

Marie Curie Research Grants Scheme

Dr Morag Farquhar, University of East Anglia

Accessing and delivering person-centred care in advanced non-cancer conditions: developing and piloting a Support Needs Approach for Patients (SNAP) with advanced COPD

Duration of project: 30 months

Start date: 1st March 2017

Budget: £165,042

Abstract

Background

Chronic Obstructive Pulmonary Disease (COPD) is a progressive respiratory condition with high symptom burden affecting substantial and growing numbers of people, at high cost to the NHS. When COPD is advanced patients can become housebound and the burden on informal carers considerable. There are known unmet care and support needs in advanced COPD, including palliative and end of life needs. Health service policy and good practice guidelines increasingly recommend person-centred care as a means of improving care and support for this patient group. Person-centred care advocates a collaborative approach between health care professionals (HCPs) and patients in which patients are enabled to identify and prioritise areas where they need support. Evidence highlights limited use of this approach in advanced COPD. Barriers to delivery include: unpredictability of the non-cancer trajectory, patient difficulties in articulating needs, and organisational and medical agendas that drive service contacts limiting consideration of patient-identified need. We require interventions (evidence-based tools and approaches) to overcome these barriers: interventions to determine supportive and palliative care needs, in order to initiate and deliver person-centred care and support to patients with non-cancer diseases.

The Support Needs Approach for Patients (SNAP) is an intervention that addresses this gap by enabling person-centred care through an evidence-based tool for identifying and communicating patient support needs. The rationale for this approach is based on the evidence-based Carer Support Needs Assessment Tool (CSNAT) Approach, designed to enable person-centred care for carers of patients at the end of life, increasingly used in a clinical practice nationally and internationally. Modelled on CSNAT, a tool to identify patient support needs has been developed for SNAP, grounded in data from patients with advanced disease (SNAP1 Study). The tool now requires validation and the approach requires exploration of its feasibility/acceptability (SNAP2 Study). Developed in collaboration with key stakeholders, and informed by both Normalisation Process Theory and the MRC framework for complex interventions, the SNAP tool could enable proactive identification of support needs, facilitating conversations between patients and HCPs, potentially ameliorating crises, with positive impacts on palliative care outcomes and service costs.

The SNAP intervention consists of:

- 1) the SNAP tool – designed for purpose, comprising a set of evidence-based questions for patients to help them consider areas where they need more support, rather than HCP-identified concerns
- 2) the SNAP approach – a needs-led conversation between the patient and HCP to express, prioritise and address unmet support needs identified through the patient-completed tool.

Aim

To enable person-centred care in patients with advanced COPD by developing and exploring the feasibility and acceptability of a new intervention: the Support Needs Approach for Patients (SNAP).

Research Questions (RQs)

- RQ1) Is the evidence-based support needs tool, integral to the Support Needs Approach for Patients (SNAP), valid for patients with advanced COPD?
- RQ2) What are the barriers and facilitators to adopting and delivering SNAP in primary, community, and secondary care?
- RQ3) What should a SNAP training and support package for health care professionals look like?
- RQ4) What should a protocol for the formal evaluation of SNAP look like?

Methods

An MRC Phase I three-stage sequential mixed-method study to address the four research questions.

Stage 1 (RQ1): SNAP Tool Validation

- Task 1.1: Initial validation – focus groups with patients with advanced COPD
- Task 1.2: Main validation – postal survey of 200 patients with advanced COPD

Stage 2 (RQ2-RQ3): SNAP Feasibility Study (pilot in three clinical settings: primary, community and secondary care)

- Task 2.1: Development of SNAP Training and Support Package
- Task 2.2: Introductory and training workshops in each pilot clinical setting
- Task 2.3: Four-month feasibility work in each pilot clinical setting
- Task 2.4: Interviews with patients who experienced SNAP in each pilot clinical setting
- Task 2.5: Focus groups with HCPs who delivered SNAP in each pilot clinical setting
- Task 2.6: Refinement of SNAP Training and Support Package

Stage 3 (RQ4): Protocol development for future formal evaluation of SNAP

- Task 3.1: Identification of relevant outcomes
- Task 3.2: Development of experimental design

Proposed findings

This study will deliver four key outputs:

- developed and defined intervention: the Support Needs Approach for Patients (SNAP)
- including validated SNAP tool, integral to the intervention
- SNAP training and support package
- study protocol to formally evaluate SNAP