

Results Data was collected from a large range of health professionals working with palliative care patients. It was found that approximately 34% of respondents were not aware of any oral care guidelines for palliative care patients. Those that did were mostly aware of the NICE guidelines.

There was variation between all respondents as to what treatment was routinely given for various oral conditions. Some practices restricted in certain trusts were shown to be used elsewhere, for example foam swab use (70%), which is not routinely recommended by dental professionals.

Although the majority of respondents reported their patients have personalised oral care plans in place, 43% do not.

Conclusions Clearer and more concise guidelines for oral care in palliative care patients is needed to ensure staff are able to offer the same level of evidence-based care consistently across the UK. The importance of oral care plans for these patients should be promoted, to ensure patients have continuity of care.

93 PATTERNS OF GENERAL PRACTICE PRESCRIBING IN THE LAST YEAR OF LIFE

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Background Little is known about patterns of prescribing in the last year of life in primary care.

Methods Recently completed analysis of UK Clinical Practice Research Datalink (CPRD), a large database extracted from GP records that is representative of the UK population. Prescribing data for the last 12 months of life were extracted from 1 18 571 patients' GP records who died between September 2010 and August 2015. Two clinicians used British National Formulary codes to identify eight palliative care drug categories: antiemetics, anti-secretory, benzodiazepines, steroids, strong injectable opioids, strong patch opioids, strong enteral opioids, and weak oral opioids. The percentage of patients prescribed each medications was calculated at weekly intervals during the year before death, further stratified by cause of death and age at death. Random effects logistic regression models were run adjusted for age-group, sex, and cause of death.

Results Levels of prescribing significantly increased for all drugs at time of death compared with one year before death (with the exception of weak oral opioids and steroids where results were inconsistent across ages, genders, and causes of death). The largest increase was for 90+ year old male patients prescribed strong injectable opioids (OR: 21032, 95% CI: 3499 to 12641) and the greatest decrease for females prescribed steroids who died of external causes (OR: 0.52, 95% CI: 0.34 to 0.70). Patients who died of cancer generally showed the most marked increase in prescribing towards the end of life compared with other causes of death.

Conclusions Primary care patterns of prescribing in the last year of life has not been previously investigated. The findings of this recently completed study of a large nationally-representative dataset reveal increasing GP prescribing in response to the rising symptom burden of all patient groups as death approached. The implications for clinical practice and future research will be discussed.

94 GUIDELINE DEVELOPMENT FOR THE MANAGEMENT OF AGITATION IN THE LAST WEEKS OF LIFE

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Background Agitation is a distressing and common symptom at the end of life; despite this the evidence for the management of this symptom is poor.

Aim

- Audit clinical practice around management of terminal agitation with patients and healthcare professionals (HCPs) against regional standards.
- Use audit outcomes to update regional standards and guidelines

Method

- Systematic literature review examining the evidence base.
- Survey of HCPs working in specialist palliative care.
- Retrospective case note review of patients with a diagnosis of terminal agitation receiving specialist palliative care in hospital, hospice or community settings.

Results Below is a summary from 185 responses from 11 different healthcare settings in the Merseyside area from retrospective case note review:

- Hospice 54.5%, Hospital 29.7%, Home 11.8%, other including Nursing homes 3%.
- Main reversible causes documented included: pain; breathlessness; constipation and urinary retention.
- 94% of patients had medications reviewed.
- Non-pharmacological interventions formed part of the overall management plan.
- 82% of patients had psychological and spiritual support offered to the patient and or family.
- First line pharmacological intervention is Midazolam, Levomepromazine is second line.
- In 92% of cases a Syringe driver (CSCI) was used.
- Majority of deaths occurred in 3 days or less
- Communication with patient and family formed a key theme.

At the time of death:

- Midazolam prescribed in 146 cases (mean 26 mg – range 0–60 mg).
- Levomepromazine prescribed in 61 cases (Mean 56.8 mg – range 5–250 mg).
- Haloperidol 25 cases (Mean 3.5 mg – range 1–8 mg).
- Phenobarbital 9 cases (Mean 922 mg – range 200–1200 mg).

Conclusion This Audit revealed the challenges and wide variation in practice with regards to management of terminal agitation. These findings have informed an update of the regional palliative care guidelines.

95 THE 'SUPPORT OF CARE CYCLE': INTEGRATING ETHICS INTO HEALTHCARE PROFESSIONAL SUPPORT AND DEVELOPMENT IN HOSPICES

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Background High-quality hospice care is dependent on an expert caring and resilient workforce who can cope with the

significant physical and emotional demands of palliative care. Consequently, hospices employ a range of strategies to support and develop their staff, but it is not clear which are the most helpful, the best value or whether certain combinations are needed. Though ethical considerations are a prominent and common source of distress for hospice staff, clinical ethics rarely receives as explicit or frequent attention within hospices when compared to other support structures.

