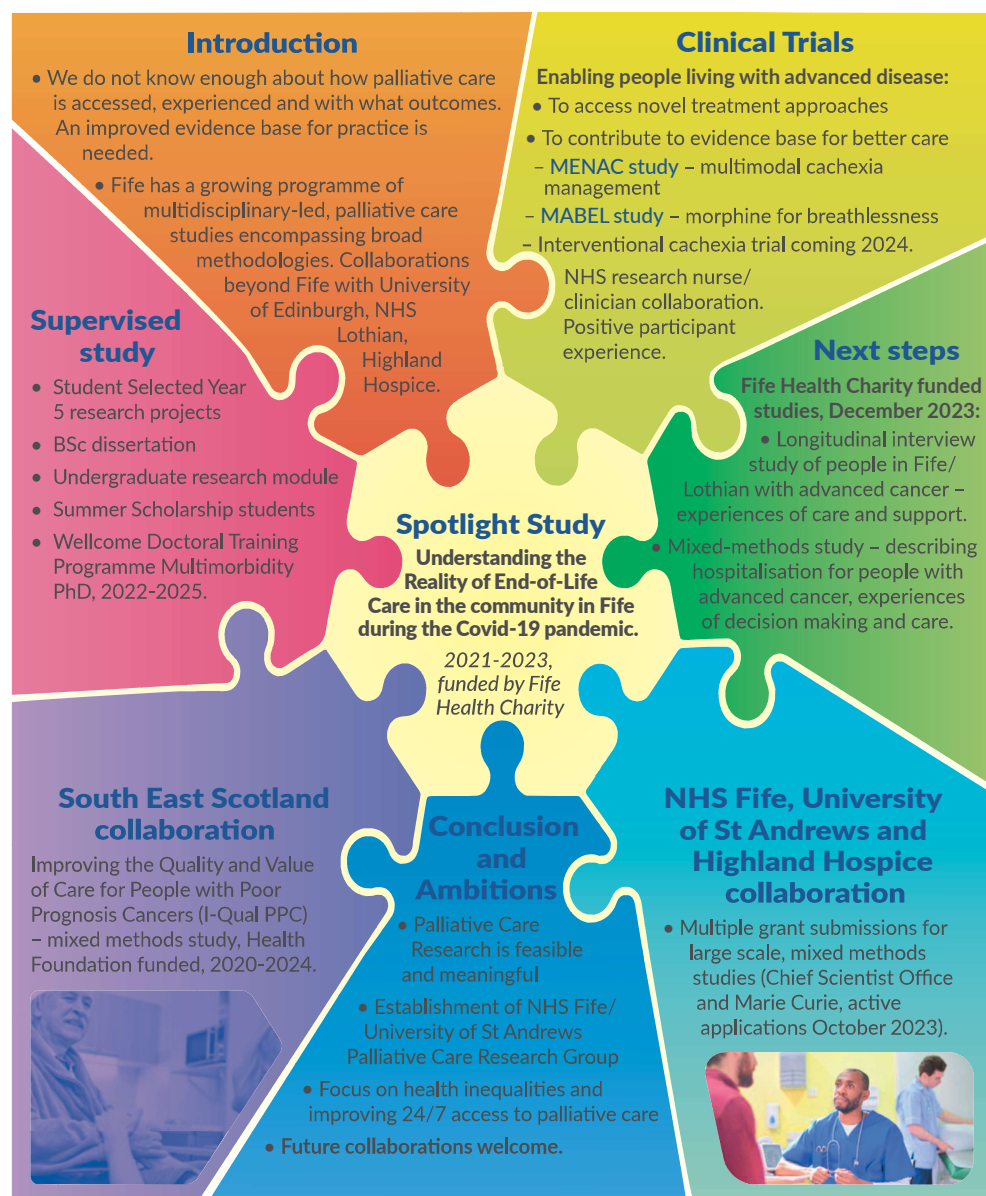


Palliative Care Research in Fife: Developing an evidence base for improved policy, practice and care through collaboration and action

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Spotlight Study

Understanding the Reality of End-of-Life Care in the community in Fife during the Covid-19 pandemic.

2021-2023, funded by Fife Health Charity.

Background:

More people across UK have been receiving home-based end-of life care since Covid-19 pandemic. We do not understand enough about the experiences of people receiving care, and of their unpaid caregivers.

Objectives:

- To describe trends in place of care and death in Fife
- To describe scope/limitations of research examining lived experiences
- To explore lived experiences of dying people in home settings in Fife and their unpaid caregivers in Fife.

Methods:

- Public Health Scotland LIST analyst data linkage
- Scoping review of experiences of UK home-based end of life care
- Prospective, in-depth interview study with people dying at home and their unpaid caregivers, and bereaved family caregivers. June 2021-November 2022.

Key findings:

- Around 40% more people are being cared for at home in Fife over their last weeks and months of life
- Limited existing research around experience, only one dying person interviewed between 13 studies. Inadequately described populations, cancer over-represented
- 20 Fife families interviewed: 27 individuals including 7 patients, 11 caregivers in bereavement.
 - Heavy burden, uncertainty, and emotional overwhelm of caring.
 - Need for negotiation with array of professionals
 - Carers managed anticipatory grief alongside their overwhelming fatigue, narrowing of everyday life and witnessing suffering.
 - Patients engaged in emotional labour to minimise their demands upon their caring relative.
 - Communication was central. Carers deeply valued the respect and tenderness shown by formal carers.
 - Consistent, predictable and 'joined up' services were key – 'One singer, one hymn sheet' (bereaved family caregiver)
 - The impact of Covid-19 included the lack of face-to-face visits, fear of infection, restricted family time, depriving patients and caregivers of much needed support.
- Feedback event for bereaved caregiver participants November 2023
- Co-design with public to generate recommendations, early 2024 – 'deliberative discussion' methodology.