Lessons learnt

1. Teach by example: Observing senior clinicians discussing corneal donation was most likely to change practice;
2. Share resources and learning;
3. Involve senior leaders early;
4. Include family early;
5. Early formal MDT education programme is essential.

Conclusion This ongoing IQT project has had a huge impact on practice at the hospice. Patients' wishes to donate has become part of the language of handovers. We aim to share our learning and resources across all Welsh hospices and increase the number of patients given the opportunity to become donors should they wish.

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4 A LIFE OR 'GOOD DEATH' SITUATION? A WORLDWIDE ECOLOGICAL STUDY OF THE CONTEXTS OF COUNTRIES WHICH HAVE AND HAVE NOT IMPLEMENTED PALLIATIVE CARE

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Background Palliative Care (PC) advocates argue that service implementation is feasible in all settings. Yet, services have developed patchily in low and middle-income settings. Beyond Human Development Index indicators, little thought has been given to the broader development challenges facing nations tasked with implementing PC.

Aim To describe how indicators of national development relate to levels of PC services in nations around the world.

Methods An ecological study to identify relationships between potential predictor variables and countries' level of PC development. 28 predictor variables from 6 domains were selected using hypothesised relationships with levels of PC development: disease demographics, socioeconomics, health systems, politics, demographics and economics. The outcome variable was level of national PC development on a six-point scale. Spearman's correlation test was used, significance level <0.05.

Results 26/28 variables were significantly associated with levels of PC development in 207 countries. PC is more developed in countries with high: percentage of deaths from non-communicable disease, population proportion aged 65+, gross national income and tourism. Development is lower in countries with high levels of: political corruption, infant mortality, deaths by infectious disease and weak democracy. Prevalence of undernourishment and levels of private health expenditure were not associated with PC development.

Discussion PC development is highly consistent with broader national development indicators. Development is less in countries where acute deaths are more likely and any benefits from PC provision, short-term. In such countries, resources may be prioritised towards life prolonging therapies and key aspects of PC need only, prior to fully integrated palliative services. Calls for accelerated development of PC services must be informed by in-depth understanding of national development contexts, local needs and opportunity costs.

5

THE INTERNATIONAL 'CARE OF THE DYING EVALUATION' (CODE) PROJECT: USING BEREAVED RELATIVES TO ASSESS CARE FOR DYING CANCER PATIENTS IN EUROPE AND SOUTH AMERICA

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Background The concept of a 'good death' is unique and individual; yet key elements of good quality of care for the dying make it a global issue. The aims of the International CODE project (2017–2020) were to:

- assess quality of care for dying cancer patients within seven European and Latin American countries, by undertaking a bereaved relatives' survey
- use survey results to implement clinical changes within one European and one South American country.

Methods

- Translate 'Care Of the Dying Evaluation' (CODE) questionnaire using standardized procedures; adapt CODE for different cultural settings using pre-testing survey methods involving patient and public representatives and bereaved relatives.
- Conduct post-bereavement survey (by post, interview or on-line completion) to those with a family member dying from cancer in hospital (>100 completed questionnaires per country).
- Discuss preliminary survey findings at public engagement events; focus on interventions to improve areas perceived to be poorer in quality.
- Future work involves quality improvement strategies to implement clinical changes and further psychometric testing of questionnaire.

Results Translation and pre-testing work conducted (involving 48 patient and public representatives and 35 bereaved relatives). Modified nominal group technique helped form consensus about international version of the questionnaire (i-CODE). Preliminary reporting (601 completed questionnaires) showed perceptions about care were generally good. Although there were differences between countries, focusing on improving communication about the provision of fluids and what to expect when someone is dying represent areas for improvement. Plans in progress for public engagement events (Autumn, 2018).

Conclusions A common, core international questionnaire has been developed with key questions relating to quality of care for the dying; this will help identify core areas that require improvement. User-involvement was fundamental to enhancing the face and content validity of i-CODE; it will continue to be instrumental in converting the research findings into the meaningful clinical change.