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The engagement of young people in the advance care planning process: A tale of two studies

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This presentation is based on my PhD and a piece of subsequent research which explored the views and experiences of young people, their parents/carers, and healthcare professionals of the advance care planning process for Children and Young People (CYP). Advance care planning for CYP is relatively new in the UK. Consequently, there is a lack of understanding about the engagement of CYP in their own planning process, optimal timing of discussions, and the facilitators and barriers to the engagement of them in their own care planning. A qualitative study was initially employed, using semi-structured interviews with fifteen people across all participant groups to construct four case series. In the second study, an online questionnaire was used to collect data; 122 participants were included in the study. Data from both studies were analysed thematically. Advance care planning is reported to be best initiated by a consultant when the young person is in their mid-teens, their condition is stable, and before they transition to adult care. Engagement is considered to be facilitated by appropriate communication, developing relationships prior to initiating advance care planning, and written support for everyone involved in the process. Standardised documentation and additional training can help support the initiation and use of advance care planning, reduce misperceptions, and generate greater confidence in participating in the process. A larger multidisciplinary team, with better communication, will help support improved relationships between professionals which will filter down to the families. These factors were supported by training and education for healthcare professionals and a flexible and innovative structure and cultures of organisations.

Recent Publications

1. Hughes, B., & Lewis Harkin, B. (2022). The Impact of Continuing Bonds Between Pet Owners and Their Pets Following the Death of Their Pet: A Systematic Narrative Synthesis. *OMEGA - Journal of Death and Dying*, 0(0). <https://doi.org/10.1177/00302228221125955>
2. Hughes, B., & Jones, K. (2022). Young People's Experiences of Death Anxiety and Responses to the Covid-19 Pandemic. *OMEGA - Journal of Death and Dying*, 0(0). <https://doi.org/10.1177/00302228221109052>
3. Hughes B, O'Brien M, Flynn A, Knighting K. Views and experiences of young people, their parents/carers and healthcare professionals of the advance care planning process: A summary of the findings from a qualitative study. *Palliative Medicine*. 2022;36(5):841-854. doi:10.1177/02692163221083447

Biography

Ben Hughes has worked in education for over 20 years and, as part of his work in higher education, has written and developed programmes of study and taught a range of subjects, such as philosophy, social work, education, English, Nursing, Health and Social Care, and Criminology. He teaches full-time at the University of Bolton on postgraduate courses, which includes supervising dissertation and PhD students. He also contributes to modules in Death, Dying and Bereavement as well as Health and Social Care, and the Access programme at the Open University. He has a multi-disciplinary approach to teaching and research and involved in work which explores and informs policy around vulnerable groups, marginalised populations, young people, health, and education. He serves on the editorial board of one journal and reviews for a number of others.

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