Methods We critically reviewed the staff support and development structures at a large hospice in southeast England, spanning: informal colleague support, reflective practice sessions, teaching, line management and specific additional support such as clinical supervision, Clinical Ethics Committee (CEC) and Schwartz Rounds.

Results Our review identified, then compared and contrasted, the key mechanisms of staff support and development: – CEC (what is the ‘right thing’ to do) – Reflective Practice (how to best go about doing the ‘right thing’) – Clinical Supervision (being personally able to do the ‘right thing’) – Schwartz Rounds (how doing the ‘right thing’ feels).

Conclusion Appropriate staff support and development is vital for hospices to deliver high quality, sensitive and individualised patient care. Four mechanisms appeared pivotal in their ability to support and develop staff in their professional roles. Despite clear overlaps, appreciation of their differences was fundamental in understanding their collective benefit: – CECs: being ethical – Reflective practice: being organised – Clinical supervision: being educated – Schwartz Rounds: being human. Subsequently, we propose the ‘Support of Care Cycle’ where each element informs the next in a virtuous spiral. As interdependent, to miss any component would undermine a hospice’s staff support and development structures. Thus, hospices need to provide all four of these cornerstones, including the often neglected clinical ethics.

96 INVOLVING PEOPLE WITH DEMENTIA WHO LACK CAPACITY IN RESEARCH

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Background Empowering people with dementia to be involved in research at all stages of the disease is, respectful of individuals, maintains personhood and is equitable. It is therefore consistent with best practice in dementia care. Research is important for improving dementia treatments, care and service delivery. However, involving people with dementia who lack capacity or who have fluctuating capacity in research is challenging and requires careful consideration to avoid potential harms.

Methods This paper reports a novel and successful method for recruitment into two research studies of people with dementia. The first study investigated cancer services provided for people with dementia who received cancer treatment in 2014/2015. The second study investigated crisis intervention in the community for people with dementia and their family members in 2017. The coproduced approach has enabled people with dementia in primary and secondary care receiving services in their own homes, out-patient clinics and in hospitals to take part in research.

Results This paper will discuss how the researchers:

- Devised method that accommodated the needs of people with dementia for obtaining formal written consent or support for participation from a Consultee, as required by the Mental Health Act 2005.
- Negotiated the challenges of ethical and other approvals.
- Developed training for research assistants in the assessment of mental capacity and recruitment of people with dementia.

The presentation will include a flow diagram of the recruitment process. Other researchers should then be able to adopt or adapt the approach for studies involving people with dementia.

Conclusions There are challenges to involving people with dementia in research, but they can be overcome. What our research teams have learnt has informed the recently launched ‘Research and impaired mental capacity in adults: guidance for researchers’ published by Healthcare Research Wales.¹

REFERENCE

1. https://www.healthandcareresearch.gov.wales/uploads/News/research_and_impaired_mental_capacity_in_adults-guidance_for_researchers.pdf

97 REVIEW OF DATA FROM THE 2016 OFFICIAL REPORTS OF THE DUTCH TERMINATION OF LIFE ON REQUEST AND ASSISTED SUICIDE ACT AND OREGON'S DEATH WITH DIGNITY ACT

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Of 6091 notified cases of physician assisted suicide (PAS)/ euthanasia (PAE) in the Netherlands, 3840 (63%) were 70 years or over: the proportion rises to 86% (5248 PAS/PAE deaths) if over-60s are included.

Oregon’s official report on their PAS law, which requires a prognosis of <6 months, shows 71% of PAS deaths in 2016 were aged 65 or over (median 73 years).

Both legislatures show rising incidences of PAS/PAE since legislation came into force.

In the Netherlands the annual numbers of deaths initially remained stable and fears of rising death rates were thought groundless. After 2007, the annual numbers of deaths began to rise steeply. In 2016, 1 in every 25 deaths the result of legalised PAS or PAE. A law like Holland’s 2001 Act would probably result in around 21 000 such deaths annually in England and Wales.

In 2010, of 3,136 Dutch PAS/PAE notified, 2781 (89%) were related to cancer, cardiovascular and neurological disorders and 11 per cent to other conditions. By 2016 a rising proportion (17%) related to multiple geriatric syndromes, dementia (n=141), psychiatric disorders (n=60), and other conditions. Statistics Netherlands data confirms this trend.

Extension of euthanasia caused psychiatrist Boudewijn Chabot, whose prosecution preceded Dutch legislation, to express concern, writing that the foundation of the law has been gradually eroded so that now it ‘does not provide protection to people with dementia and psychiatric problems.

Non-assisted suicide rates have not fallen where PAS/PAE is legalised, but the introduction of PAS seemingly induces more self-inflicted deaths than it inhibits. WHO data shows higher-than-average suicide rates per 1 00 000 population (2015) of 20.5 in Belgium, 15.1 in Switzerland, 12.3 in Canada, 11.9 in