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RESPONDING TO THE END-OF-LIFE OPTION ACT IN CALIFORNIA

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GUIDANCE FROM UK EXPERTS ON HOW TO ENABLE BETTER END-OF-LIFE CARE AND FACILITATE HOME DEATHS

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Despite a growing desire amongst patients to spend their last days at home, many are unable to do so, leaving a lasting effect on both patients and families. We undertook a qualitative study with in-depth, semi-structured interviews in England, UK. A combination of face-to face and telephone interviews were conducted with 33 experts in the field of end-of-life care. These included policy makers, academics and hospital and community healthcare professionals from leading UK organisations. Interviews were transcribed and thematically analysed. As a result, three overarching themes were identified: 'education'; 'planning' and 'managing people'. These were further divided into a total of 12 sub themes containing practical guidance on enabling better end-of-life care. The theme of 'planning' contained seven subthemes including 'policy', 'cost' and 'coordination'. The 'education' theme included 'communication' and 'perceptions of death'. Of particular significance was the identification of the growing stigma and fear surrounding end-of-life amongst patients and healthcare professionals alike. 'Managing people' as a theme included the impact of 'patient preferences' and 'family influences' on enabling comfortable death at home. In conclusion, multiple barriers and facilitators to achieving death at home were identified in this study. The lack of training, education and funding within the National Health Service was highlighted, as was the importance of sociopolitical factors. These include the lack of social networks amongst elderly patients and the inequality of resource provision in hospitals and communities. We offer a list of recommendations to combat these barriers, paying specific attention to UK end-of-life policy and education.

PATIENT PREFERENCES FOR LIFE-SUSTAINING TREATMENT AND CONCORDANCE WITH THE POLST FORM

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The Physician Order for Life Sustaining Treatment (POLST) Paradigm is a promising system for documenting treatment preferences of patients with advanced illness. Studies show that orders documented on POLST forms are largely concordant with care provided, but to align patient goals, preferences, and values with care provided, POLST forms must reflect patient goals, preferences and values. Using the Willingness to Accept Life-Sustaining Treatment (WALT) Instrument to elicit treatment goals, this study evaluated sensitivity of participants' preferences to treatment intensity and outcomes (cognitive impairment, physical disability, and probability of death), and alignment between WALT responses and POLST forms. A convenience sample of 42 residents with POLST forms was recruited from three nursing homes and two assisted living facilities. Participants' responses to the WALT and orders abstracted from participants' POLST forms were compared to evaluate alignment. Preferences remained stable across different treatment intensity scenarios for 48% of participants and across different outcome scenarios for 33% of participants. Among 14 participants whose preferences were stable across all scenarios, eight articulated preferences that were fully aligned with their POLST. Three of 16 participants whose POLST ordered full treatment wanted comfort measures only. One of nine participants whose POLST form ordered comfort measures only wanted full treatment. Research is needed to develop decision-making strategies to assure that treatment-sensitive or outcome-dependent patient preferences are accurately reflected in POLST forms. Additionally, more research is necessary to understand the potential for misalignment between POLST forms and patient goals, preferences, and values to assure alignment with care provided.

POLICY CHALLENGES FACED BY THE CURRENT UK HEALTHCARE SYSTEM IN ACHIEVING PATIENT DEATH AT HOME

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Evidence suggests that the majority of patients wish to die at home. However, this is attainable for few.

A systematic literature review (SLR) was conducted with a mixed methods approach by analyzing qualitative and quantitative studies. In the SLR 3241 papers were retrieved. 72 primary data articles remained after the screening and filtering processes. Qualitative articles were synthesised using a meta-ethnography technique in order to develop key themes. Quantitative articles were analysed using a descriptive approach to highlight further themes. The emerging themes from the meta-ethnography synthesis and the analysis of the quantitative papers were amalgamated to produce a set of overarching barriers and facilitators.

6 barriers and 4 facilitators to achieving death at home were identified primarily from the meta-ethnography process. Further concepts of 'demographics' and 'interventions' were produced from the quantitative data analysis that had both barrier and facilitator components. The overarching topics included logistical issues in getting both the patient and equipment home, lack of continuity of care and geographic variation in resource provision, including 24/7 care, all that pertained to policy influence. In conclusion, this review shows that addressing these identified factors by reviewing and amending surrounding policy, could allow more patients to achieve death at home. However, it is important to acknowledge the qualitative nature of these results as such, further research is required to identify the relative impact that changing specific policies would have on patients' ability to achieve home death.

