reported in the VOICES study by family and carers of patients dying in hospitals (Office of National Statistics, 2016b) which can be up to 32%, with 4% of pain having not been at all relieved and 28% of pain being partially relieved.

The estimates presented in this study are more conservative and assume levels of unrelieved pain between 1.4% and 12%, which corresponds to unrelieved pain reported by family and carers of patients dying in hospices in England. We know from the VOICES data that reported levels of unrelieved pain are significantly lower in hospices than in other care settings, including hospitals. As noted above, the lower threshold - around 1.4% - includes only patients whose pain has not been at all relieved may indicate a lower bound that includes patients with refractory pain considering the higher levels reported in the clinical literature between 10% and 15% of unrelieved pain for cancer patients (O'Brien and Kane, 2014).

A potential inconsistency in our approach is that while evidence from the VOICES study was collected among adults, we apply its estimate of unrelieved pain to the total number of deaths registered in England and Wales, which includes children as well. Given that according to latest ONS figures England and Wales, deaths of people under 19 years represent only 0.83% of total registered deaths, we can state that our estimates are very close to the adult-only population estimates. We presented our estimates without differentiate by age because of the data available in relation to deaths by place of death (home, hospital, hospice, care home, other communal establishment or elsewhere).

The literature also recognises that whilst the majority of patients will respond well to standard palliative medicine approaches to pain relief, a significant minority will benefit from the unique skills and expertise of a specialist pain service. However, the referral of palliative care patients to specialist pain clinics is rare in the UK (Kay et al., 2007).

Finally, the advance of chronic diseases and increased life expectancy predict an increasing need for palliative care, with care homes expected to be the most common place of death by 2040 (Bone et al., 2018). If the current unmet needs in specialist palliative community care continue, it will result in growing numbers of patients whose pain is unrelieved at the end of life.

By 2040, the number of patients in need of palliative care in England is expected to grow between 25% and 42% percent (Etkind et al., 2017). Assuming the level of pain relief that specialist palliative care teams can currently deliver remains constant, up to an estimated 178,879 palliative care patients would die in pain every year by 2040. There would still be 72,007 dying in pain (partial or no pain relief) even if the current hospice- standard of palliative care was provided to all patients in need by 2040.

A static extrapolation based on the number of deaths in the UK in 2016 relative to England implies a 21.7% increase in the number of deaths with unrelieved pain in the UK by 2040.

Glossary

This study adopted the following definitions from different sources

End of Life Care

End of life care is support for people who are in the last months or years of their life.

End of life care should help you to live as well as possible until you die and to die with dignity. The people providing your care should ask you about your wishes and preferences and take these into account as they work with you to plan your care. They should also support your family, carers or other people who are important to you.

You have the right to express your wishes about where you would like to receive care and where you want to die. You can receive end of life care at home, or in care homes, hospices or hospitals, depending on your needs and preference.

People who are approaching the end of life are entitled to high-quality care, wherever they're being cared for

Source: "What end of life care involves" NHS <https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/>)

General(ist) Palliative Care

Providing general palliative care is part of many health and social care professionals' jobs. You might see these people regularly as part of your clinical treatment:

- your GP
- community nurses
- social workers
- care workers
- spiritual care professionals

These professionals should be able to assess your care needs, and those of your family and friends. They should meet those needs where possible and know when to seek specialist advice. The aim of general palliative care is to provide:

- information for you and your family or friends, and signposting to other services
- accurate and all-round assessment of your needs
- coordination of carer teams in and out of hours
- basic levels of symptom and pain control
- psychological, social, spiritual and practical support
- good communication with you, your family or friends and the professionals supporting you

Source: Marie Curie (<https://www.mariecurie.org.uk/help/support/diagnosed/recent-diagnosis/palliative-care-end-of-life-care>)

Hospice care

Hospice care seeks to improve the quality of life and wellbeing of adults and children with a life-limiting or terminal illness, helping them live as fully as they can for the precious time they have left. It aspires to be accessible to all who could benefit and reflect personal preferences and needs.

Source: Hospice UK (<https://www.hospiceuk.org/about-hospice-care/what-is-hospice-care>)

Palliative care

Palliative care is for people living with a terminal illness where a cure is no longer possible. It's not just for people diagnosed with terminal cancer, but any terminal condition. It's also for people who have a complex illness and need their symptoms controlled. Although these people usually have an advanced, progressive condition, this isn't always the case.

Palliative care aims to treat or manage pain and other physical symptoms. It will also help with any psychological, social or spiritual needs. Treatment will involve medicines, therapies, and any other support that specialist teams believe will help their patients. It includes caring for people who are nearing the end of life. This is called end of life care. Source: Marie Curie (<https://www.mariecurie.org.uk/help/support/diagnosed/recent-diagnosis/palliative-care-end-of-life-care>)

Refractory pain

Pain suffered by people who still have inadequate pain control, despite optimised use of systematic analgesics.

Source: O'Brien, T. and Kane, C. M., (2014).

Specialist Palliative Care

Specialist palliative care services manage more complex patient care problems that cannot be dealt with by generalist services. Specialists usually work in teams to offer joined-up care and you might see one or more specialists when you're referred. Specialist teams include:

- doctors and nurses
- counsellors
- specialist allied health professionals, such as physiotherapists, occupational therapists, dieticians and social workers

Specialist palliative care services may be provided by the NHS (local health and social care trust in Northern Ireland), local councils and voluntary organisations. These could include inpatient and outpatient facilities and bereavement support services for relatives of patients.

Source: Marie Curie (<https://www.mariecurie.org.uk/help/support/diagnosed/recent-diagnosis/palliative-care-end-of-life-care>)

Supportive care

This is care which helps people with cancer and other life-threatening illnesses and their families to cope with the disease and its treatment throughout the patient pathway. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease.

Source: Glossary from Association for Palliative Medicine of Great Britain and Ireland, 2012

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