

Marie Curie Research Grants Scheme

Professor Richard Harding, King's College London
Professor Fliss Murtagh, Hull York Medical School

Understanding and improving community-based palliative care outside of normal working hours.

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Research abstract

Background

Most people prefer care at home. However, provision of community specialist palliative care (SPC) outside of normal working hours ('out-of-hours') in the UK is highly variable. Service components differ markedly and discontinuity of care is common.

Without adequate 'out-of-hours' support, patients are at risk of being 'crisis-managed' with emergency department (ED) attendances and unplanned admissions. Two-thirds of ED attendances are 'out-of-hours', SPC patients commonly attend ED for; pain, breathlessness, vomiting, and weakness, with > 50% resulting in unplanned admissions. Frequent ED visits indicates poor end-of-life care, are associated with increased patient/family distress and dissatisfaction, and worse bereavement outcomes. 'Out-of-hours' care is the top research priority from the James Lind Alliance, yet it has not been addressed.

A literature review found that models of SPC are not defined. We developed criteria to describe/compare models of SPC, but this needs further development for 'out-of-hours' provision, which is complex and combines specialist and generalist community services. The lack of a consistent method to delineate models of 'out-of-hours' care is leading to; poor quality evaluations of services, uncertainty over effectiveness/cost-effectiveness, and inability to advance the state of the science.

This sequential three phase mixed-methods study aims to characterise different models of 'out-of-hours' community-based SPC, develop a typology for models, and compare the experiences of patients/families receiving differing models of 'out-of-hours' care.

Methods

Phase 1: Systematic literature review

Aim: To systematically review evidence on effectiveness and cost-effectiveness of models of 'out-of-hours' community SPC.

Objectives:

- 1a. To describe the reported components of out-of-hours community SPC including which components are most effective
- 1b. To determine their clinical effectiveness in terms of patient & family-reported outcomes,
- 1c. To determine cost-effectiveness
- 1d. To identify gaps in the evidence

Methods: Systematic review of quantitative and qualitative studies from electronic databases and grey literature. Data will be reported using description, narrative synthesis and where appropriate meta-analysis following PRISM guidelines.

Output/impact Phase 1: Publication, policy brief, evidence of criteria/components to inform Phase 2

Phase 2: Characterising models

Our criteria to define models of palliative care, do not extend to variations in generalist/primary provision which influence how models of 'out-of-hours' community SPC operate. Therefore, we will:

Aim: To characterise existing UK 'out-of-hours' community-based SPC models and generate a typology of models.

Design: A multicentre, sequential mixed methods study (focus groups, Delphi study, and structured interviews)

Methods:

- 2a. Conduct two focus groups with patients/families and two with SPC professionals to determine components required for effective and integrated 'out-of-hours' care.
- 2b. Undertake a Delphi study to refine and rank components according to their importance for delivery of effective 'out-of-hours' care.
- 2c. Apply our existing SPC model criteria and the newly developed components using structured interviews with 15-20 sites to understand what components are provided by generalist/primary services, by SPC, by both, or not at all, to produce a typology of community-based 'out-of-hours' care and classify models of SPC.

Output/impact Phase 2: Publication of typology of 'out-of-hours' palliative care, including ranked importance of components to inform Phase 3.

Phase 3: Patient experience

Aim: To explore and contrast patients' and families' experiences of different models of 'out-of-hours' community-based palliative care, and elucidate drivers of service utilisation (ED attendances and unplanned admissions) and preferred place of care

Design: A multicentre qualitative study with patients/family purposively sampled from three SPC services with differing models of 'out of hours' care (using Phase 2 definitions).

Methods: Patient and family dyads will be purposively sampled (age, gender and cancer/non-cancer, Phase of Illness) to allow for case-mix variations. Interviews will begin asking patients about their service utilisation. This will guide the interviews to explore patient/family experiences of 'out-of-hours' care and the effects on preferred and actual place of care. We will interview patients and family dyads from each model of care until data saturation (anticipating ~20 dyads for each model).

Output/impact Phase 3: Publication on patients'/families' experience from different models of 'out-of-hours' community-based care, and policy brief.

Proposed Findings

This study will deliver a systematic review, typologies and experiences of care, moving forward the state of science providing essential evidence for health policy decision-makers to make informed decisions on service provision. This will move the state of science to readiness for robust experimental comparative designs.