Changes in Dignity and Respect at the End of Life: Cross-Sectional Analysis of Data from the Voices Bereavement Survey (2011–2015)

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Background An aim of the National End of Life Care Strategy (2008) was to improve dignity and respect in end of life care (EoLC). The VOICES survey was commissioned in 2011 as the first national post-bereavement postal survey, a key component of which was to assess dignity and respect at the end of life. The aim of this study was to explore changes in dignity and respect perceived by bereaved relatives over the five-year period that the VOICES survey was commissioned.

Methods Aggregate data from VOICES post-bereavement surveys (2011–2015) was obtained from the Office of National Statistics. Information about dignity and respect was extracted and dichotomised into satisfied (‘always’and ‘most of the time’) and unsatisfied (‘some of the time’and ‘never’). A chi-squared test for trend was used to analyse changes over time in dignity and respect, for each of seven categories of health care professionals.

Results There were 1 072 206 responses to the VOICES surveys over 5 years (average response rate 44.4%). Improvements in perceived dignity and respect from 2011 to 2015 were found with respect to five categories of health care professional: GPs (0.7% improvement in satisfaction to 60.9%, p=0.016); hospital doctors (1.7% improvement to 85.0%, p=0.0036); hospital nurses (5.2% improvement to 80.6%, p<0.0001); hospice doctors (0.8% improvement to 95.3%, p=0.0001); hospice nurses (1.9% improvement to 95.2%, p=0.0001). District/community nurses showed a 1.4% decrease in satisfaction to 92.6% (p<0.0001). Care home staff showed no change (p=0.2).

Conclusions The data has demonstrated a general trend of improvement with regard to dignity and respect experienced from healthcare professionals. District/community nurses showed a decrease in dignity and respect however, this could be attributed to a regression to the mean or due to their high baseline, therefore this would not be cause for concern. The low satisfaction demonstrated with GPs should be investigated.

The Gold Standards Framework for Improving the Quality of End-of-Life Care in the Community: A Systematic Review and Qualitative Synthesis

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Background The Gold Standards Framework (GSF) was established in 2000 to help ensure delivery of high-quality end-of-life care within general practices, and has since been adapted for care homes and hospitals. The GSF has been endorsed by the UK Department of Health, with a national roll-out seeing all UK general practices and 25% of care homes adopting the GSF in some form. The evidence base for the GSF in the community has not been systematically evaluated. The aim of this study was to synthesise the qualitative evidence for the GSF on improving end-of-life care in the community.

Method A systematic literature review of published research from 2000 to 2018 using Medline and PubMed databases, in line with PRISMA guidelines. A thematic matrix analyses approach was adopted. Studies were quality assessed using the QualSy tool.

Results Of the 115 studies identified, 19 studies reported on qualitative findings of the GSF implementation in the community setting. All 19 studies collected data from staff members and 4 studies also included patients and/or relatives. The GSF was felt to facilitate improved written and verbal communication in both nursing care homes and primary care teams, and to enhance methods of teamworking. 16 of 19 studies reported increased uptake of a palliative care register to identify end-of-life patients. Barriers to use of the GSF included a lack of sustainability due to high staff turnover, as well as an increased workload and difficulties in discussing end-of-life care with relatives.

Conclusions These findings support the use of the GSF in improving the quality of end-of-life care through collaborative working and increased communication across healthcare teams. Further studies are required to understand attitudes of patients and relatives. Challenges for policy makers include ensuring end-of-life care tools are both sustainable and flexible according to local population and workforce needs.

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Why are Patients Not More Involved in Their Own Safety? A Questionnaire-Based Survey in a Multi-Ethnic North London Population

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Background An estimated 8.500 000 cases of unintentional medical injuries occur every year, at least half of which are thought to be preventable. Patients receiving palliative care are particularly vulnerable to medical errors and their consequences. Patient participation in their own safety has well-demonstrated benefits in reducing errors. Understanding how patients feel about participating in their own safety and how to improve patient engagement could help reduce medical errors in palliative care. The authors sought to examine patient participation in a range of safety-related behaviours and investigate how they varied with different patient demographics.

Methods A 20-point questionnaire was employed exploring safety-related behaviours, particularly looking at patient willingness to challenge healthcare professionals and to notify them of potential errors. Data on sex, age, ethnicity, English language proficiency, duration in the United Kingdom, employment and education status was also collected.

Results 195 patients were invited to participate in this study and 175 patients completed the questionnaire. Female patients who had tertiary education, those who were fluent in English and under the age of 60 years were statistically more likely to feel responsible for their own safety and take an active role in their safety. Older male patients of lower education status are statistically less likely to question staff on hand hygiene.
**Conclusion** Despite numerous campaigns to improve patient involvement many still do not participate in their own safety. Patients without tertiary education, patients over 60, and those who are not fluent in English are much less willing to challenge healthcare professionals about safety-related issues. Understanding the impact of patient demographics on participation in safety behaviours could help to create novel, more targeted strategies to improve patient safety. This could effectively reduce preventable medical errors in palliative care medicine where patients are more vulnerable to such errors.

