

Care at the end of life: experience and support needs of older family caregivers of people with advanced cancer

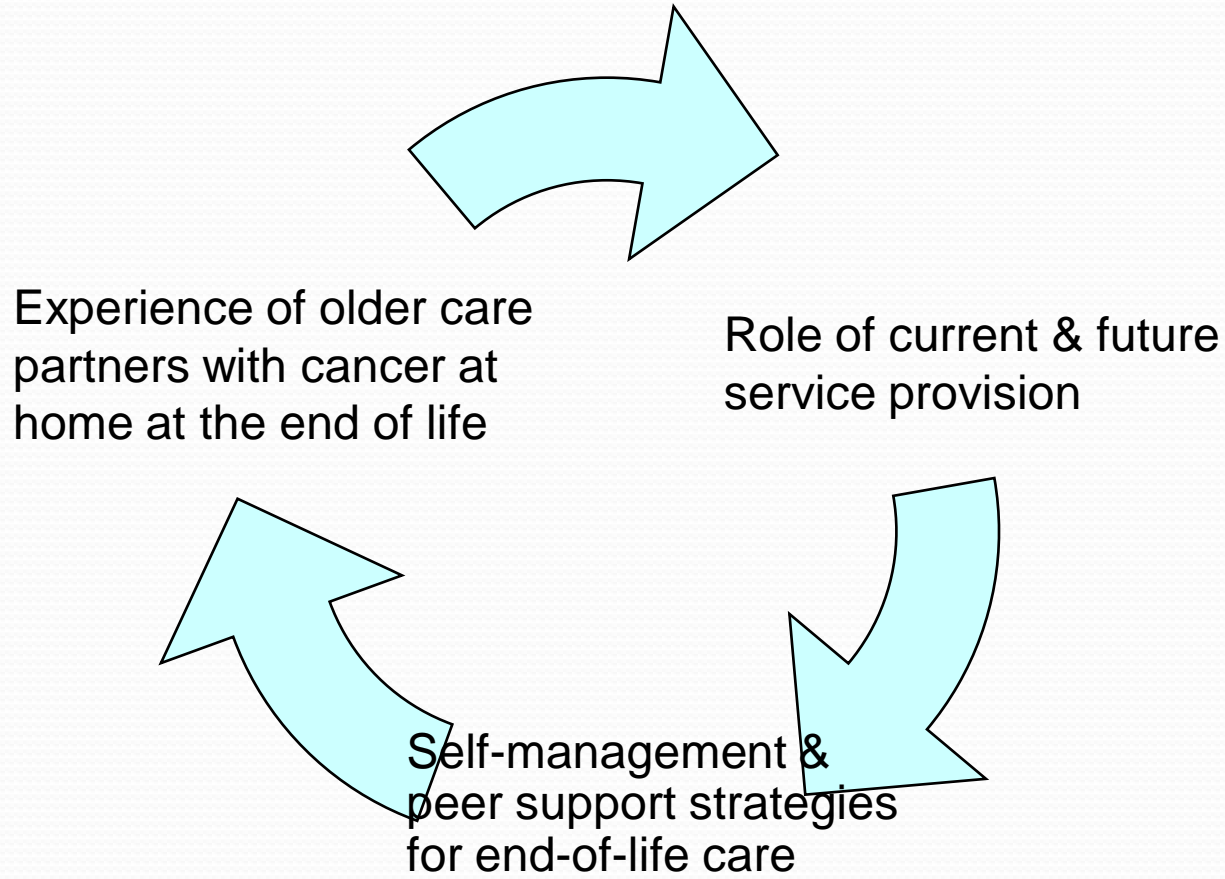


Cancer Experiences Research Collaborative/
Dimbleby Cancer Care Research Fund

Research team

- Christopher Bailey, Julia Addington-Hall, Jessica Corner, Susan Duke, Ali O'Callaghan (School of Nursing & Midwifery, University of Southampton)
- Michael Moore, Geraldine Leydon (Primary Medical Care, University of Southampton)
- Carol Davis (Southampton University Hospitals Trust)
- Roger Wilson (National Cancer Research Institute Consumer Liaison Panel)
- Jane Seymour (School of Nursing, University of Nottingham)
- Caroline Sanders (National Primary Care Research and Development Centre, University of Manchester)

