

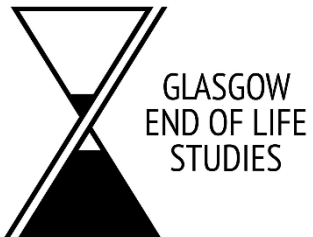


University
of Glasgow

Unreached: An interview study to capture experiences of financial insecurity at the end of life in the UK

Presenter: Dr Sam Quinn

Project Team: Dr Naomi Richards, Prof Lynn Calman, Dr Michelle Myall, Dr Jo Williams, Prof Mari Lloyd-Williams, Dr Caroline Mogan



University of
Southampton



LIVERPOOL
JOHN MOORES
UNIVERSITY



FUNDED BY
**Marie
Curie**



Introduction

- Over 90,000 people in the UK die in poverty annually, yet little attention is given to their lived experiences.
- The *Dying in the Margins* visual study revealed the hidden costs faced by people at the end of life in urban areas.
- The UK-wide 'Unreached' study aims to understand how financial insecurity affects access to care and support for people living with serious advanced illnesses.
- This presentation will focus on individuals residing in rural, coastal, and island communities in Scotland.



Photograph: Margaret Mitchell (all rights reserved).

Dying in the Margins Findings Paper:





Current evidence

- Financial hardship contributes to disparities in end-of-life care in rural areas, where patients are less likely to receive hospice services and more likely to have ICU admissions (Hutchinson et al., 2021).
- Rural patients and caregivers face financial burdens and limited access to information, resulting in challenges in receiving adequate end-of-life care; informational needs and the cost of commuting for treatment are significant issues in rural settings (Rainsford et al., 2017).
- Rural patients are less likely to die in inpatient hospice units compared to people living in urban areas (del Rosario et al., 2019).



Methods

- Ongoing qualitative study involving in-depth semi-structured interviews with participants (target n=20).
- Participants include individuals with serious advanced illnesses and their carers (including bereaved carers), recruited through national support services, third-sector organisations, and social media across Scotland.
- A thematic approach is being employed to analyse data on financial and practical challenges, highlighting community assets and sources of local support.



Sample

Characteristic	Detail
Key Location(s)	Scottish Islands (n=5), Central belt (n=2), West coast (n=1)
Gender	Female (n=5), Male (n=3)
Roles	3 carers – Spouse (n=2), Sibling (n=1) and 5 people living with advanced illness
Ethnicity	All self-identified as “White Scottish”
Age Range	49-78 (mean: 61.3)
Conditions	Dementia as a result of traumatic brain injury, stage 3 diabetes mellitus, late-stage multiple sclerosis (MS), prostate cancer, ovarian cancer, pancreatic cancer, and pulmonary fibrosis.
Interview Format	Videoconferencing (n=4), Telephone (n=4)



Preliminary results 1

Housing Repairs and Adaptations:

Expenses for home repairs and adaptations presented significant financial hurdles for some participants.

“She couldn't have used that fire because she couldn't afford to repair the chimney and get the debris cleared out.”

— Participant 4's Link Worker

Community and Charitable Support:

Strong community ties emerged as a vital support system. Neighbours, local charities, and families provided financial aid and practical assistance, highlighting the importance of these community networks.

“I go there on every second Wednesday, the Ladies' Cancer Group, but so far, I haven't met anybody who's got the same as me. But it's good even just to talk to them and find out different things.”

— Participant 5



Preliminary results 2

High Energy Costs:

Participants reported significant heating expenses due to poorly insulated homes and reliance on coal and oil central heating.

“We don't have mains gas up here. Our electricity tariff is severe, so before you factor it in the wind chill factor and coal.”

— Participant 5

Transportation:

Limited public transport options forced some participants to rely on expensive taxis. Local charities and the Motability scheme were seen as valuable tools in mitigating this.

“[Brother]'s got a mobility car, which thankfully we got a grant for, which we're really pleased with. He can get out and about in that. But that's 65 quid to fill up every so often.”

— Participant 3



Conclusion

- Preliminary findings highlight the financial and practical challenges faced by people with serious advanced illnesses in rural Scotland, emphasising their reliance on community support.
- Mutual aid and local assets are strengths that are often under-recognised, indicating a need for community-based and public health approaches that integrate informal support mechanisms.
- Engaging with key stakeholders to co-develop recommendations will culminate in published guidance and a policy brief to better support those experiencing financial insecurity at the end of life.



University
of Glasgow

Thank you for listening.

We are still recruiting so please get in touch!

Email: Sam.Quinn@Glasgow.ac.uk

Tel: 07484 006217

Poster location: 32

References

Hutchinson, R.N., Han, P.K.J., Lucas, F.L., Black, A., Sawyer, D., & Fairfield, K. (2021). Rural disparities in end-of-life care for patients with heart failure: Are they due to geography or socioeconomic disparity? *The Journal of Rural Health*, 37(1), 254–264.

Rainsford, S., MacLeod, R.D., Glasgow, N.J., Phillips, C.B., Wiles, R.B., & Wilson, D.M. (2017). Rural end-of-life care from the experiences and perspectives of patients and family caregivers: A systematic literature review. *Palliative Medicine*, 31(10), 895–912.

del Rosario, C., Kutney-Lee, A., Sochalski, J., & Ersek, M. (2019). Does quality of end-of-life care differ by urban-rural location? A comparison of processes and family evaluations of care in the VA. *The Journal of Rural Health*, 35(4), 528–539.

#UofGWorldChangers



@UofGlasgow