**EMPIRICAL ETHICS AND PALLIATIVE CARE: A SYSTEMATIC REVIEW OF THE ETHICAL CHALLENGES IDENTIFIED BY SPECIALIST PALLIATIVE CARE PRACTITIONERS IN THEIR DAY-TO-DAY CLINICAL PRACTICE**

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**Background** Ethical issues arise daily in the delivery of palliative care. Despite much (largely theoretical) literature on the ethics of palliative care, evidence from specialist palliative care practitioners (SPCPs) about the day-to-day ethical challenges they encounter has not previously been synthesised. This evidence is crucial to inform education and training, and support staff.

**Aim** To synthesise the evidence regarding the ethical challenges which SPCPs of all professional backgrounds encounter during clinical practice.

**Methods** A prospectively registered systematic literature review using narrative synthesis methodology (Popay et al 2006) was conducted. Key words and subject headings of 8 databases (MEDLINE, Philosopher’s Index, EMBASE, PsychINFO, LILACS, WHOLIS, Web of Science and CINAHL) were searched on 03/10/2018, without time limits. Eligible papers reported original research using inductive methods to describe SPCP-reported ethical challenges, in any language. Quality was dual assessed using the Mixed-Methods Appraisal Tool. Tabulation, textual description, concept mapping and thematic analysis were used to develop and present the narrative.

**Results** 7040 records were screened. 12 studies from 9 countries were included. All included studies examined adult care. A broad range of ethical challenges were identified in 5 themes: patient-related (e.g. autonomy, truth-telling), patient-family relationship (e.g. boundaries of confidentiality, family-patient conflict), clinical issues (e.g. futility, palliative sedation), organisational factors (e.g. value differences between professions and care settings, place of care), and wider system (e.g. euthanasia, organ donation).

**Conclusion** SPCPs encounter a broad range of ethical challenges, not all of which are recognised in the ethics literature or form part of training curricula. In particular, the challenges of differing value positions between hospice and curative sectors and genetics ethics seldom occur in theoretical discussions of palliative care ethics or training, while withdrawal of life-prolonging treatment and euthanasia are more commonly represented. Findings of the review can inform SPCP ethics education, training and support.

**SYSTEMATIC REVIEW ON THE DOCTRINE OF DOUBLE EFFECT WITHIN PALLIATIVE CARE**

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**Background** The Doctrine of Double Effect (DDE) suggests pursuing a morally good action, despite foreseeable bad side-effects (including death) is still ethical, providing the bad side-effects weren’t intended (within set circumstances). Consequently, DDE is a means of freeing doctors to prescribe morphine for pain at the end-of-life without misplaced legal fears. However, increasingly the role for DDE in Palliative Care is being questioned.

Our aim was to collate the current arguments for and against a role for DDE in Palliative Care, to provide an updated position.

**Methods** A systematic literature review was performed on DDE in Palliative Care. Peer-reviewed publications included if: English; abstract (to confirm applicability); from last 5 years (2013–2018). 10 full papers were analysed and key arguments summarised. This qualitative data was combined, addressing the research question.

**Results** Persuasive support both for and against DDE in Palliative Care was identified.

**Positives;** legal prerequisite (realising treatment morbidity/mortality); important moral ‘tool’ (doctors require ‘good intentions’); and expert clinical support (championing DDE).

**Negatives;** unnecessary (no legal/clinical need); not applicable (distancing by palliative care); misforms (fuels misplaced opioid fears); paternalistic (about staff, not patient-centred); unusable (complex, and intent/motive uncontestable); risks diversion from tailored dosing (poor practice, even if well-meaning); not a blanket ‘doctrine’ (or an ‘untouchable’ defence if misprescribe opioids).

**Discussion** The literature remains divided on current importance of DDE. DDE has inherent philosophical value with historical impact and current support. However, DDE’s applicability in Palliative Care is unclear (because appropriate symptom control doesn’t cause death); inconsistencies refute the presumed need (DDE is not needed to ‘protect’ prescribers in chemotherapy-related neutropenic sepsis deaths); and DDE allows potential harm (unintentionally providing a medical defence if deliberately administer a fatal opioid overdose)... sufficient to undermine DDE’s current value. ‘Best practice’ appears a better tenet to guide doctors.

**LEAVING AN IMPLANTABLE CARDIOVERTER DEFIBRILLATOR ACTIVE AT END OF LIFE – BALANCING CURRENT AND POTENTIAL FUTURE HARMs**

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The number of people with implantable cardioverter defibrillators (ICDs) has increased. Consequently more people approaching the end of their life have an ICD in situ.

Sensitive and timely conversations enable a planned ICD deactivation to take place in the majority of people approaching the end of their life. However, in a small number of cases, our multi-professional team have not been able to reach