

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