

Proposal for DfE scholarships for the academic year 2019/2020

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Title: To explore the role of the family in palliative care decision-making for patients with an implantable cardiac device.

Background: International guidelines recommend patients with an Implantable Cardioverter Defibrillator (ICD) and their families are informed about deactivation^{1,2}. Recent empirical studies found diversity in family members' involvement in palliative discussions and decision-making including ICD deactivation^{3,4}. Furthermore healthcare professionals were more confident ($p=0.014$) to discuss deactivation when the patient had a family member who shared healthcare decisions^{4,5} in keeping with the crucial role played by family members reiterated by the majority of international published studies. The crux is, that there is a lack of clarity on the role of the family

Aim: To explore the role of the family in complex palliative decisions with patients in advanced heart failure

Objectives:

1. To evaluate the incidence of family involvement in palliative decisions
2. To explore the experience of patients and family members involved in palliative conversations
3. To present data from 1&2 to a group of key stakeholders including patients, family members and healthcare professionals to inform a discussion that will result in the development of a set of recommendations on family involvement in palliative decision-making.

Methods: A mixed methods approach will be employed incorporating three phases.

Phase One: Objective 1

A retrospective case note review of patients who have died over the last 12 months. A cross-sectional sample of all patients who have died with advanced heart failure (NYHA III & IV) and with an implantable cardioverter defibrillator in situ will be identified by the heart failure clinical teams. Clinical audit approval will be sought from Belfast, South-Eastern and Southern Health & Social Care Trusts to retrieve and search patients' notes for data related to end of life decision-making.

Phase 2: Objective 2

Informed consent will be obtained from patients ($n=15$) and caregivers ($n=15$) before semi-structured interviews conducted to explore their experience of making palliative decisions. These will include 5 patients each from Belfast, South-Eastern and Southern Health & Social Care Trusts over a twelve-month period. Eligible patients will be identified by the Cardiology Consultant or Heart Failure Nurse and invited to participate. Interviews will be audio-recorded, transcribed verbatim and thematically analysed using a content analysis approach. The research team are experienced in exploratory work involving this patient population and their caregivers.

Phase 3: Objective 3

A Workshop will be convened and data from 1&2 will be presented to a group of key stakeholders including patients, family members and professionals to inform a discussion that will result in the development of a set of recommendations on family involvement in palliative decision-making.

Expected outcomes: Our society is changing, with an increasing elderly population and more advanced therapies. Understanding the role of the family in palliative discussions is required as more frequently family members are being asked to make critical end-of-life decisions for their loved one. Outcomes of this study has implications for current practice, education and policy

References:

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- 2: Lampert R, Hayes DL, et al. Management of Implanted Cardiac Rhythm Devices at End of Life. *Heart Rhythm* 2010; 7: 1008-1026
- 3: Lee MC, Sulmasy DP, et al. Decision-making of patients with implantable cardioverter-defibrillators at end-of-life. Family members experiences. *Am J Hosp Palliat Care* 2016; 34(6): 518-523
- 4: Hill L, Fitzsimons D, et al. patients and professional factors that impact the perceived likelihood and confidence of healthcare professionals to discuss implantable Cardioverter Defibrillators Deactivation in advanced heart failure. *JCN* 2018; 33(6): 527-535
- 5: Fluor C, Bolse K et al. Spouses' reflections on implantable cardioverter defibrillator treatment with focus on the future and the end-of-life: a qualitative content analysis. *J Adv Nurs* 2015 70 (8): 1758-1769