

Dimbleby Marie Curie Cancer Care Research Fund - Project Grant

Project details

Professor Scott Murray, University of Edinburgh

A feasibility study of early identification, assessment and support for informal carers in primary care.

Duration of project: 24 months

Start date: October 2012 (TBC)

Budget: £122,000 (TBC)

Abstract

This project addresses the need to identify and better support informal carers of people with cancer and other conditions who are approaching the end of life. It proposes and tests a novel primary-care based intervention, supported by Voices of Carers Across Lothian (VOCAL), that will overcome the barriers to the prospective identification of carers who either may not be aware that the person they care for is approaching death, or may not identify themselves as carers. Systematic carer identification, assessment and targeted support will empower carers as the cared-for person's illness advances, and will in turn enhance the quality of care that the patient receives.

The objectives of this project are: 1) to develop and refine a preliminary model of carer identification, assessment, support and referral; and 2) To pilot and evaluate the intervention in four general practices. The project will be conducted in two stages reflecting the MRC new guidance on developing and evaluating complex interventions (MRC, 2008). During the design stage we will conduct two literature reviews; synthesize in-house studies of carer experiences; and conduct four focus groups. This will allow us to model the key outcomes and processes that will form part of our intervention and determine how it will be delivered. During the second stage our model will be piloted in four general practices. The intervention will involve: the identification of a carer co-ordinator in each practice; the development and operationalization of a set of strategies for systematically identifying informal carers (who are registered with the practice) of people approaching the end of their lives; the use of practice registers to identify both informal carers and patients who may be the recipients of informal care; the development of criteria to identify vulnerable carers and the mapping of referral pathways to local carer organizations. We will also test and refine patient-centered outcomes suitable for the subsequent study.

This intervention has the potential to greatly increase the number of informal carers that are identified, enhance the support they are offered and strengthen the links between GPs and local carer services. Having conducted and learned from this proposed feasibility study, we plan in future to conduct a large multi-centered trial to roll-out our model of carer identification, assessment, support and referral in a large number of Primary Care Teams and carer organizations UK-wide, so that such good practice can be made routine care in the UK.