Care at the end of life: experience and support needs of older family caregivers



Care of older adults research theme

- Key objectives:
 - To identify older adults' priorities in end of life care
 - To examine older adults' and informal carers' preferences for involvement in care decision-making
 - To understand older adults' preferences for place of care and develop interventions to improve opportunities to be cared for in a place of their choice at the end of life
 - To explore how older adults may be involved in the design of interventions related to preferred places of care and death

Background

- Cancer & ageing:
 - Cancer risk increases with age
 - Ageing of population a determinant of future need
- Until four weeks before death, people who do/don't die at home spend on average 1.5 days per week or less in inpatient care
- Policy (or preference) encourages management of patients in community settings
- Limited evidence about complex needs of older people affected by cancer
- Importance of lay knowledge in managing health care need
- Little information about the nature of older people's 'caring partnerships' towards the end of life
- Little evidence to show what self-initiated strategies are (or could be) used, e.g.
 - peer education, web-based support

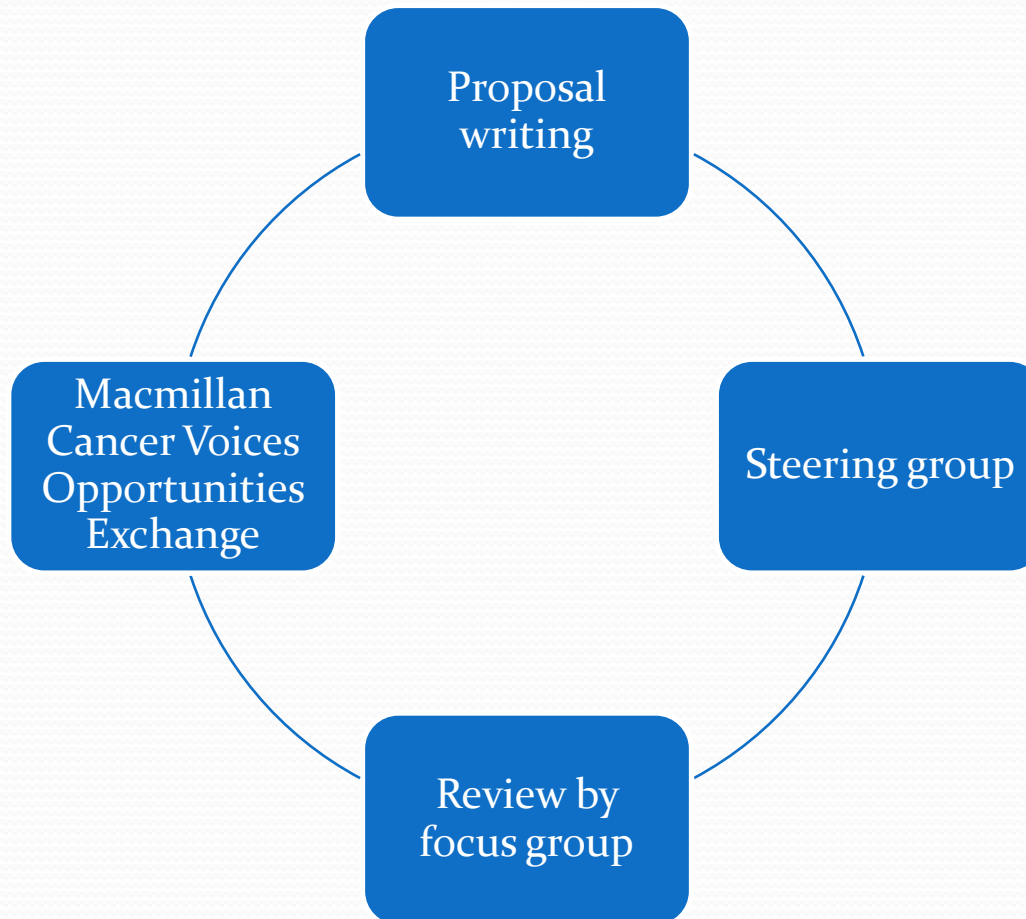
Aims

- Describe the experience and support needs of older family members caring for an older partner or relative with advanced cancer at home
- Evaluate the role of current service provision in supporting family members providing end-of-life care
- Assess the feasibility of working with family caregivers to develop self-management and/or peer support strategies for end-of-life care