RESPONDING TO THE END-OF-LIFE OPTION ACT IN CALIFORNIA

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The legalization of physician-assisted death in California, via the End of Life Option Act, expands the possible

pathways open to older adults facing the end of life. The law raises many questions, ranging from the practical to the philosophical. In order to prepare healthcare providers to care for adults who might request physician-assisted death, we invited 112 key stakeholders from across California to share their expertise in the areas of ethics, medicine, advocacy, and the law in a statewide conference. Six healthcare professionals and researchers from Oregon and Washington presented their experience with their states' laws, and California healthcare leaders led discussions on a range of topics. The goal of the conference was to identify issues providers and healthcare systems may consider in responding to the law, in order to expand and improve end-of-life care generally. We report major themes identified by participants: (1) All healthcare systems should develop policies that reflect the values of the organization; (2) Institutions must anticipate and address the implications for vulnerable patients, such as older adults, in order to mitigate harm; (3) Institutions should create policies that account for conscientious objection and moral distress among providers; and (4) Palliative care should be an essential part of the response. The process of developing a response to the End of Life Option Act provides healthcare systems the opportunity to reflect on the law's ethical and social implications and thereby implement system-wide changes that can benefit all patients facing the end of life.

VOLUNTEER-PARTNERED END-OF-LIFE CARE: A COMMUNITY INITIATIVE

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Providing choices on places to be cared during the end stage of life is considered as significant in achieving quality of death. In response to this pressing need, The Hong Kong Jockey Club Charities Trust initiated a Project in whicha Volunteer-Partnered End-of-Life Care (VPEoLC) Model was developed to support community-dwelling elders with advance illnesses in Hong Kong. This paper will present a pilot test on the VPEoLC model. The VPEoLC model is developed under a collaborative effort of a social service agency and the palliative care unit of a hospital. It aims to optimize quality of life of dying patients through the seamless collaboration of volunteers, social care team, and hospital. It contains four core elements: 1) regular case review based on feedbacks from a service team with members from hospital palliative team, community social care team, volunteers, and family members; 2) C-I-E volunteer training (Classroom teaching-Internship-experiential training); 3) timely debriefing after each volunteer service; and 24-hours professional support. A pilot test was conducted on 14 elders. A pre-post-follow up design was adopted and participants were assessed on their symptoms, information needs, practical concerns, anxiety or low mood, family anxieties and feeling of being at peace with the Integrated Palliative care Outcome Scale. Data were collected from the clinical records. The pilot test results support the effectiveness of the VPEoLC model in symptom control and emotional support. Learning from the pilot test will also be discussed.

DEVELOPMENT OF COLLABORATION INDEX BETWEEN NURSES AND CARE WORKERS IN END-OF-LIFE CARE

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Purpose: It is predicted that there will be an increasing need for in-house end of life care services at Japan's intensive care homes for the elderly. Therefore, collaboration between nurses and care workers will become essential in order to ensure the quality of nursing care. The purpose of this study is to develop a tool for both nurses and care workers to be used in order to conduct a self-evaluation on how they collaborate with each other.

Method: We conducted a qualitative and inductive analysis of semi-structured interview survey with both nurses and care workers. We then made a list of items as a suggestion for forming a collaboration index for each job. We examined the validity of the content of the suggested items by conducting an anonymous self-written questionnaire among nurses and care workers of intensive care homes for the elderly throughout the country. We considered items with a content validity index (CVI) above 0.8 to be valid, and those below 0.8 to be invalid. Those considered invalid were either deleted or the expression was revised according to the content of the free written comments.

Result: From the result of the analysis of the interview survey, for nurses' collaboration index, we drew out 74 items under 3 concepts. For care workers' collaboration index, we drew out 59 items under 3 concepts. Of the 74 items of nurses' collaboration index, 57 items scored above 0.8 on CVI, and 17 items scored below 0.8 (CVI 0.45 to 0.79), among which 8 items were deleted and 9 items were revised according to the content of the free written comments, finally leaving 66 items on the table. Among the 59 items of care workers' collaboration index, 38 items scored above 0.8 on CVI, and 21 items scored below 0.8 (CVI 0.61 to 0.79), among which 8 items were deleted and 13 items were revised according to the content of the free written comments, finally leaving 51 items on the table.

Conclusion: Based on the interview survey conducted among expert staff of intensive care homes for the elderly, we were able to form collaboration index that systematically organizes the content of collaboration between nurses and care workers.

A RELATIONAL MODEL OF AGING, ILLNESS, AND PALLIATIVE CARE AND ITS APPLICATIONS

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Relational perspectives continue to gain prominence in ethics in health and long-term care and in aging research. A key focus of this theoretical approach is the social nature