



Energy Hardship for People with Palliative Care Needs at Home: Understanding Issues and Promoting Actions

Executive Summary

Image Credits

Senior Man Wearing Extra Clothes With Hot Drink Trying To Keep Warm At Home In Energy Crisis
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Acknowledgements

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Finally, we wish to acknowledge all of the participants: palliative care patients, family carers, palliative home care and night nurses, and staff from the energy supply companies, without whose participation, the study could not have been undertaken. Thank you all very much.

Background

People with palliative care needs and their carers may be more likely to be unable to afford to heat their homes adequately, for example if their income from work is reduced following a diagnosis. Energy usage (and therefore costs) may also increase if they and their carers are spending more time in the home. They are also often more vulnerable to the cold because of their treatment and condition. Living in a cold home adversely impacts their physical health and mental well-being at a time of crisis in their lives.

In this report, the term 'energy hardship' is used to broadly define when households cannot afford energy use or access energy services. The three major causes of energy hardship are poor energy efficiency of housing and household appliances, low household income, and high energy prices. While measures are in place in Ireland to address these causes (for example home retrofitting schemes, energy company policies for vulnerable customers, and means-tested financial supports), for a range of reasons these measures may not be accessible to all who need them. There is limited awareness and understanding of the specific increased energy needs of those in need of palliative care; how energy companies, energy regulators or government policy makers can support this vulnerable group; and what role health and social care professionals can play.

About the research

This study was funded under the Irish Cancer Society Palliative Care Call 2022 (PCA22DEN) and was undertaken between March and December 2023 by a team of researchers led by Dr Suzanne Denieffe, South East Technological University.

Study Aim: To examine and address the evidence gap in energy hardship for people receiving palliative care at home, and make informed recommendations to key decision-makers who may address this issue. People with a life-limiting cancer diagnosis were a group of particular interest within this wider population.

Study Design: This study used a mixed methods design consisting of a scoping review of energy hardship literature; an online survey with palliative home care nurses; individual interviews/questionnaires with the Irish energy providers / regulator; and individual or group interviews with people receiving palliative home care or family carers of someone who is received or receiving palliative home care.

Findings

Scoping review of energy hardship literature

A scoping review using Arksey and O'Malley's (2005) framework identified that literature on energy poverty and palliative care is scarce. Only three documents were found that presented a direct connection with the topic. The literature in the scoping review on impacts of energy hardship on health indicates that living in energy hardship may cause significant impacts on the physical and mental health and wellbeing of individuals, contributing to respiratory illnesses, such as asthma, and circulatory diseases. anxiety and depression, as well as increased morbidity rates and mortality risk.

Night Nurse and Palliative Home Care Survey Results

- Sixty-one night nurses and palliative homecare nurses working across 25 counties participated in the survey.
- Only 13% of nurses reported that the homes where they provided support were 'always' adequately warm.
- One third of nurses had experienced a case where they felt the person they were caring for had to go without heating.
- Almost a third (31%) of nurses reported that a person they had cared for, or their family, had initiated a conversation about energy hardship.
- Housing issues identified by the nurses included draughts, condensation, damp and mould.
- Half of the nurses (49%) believed someone they had cared for was struggling to make ends meet financially, while 44% responded 'I do not know'.
- Stories or experiences related by nurses referred to people staying in bed to keep warm, or in one heated room; the impact of financial worries; and supports from wider family / community, charities and social workers.

Energy Providers and Regulator Results

- Seven energy providers participated using the questionnaire and two staff from the regulator, the Commission for the Regulation of Utilities (CRU) were interviewed.
- Under its legal mandate, the regulator is responsible for implementing energy-specific customer protection measures.
- Protective measures include registers of vulnerable customers to ensure disconnections are minimised, and reconnections prioritised.
- Customers need to self-register as vulnerable. Participants from the regulator and several energy providers reported that not all vulnerable customers are registering. A suggested reason for this among older adults was lower levels of digital literacy with a reluctance or an inability to engage with online services such as registrations.
- All suppliers interviewed confirmed that their customer service teams receive training on how to deal with customers who are experiencing financial difficulties, supports for customers registered as vulnerable, and sign-posting customers to other relevant supports such as Money Advisory Budgeting Services (MABS).
- Some companies had voluntarily instigated a hardship fund since 2022 due to the cost-of-living crisis, which they operated in conjunction with MABS or identified charities.

