PhD Proposal
Overcoming negative perceptions around palliative care
Supervisors: Professor George Kernohan; Dr Wendy Cousins
Advisor: Dr. Joanne Jordan

Background
Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual (WHO, 2015). Given an aging global population and increasing numbers of people with long-term conditions, the growing need and value of palliative care has been confirmed (WHO, 2015). Despite this, international research continues to highlight a reluctance to engage with palliative care, whether this be as a patient (Aapro, 2012; Zimmerman, 2016) a clinician (Fibet, 2008) or a member of the public (McIlfatrick et al., 2014). This reluctance is of significant concern given the immense benefits to be attained from timely (referral to) palliative care (Adams et al., 2009; McAteer & Wellberry, 2013; Melvin & Oldham, 2009).

One area of palliative care that has the potential to contribute to positive awareness-raising amongst patients, practitioners and the public alike is palliative care day services (PCDS). This potential is premised on the specific aims and focus of PCDS, namely, to promote patient rehabilitation and quality of life. Moreover, PCDS can be seen to operate at the ‘interface’ of primary/community and in-patient care, allowing an introduction to palliative care in an environment in which the focus is explicitly on living (and not dying). PCDS has been defined as ‘a service that enhances the independence and quality of life of patients through rehabilitation, occupational therapy, physiotherapy, the management and monitoring of symptoms, and provision of psychosocial support’ (NCHSPCS, 2000). It can include a wide range of interventions, integrating physical care with that focused on psychosocial and spiritual wellbeing. As such, it is premised on a multi-disciplinary / professional approach (Kernohan et al., 2006). It has been routinely evaluated as well received and delivering significant benefits to patients and their carers (Stevens et al., 2011).

Aim
Building on an existing programme of research, we aim to explore positive awareness raising amongst patients, their professional carers and close family others, likely to promote engagement with palliative care.

Theoretical perspective
Hodges Health Career model will be used as a metacognitive theory to guide the PhD, with a more specific psychological theory, namely Terror Management Theory, to inform methodology.

Design and Methodology
The study will be conducted over three phases. Phase 1: the conduct of a systematic literature review and consultation with patients, their professional carers and close family others to identify the issues underpinning reluctance to access / engage with palliative care.
This will likely address more generalised ‘death denying’ cultural phenomena. **Phase 2:** using the findings from Phase 1, the design of a tailored intervention, focused on promoting positive awareness-raising of the aims, content and delivery of palliative care. The intervention will be tailored for 3 specific audiences: primary care clinicians who are well positioned to refer patients for care (e.g. GPs, District Nurses, MacMillan community nurses); individuals likely to benefit from palliative care but who have so far failed to access the services; and the close “family others” of these patients. **Phase 3:** a pilot of the intervention undertaken in one setting, with the aim of delivering preliminary findings on clinical (and cost) effectiveness, including barriers and facilitators. The latter evidence will be gathered through a process evaluation.

**Conclusion**

The proposed study will contribute to a limited evidence base concerning how to promote awareness of and engagement with palliative care, capable of helping to overcome ongoing problems associated with late or even complete lack of access by those who could most benefit from the services.

**References**


