Palliative Care Research in Fife:

Developing an evidence base for improved policy, practice and care through collaboration and action

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Introduction

- We do not know enough about how palliative care is accessed, experienced and with what outcomes. An improved evidence base for practice is needed.
 - Fife has a growing programme of multidisciplinary-led, palliative care studies encompassing broad methodologies. Collaborations beyond Fife with University of Edinburgh, NHS

Supervised study

- Student Selected Year
 5 research projects
- BSc dissertation
- Undergraduate research module
- Summer Scholarship students
- Wellcome Doctoral Training Programme Multimorbidity PhD, 2022-2025.

Clinical Trials

Enabling people living with advanced disease:

- To access novel treatment approaches
- To contribute to evidence base for better care
- MENAC study multimodal cachexia management
- MABEL study morphine for breathlessness
- Interventional cachexia trial coming 2024.

NHS research nurse/ clinician collaboration. Positive participant experience.

Next steps

Fife Health Charity funded studies, December 2023:

 Longitudinal interview study of people in Fife/ Lothian with advanced cancer – experiences of care and support.

Mixed-methods study – describing hospitalisation for people with advanced cancer, experiences of decision making and care.

Spotlight Study

Highland

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

South East Scotland collaboration

Improving the Quality and Value of Care for People with Poor Prognosis Cancers (I-Qual PPC) – mixed methods study, Health Foundation funded, 2020-2024.



Conclusion and Ambitions

- Palliative Care Research is feasible and meaningful
- Establishment of NHS Fife/ University of St Andrews
 Palliative Care Research Group
- Focus on health inequalities and improving 24/7 access to palliative care
- Future collaborations welcome.

NHS Fife, University of St Andrews and Highland Hospice collaboration

 Multiple grant submissions for large scale, mixed methods studies (Chief Scientist Office and Marie Curie, active applications October 2023).



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 endof life care since Covid-19 pandemic. We do not understand enough about the experiences of people receiving care, and of their uppaid caregivers.

Objectives:

- 1. To describe trends in place of care and death in Fife
- 2. To describe scope/limitations of research examining lived experiences
- 3. 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.