- Additional measures introduced in 2022 included a winter period moratorium against disconnection; extended debt repayments; a requirement for customers with a financial hardship to be placed on the cheapest tariff available from their supplier; and enhanced requirements on suppliers to actively promote the vulnerable customer register and the protections it offers.

Patient and Family Carer Results

- Five people receiving palliative home care and three family carers took part in interviews.
- All participants agreed that energy hardship was an issue for people receiving palliative care at home. The mental and physical impacts of this could be substantial.

'I think people need to know what it is like when you are really stressed trying to pay bills and trying to cope and care for your relative at home. I was really stressed in the months before [relative] died - I ended up not sleeping and had to get sleeping tablets from my GP. A lot of this stress was financial'.

(P8, family carer)

- Participants said that due to illness, treatment, or their caring role, they were at home more than previously and felt the cold more. All participants spoke of the need to keep the house warm, including heating bedrooms during the day as they were in use for rest. All spoke of the increased cost of heating their homes, regardless of the fuel used.

'I am confined to the house for 8 hours a day due to PEG feeding, I need to have an electric heater on in the room in which the PEG is going'.

(P5, person receiving palliative care)

- Several of the participants mentioned the energy efficiency of their housing, and said they were living in old, poorly insulated houses. The cost of upgrades was mentioned as a barrier to changing this.
- There was low awareness of, or uptake of various existing energy hardship interventions:
 - Only one participant had changed supplier in the past five years
 Other participants perceived a range of barriers:

'It can be hard to understand contracts and compare terms'

(P1, person receiving palliative care);

'I am not comfortable doing this administration in the digital format'.

(P4, person receiving palliative care);

'No, as it seems like too much bother'

(P8, family carer).

- One participant had contacted an energy supplier to set up a payment plan as they went into financial arrears, saying they found them helpful. There was however stigma associated with this:

'[relative] would have hated anyone knowing we were struggling.... I ended up not even telling [relative] the full story of what we owed - I didn't want to upset them. I am still in that payment plan'. (P8, family carer)

- There was low awareness of the possibility of registering as vulnerable customer on medical grounds, or that energy companies could direct customers towards Money Advice and Budgeting Services or charities.
- The winter energy credit scheme was widely welcomed. There was a desire for future supports to consider health-based needs alongside any means-testing applied.

Conclusion

This study, which was the first of its kind in the Republic of Ireland, aimed to address the lack of evidence on energy hardship for people who receive palliative care at home, including those with life-limiting cancer diagnoses. Although there is little empirical evidence specific to energy hardship in the palliative care context, existing literature on the impacts of energy hardship on physical and mental health strongly highlights the challenges that individuals face in such situations.

Our primary research found that energy hardship was recognised – by nurses, family carers, and those receiving care - as an issue where people receiving palliative care at home have specific needs and potential vulnerabilities, due to a range of interlinked factors. While interventions are in place in Ireland to address causes of energy hardship, evidence from all participant groups demonstrated that these were not accessible to all those who needed them. Qualitative data from people receiving palliative care, family carers, night nurses and palliative home care nurses powerfully illustrated the negative impacts of energy hardship on the lives of both those receiving palliative care at home, and their families.

Based on this research, we provide 12 specific recommendations for governmental organisations, energy suppliers and health and social care professionals, which address the need for collaboration to:

- Recognise people with palliative care needs as a population susceptible to energy hardship
- Engage with the palliative care sector to inform decision-making on energy efficiency and energy hardship supports – for example via the Commission for Regulation of Utilities community forum.
- Improve accessibility of existing energy-hardship supports, for example by providing information and access routes which are not reliant on digital technology or skills
- Provide relevant front-line staff with training and resources to recognise and support people with palliative care needs who are at risk of energy hardship
- Ensure means-based models for the provision of financial supports relevant to energy hardship take account of medically-driven needs, with assessment and support in place relevant to financial and energy hardship for those receiving palliative care.

