

Optimising palliative care for older people in community settings: development and evaluation of a new short term collaborative service

Abstract in plain English

This study aims to work with an NHS community trust to develop and evaluate a new short-term palliative care service for frail older people with or without dementia in community settings (including care homes without nursing). The service is delivered through close working between specialist palliative care teams and the community services like district nurses and general practitioners. People are increasingly living to advanced ages and dying with frailty and, for many, dementia. Palliative care is advocated for older people to improve their quality of life, but with little understanding on how to achieve this.

A short-term palliative care service may benefit older people by palliative care services working with community services to provide additional shared support for older people with frailty that experience, for example, distressing symptoms. The study uses two phases. Phase 1 develops the intervention of short-term palliative care using: a postal survey to bereaved relatives of people aged over 75 years to determine preferences for care and personal goals; and then, asking recipients and providers of care about the findings from the survey and the best ways to develop the new palliative care service for frail older people. Phase 2 examines if it is feasible to provide the new service in practice and if it benefits patients. This involves 50 frail older people with deteriorating wellbeing, and their carers, assigned to receive the short-term palliative care service or usual care. The new service is delivered by two specialist community palliative care teams working with four community nursing teams. We will see how well the new service compares with usual care in improving participants' quality of life, reduces carers' burden and differences in cost. The findings will tell us if this new service is likely to benefit patients and their families and how we should carry out a larger study to see if this was the best way to deliver palliative care to frail older people in the community.

Scientific abstract

Background: This study intends to work with NHS staff in a community trust to develop and evaluate a new short-term collaborative palliative care service for frail older people with or without dementia in community settings (including care homes without nursing). People are increasingly living to advanced ages and dying with frailty and, for many, dementia. Palliative care is advocated for older people to improve the quality of life, but with little evidence of effectiveness. Short-term palliative care maybe cost effective and appropriate because it relies on existing community services, but with additional shared support from palliative care services at points of, for example, deterioration.

Aim: To develop and evaluate the feasibility of a new short-term palliative care service for frail older people in community settings (including care homes) delivered through collaborative working between specialist palliative care services and generalist community nursing teams.

Methods: The research methods follow the Medical Research Council guidance for the development and evaluation of complex interventions. This includes: Phase 1 intervention development using a post-bereavement survey to determine preferences for care and palliative care outcomes by place of death for frail older people; a stakeholder consultation on the survey findings, and the emergent intervention using the Nominal Group technique to develop the intervention identifying areas of consensus and divergence; and then, an on-line survey on the intervention components, delivery process and intended outcomes. Phase 2 will field test the feasibility of the intervention and the evaluation procedures to develop the methodology for a full randomised controlled trial (RCT) and modify the intervention. Outcomes are patients' symptom related quality of life (Palliative Outcome Scale POS-8), pain (a single item POS pain scale), carer burden (Zarit Carer Burden Inventory), and informal and formal service use to inform a model of economic evaluation (Client Service Report Inventory).