Methods

- Design
 - 2-year longitudinal study with qualitative interviews, observation, structured measure of service use
- Participants
 - 30 'care partnerships' (≥ 65 years)
 - patients nominate caregiver
 - community palliative care services
 - GP practices
- Data collection
 - *Interviews*. Semi-structured, both 'care partners', min. 2 in first 28 days, min. 3 in total
 - e.g. met & unmet need, caregiving expertise, self-management strategies
 - *Observation*. One participant nominated care-related activity
 - *Structured measure*. Self-report data on service use before and between interviews.
- Data analysis
 - constant comparative method
 - explanatory model of care partnerships

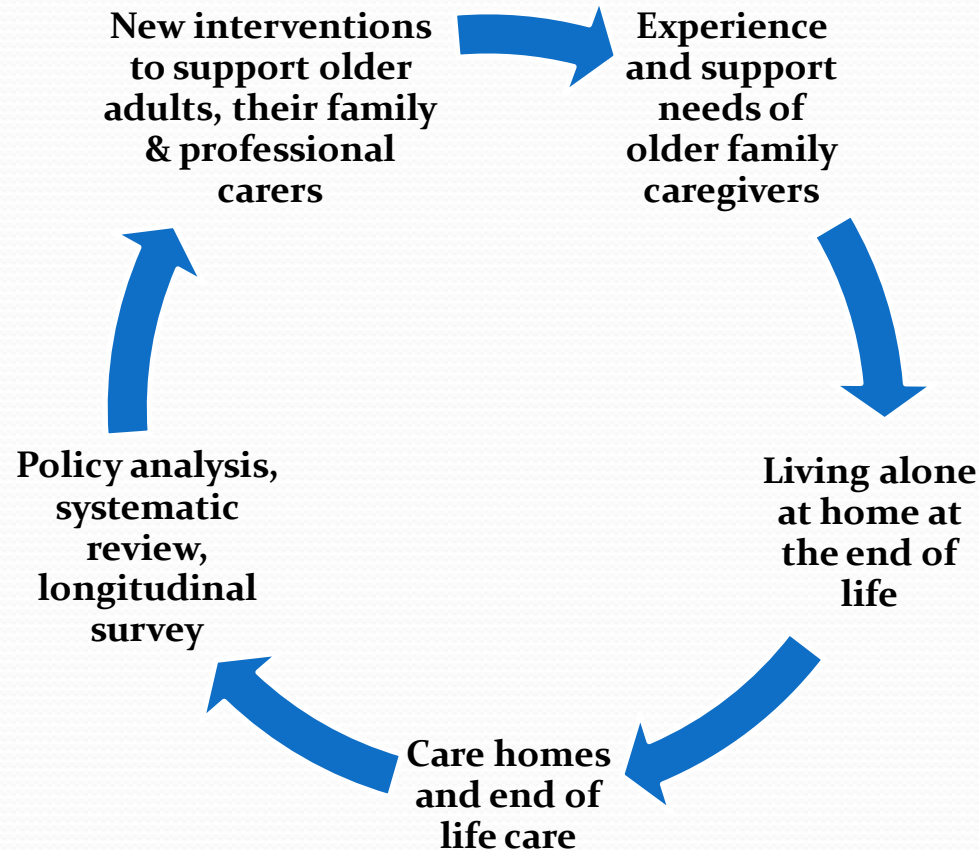
Research partners



Outcomes

- Understanding of
 - need
 - expertise
 - scope of (and for) self-management
 - support for older care partnerships at the end of life
- Recommendations for service development
- Framework for future intervention studies to support involvement of older caregivers in active management of a relative's condition and needs

Older adults research theme: programmes of work



Care at the end of life: experience and support needs of older family caregivers of people with advanced cancer



Cancer Experiences Research Collaborative/
Dimbleby Cancer Care Research Fund