Recommendations

Recommendation 1:

People requiring palliative care, including those with cancer, should be recognised by governmental and non-governmental departments and services as a population that is particularly vulnerable and susceptible to energy hardship

Recommendation 2:

There should be representation from a palliative care perspective on the CRU community representation forum.

Recommendation 3:

Front-line staff dealing with palliative care patients should receive awareness training on energy hardship and interventions. This training could be delivered through a hosted module or online webinar events.

Recommendation 4:

To better support the staff delivering services to this population, a standardised resource document should be developed. This document should assist these front-line staff in identifying households that are at risk of facing energy hardship. It should also provide an up-to-date energy hardship resources guide, including online resources and referral information for specific services, if needed.

Recommendation 5:

Relevant governmental/ non-governmental agencies need to collaboratively consider the current means-based model for social welfare payments relevant to the prevention of energy hardship to agree criteria which ensure that those with medically-based need for these payments, including people receiving palliative care at home, are not excluded.

Consideration could be given to the introduction of an easily applied generic tool (ideally self-assessment) which could be provided by care team to the person receiving palliative care or their family member, and then be followed up, if necessary, by appropriately skilled staff

Recommendation 6:

Ensure that the information related to and application processes for energy hardship-related allowances and services are available through multiple channels, including but not limited to telephone and paper-based applications.

Recommendation 7:

Healthcare professionals should encourage patients receiving palliative care to register as medically vulnerable with their energy provider.

Recommendation 8:

Provision by energy suppliers of a free phone number for people with medical needs to register as vulnerable customers.

Recommendation 9:

The criteria for extremely vulnerable customers should be extended to cover those who need a warm home environment for medical reasons, including those with palliative care needs being cared for at home. This would ensure that they cannot be disconnected for any reason from an energy supply.

Recommendation 10:

Consumers receiving palliative care need to have a better understanding of the benefits of reviewing and changing their energy suppliers, with the process made more comprehensible and easily accessible. Additional supports should be available for vulnerable individuals, including those receiving palliative care, who need extra assistance with this switching process or who do not have digital access or skills. Energy suppliers should consider having a dedicated contact point for this group and provide training to their staff on dealing with this group.

Recommendation 11:

If a person receiving palliative care is living in a house with a low BER, they should be able to seek prioritisation for retrofitting if they are renting from the local authority. Alternatively, if they apply for an SEAI scheme, they should be prioritised for assessment and retrofitting.

The SEAI could also advise and engage with the palliative care sector on the type of energy retrofitting that would cause the least discomfort to people with palliative care needs.

Recommendation 12:

To develop and implement a targeted co-designed education programme and intervention to improve the quality of life for people receiving palliative care at home, in relation to energy hardship- supported by Energy Suppliers, Government Departments, the HSE, and the Irish Cancer Society. This would ensure that people receiving palliative care would have a clear resource to support them if they are experiencing energy hardship.

Research Team

Dr. Suzanne Denieffe,
South East Technological University
(Principal Investigator)

Prof. Martina Gooney,
South East Technological University

Dr. Patricia Hunt,
South East Technological University

Dr. Muireann Prendergast,
South East Technological University

Dr. Pilar Luz Rodrigues,
South East Technological University

Dr. Mary Rabbitte,
All Ireland Institute of Hospice and Palliative Care

Dr. Mary Nevin,
Dublin City University

Dr. Peter May,
King's College London

Dr. Margaret Denny,
University of Maribor

Steering Committee

Dr. Emer Brangan,

All Ireland Institute of Hospice and Palliative Care

Dr. Brian Creedon,

Consultant Palliative Medicine Physician,
University Hospital Waterford

Ms. Irene Harbison,

Voices4Care,
All Ireland Institute of Hospice and Palliative Care

Ms. Jacqueline Reed,

Head of Education, Quality and Research,
Milford Care Centre

Mr. John Joyce,

Voices4Care,
All Ireland Institute of Hospice and Palliative Care

Ms. Ruth Lonergan,

Voices4Care,
All Ireland Institute of Hospice and Palliative Care

Dr. Tracey McConnell,

Marie Curie Senior Research Fellow
School of Nursing & Midwifery, Queens University Belfast

