

Unreached: The Impact of Financial Insecurity on People at the End of Life - Rural and Island Communities in Scotland

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Background/Aims

Every year, over 90,000 people in the UK die in poverty. Despite this, little attention has been given to the lived experiences of individuals with serious advanced illnesses and their families who face financial insecurity at the end of life. The aim of the study is to understand how poverty and financial hardship affect access to care and support for people living with serious advanced illnesses.

This poster presents findings from the Scottish sites of the 'Unreached' study, focusing on the experiences of people residing in rural, coastal, and island communities.

Methods

This ongoing qualitative study involves in-depth semi-structured interviews with participants (target n=20) recruited through national support services, third-sector organisations, and social media across Scotland. Participants include individuals living with serious advanced illnesses and their carers, including bereaved carers. The interview guide explores their lived experiences, focusing on financial and practical challenges while also highlighting community assets and sources of local support.

A thematic approach has been employed to analyse the data and identify the main themes.



Preliminary Results

Analysis of the seven interviews conducted so far in Scotland revealed several key themes:

1. High Energy Costs

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

"Our energy bills are always high up in the Highlands because we have oil central heating, and the house is always at 22°C, summer and winter."

— Participant 2

2. Transportation Challenges

Limited public transport options in rural areas forced some participants to rely on taxis, increasing costs for medical appointments and daily needs. Some local charities offered assistance, but accessibility varied.

"The local charity and their fundraising, they will pay for a taxi if you need one to get you home from a hospital or another medical appointment."

— Participant 5

3. Housing Repairs and Adaptations

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

"Parts of the chimney fell in, and that was the open fire that Janet used to heat her bedroom. 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

4. Debt and Financial Reliance on Family

Some participants found themselves borrowing money from family members or entering arrears with energy companies, adding emotional stress to financial hardship.

"I've borrowed a couple of thousand pounds in various chunks off my ex-wife to help me pay for bills and shopping."

— Participant 1

5. Community and Charitable Support

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

6. Insufficient Government Support

While government benefits and charitable grants offered some relief, participants felt that income support was inadequate to meet their needs.

Conclusion

These preliminary findings shed light on the financial and practical challenges faced by people with serious advanced illnesses living in rural Scotland. The reliance on community support underscores the strengths of mutual aid and local assets, which can be under-recognised by health and social care professionals. There is a critical need for community-based and public health approaches that acknowledge and integrate these informal support mechanisms. By understanding how, when, and where these resources are accessed, we can develop more effective strategies to support those experiencing financial insecurity at the end of life. We will engage with key stakeholders to co-develop recommendations for professionals, patients, carers, and the public, culminating in published guidance and a policy brief.

Note: Recruitment is ongoing across Scotland, with additional study sites in England, including Southampton (led by the University of Southampton) and North-West England and North Wales (led by Liverpool John Moores University).

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