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

Research Report

Proudly funded by Irish Cancer Society

AIIHPC All Ireland Institute of Hospice and Palliative Care

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List of Acronyms

AIIHPC	All-Ireland Institute of Hospice and Palliative Care
CRU	Commission for Regulation of Utilities
EPAH	Energy Poverty Advisory Hub
ESRI	Economic and Social Research Institute
FREE	Future of Rural Energy in Europe
HSE	Health Service Executive
HBP	Household Benefits Package
PPI	Patient-Public Involvement
SEAI	Sustainable Energy Authority Ireland
UHW	University Hospital Waterford

Executive Summary

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:

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 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.

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

Chapter 1
Introduction

Research has established the detrimental impact that a cancer diagnosis has on income and employment status, with the capacity to cause significant economic hardship for people living with cancer (Alzehr et al., 2022). In 2019, the Irish Cancer Society report, 'The Real Cost of Cancer', concluded that household bills and energy costs can increase by 49% following a cancer diagnosis (Irish Cancer Society, 2019). With rising costs of fuel and growing inflation affecting energy prices in Ireland, people with advanced cancer and palliative care needs are particularly vulnerable to energy hardship and resultant reduced quality of life. People with advanced cancer and palliative care needs are also more susceptible to feeling the cold as they spend more time at home and consequently have higher home heating costs.

There appears to be little consideration of the needs of people with a life limiting cancer diagnosis, or those with other life limiting diseases, by energy companies, the energy regulator, or government policy in Ireland. A comprehensive report on energy poverty and deprivation in Ireland (Barrett et al., 2022) did not consider the needs of people with palliative care needs living at home. This is likely because there is no Irish research energy poverty evidence available for this population. Marie Curie UK undertook research in 2020 on energy poverty among those receiving palliative care at home (Marie Curie UK, 2020). The Marie Curie research study drew attention to the issue and its' impact on people living with a terminal illness and family carers.

A research team led by Dr Suzanne Denieffe sought funding from the Irish Cancer Society Palliative Care Call 2022 to research the issue of home energy usage and needs of people receiving palliative care at home in Ireland from the perspectives of palliative home care nurses, people receiving care and family carers, and energy suppliers and the regulator. The study was undertaken between March and December 2023.

Chapter 2 provides the context to the study, including a review of the international literature on energy hardship and its' impact on people's health, including those with palliative care needs. The chapter also considers energy hardship and measures in place to address same in the Irish context. The study methodology and methods are outlined in Chapter 3. Chapter 4 details the study findings. Chapter 5 provides a discussion of key findings from the study with recommendations made for policy, practice, and research.

Chapter 2
Study Context

This chapter provides the study context and outlines the background of the rising costs of living in Ireland, including the increasing costs of energy (2.1) and the costs associated with a cancer diagnosis and other life limiting illnesses (2.2). It is essential to understand the meaning of the terms linked to energy hardship, and hence, the terms related to energy hardship, energy and fuel poverty are reviewed, and the rationale for using the term 'energy hardship' in the study is provided (2.3). Energy hardship and its potential impacts on health are then collated through a scoping review (2.4). The fundamental mechanisms to address energy hardship are improving housing energy efficiency and enhancing energy affordability. These measures are reviewed in the Irish context (2.5). Finally, the chapter concludes with a consideration of the knowledge gap in relation to energy hardship among patients receiving palliative care at home (2.6).

2.1 Rising Costs of Living

While it is difficult to pinpoint an exact start for the increasing costs of living in Ireland, from September 2021 the phrase 'cost-of-living crisis' started featuring more regularly in the media. In September 2021, inflation had hit a 10-year high, driven by a rise in the cost of transport, housing, restaurants, and hotels. The Central Statistics Office (CSO) data showed consumer prices rose 2.8 per cent in the 12 months to the end of August 2021 (CSO 2022). It was the sharpest level of price growth seen since November 2011. Figures from that month suggested that transport costs climbed by more than 10 per cent, while energy costs climbed by more than 7 per cent (CSO 2022).

Since then, the cost of living has continued to increase: the Central Statistics Office (CSO) estimates that prices in Ireland have risen by 7% in the year prior to March 2023. Prices on average, as measured by the Consumer Price Index, were 6.6% higher in May 2023 compared with May 2022 (CSO 2023).

Key household costs include rent/ mortgage, food, household energy, and motor fuel costs. The most notable changes in the year March 2022- March 2023 were increases in the costs of housing, water, electricity, gas and other fuels (+16.4%), food and non-alcoholic beverages (+12.7%), restaurants and hotels (+8.6%) and recreation and culture (+6.4%).

This cost-of-living increase is seen in both the rental and mortgage market. The Rent Index report is produced by the Residential Tenancies Board (RTB) and the Economic and Social Research Institute (ESRI) and provides indicators (the Rent Index) generated to track price developments in the Irish private rental market. The 2023 figures from the RTB (Quarter 1, 2023) put the average rent paid in newly registered tenancies nationally at €1,544 per month, up almost 9 per cent on the same period the previous year. For mortgage holders, the cumulative annual impact of nine increases from July 2022 to September 2023 exceeds €5,000 for many homeowners.

Outside of rent and mortgages, food is the most significant expense for most households. The cost of food in had Ireland had increased by 7.8% in September of 2023 over the same month in the previous year (Trading Economics, 2023). While there have been decreases in food costs seen, with inflation currently running at 3%, the higher prices people have been forced to pay are likely to be a feature for the long term. The cumulative impact of many months of inflationary pressure means many Irish households will likely have to spend an additional €1,000 or more on groceries between September 2023 and September 2024 than they did in 2020.

In autumn 2021, when the cost-of-living crisis emerged, household energy costs came into focus. Initially, it was predicted that Irish households might be worse off by approximately €700 each year due to higher gas and electricity bills. However, this turned out to be a significant underestimate, as energy prices more than doubled over the course of 2021 and 2022. As a result, many people saw their annual energy costs rise by over €2,000 (Pope, 2023) .

While some energy companies have announced reductions in prices between September and October 2023, if a household spent €2,000 on household energy in all forms in 2020, and €4,000 in 2022 and 2023, a 20% discount amounting to €800 would still leave them worse off by €1,200 compared to three years previously. Regarding motor fuel, before the cost-of-living crisis kicked in, a litre of petrol or diesel could be bought for less than €1.30. At the height of the crisis, the same fuel cost more than €2. In March 2022, an excise cut was introduced, which saved motorists twenty cents or so a litre. This excise cut was phased back over recent months, with motor fuel costs again rising.

When all elements are added up, including the above essential household costs along with hospitality and waste costs, Irish households will be substantially worse off by up to €7,500 over the 12 months from September 2023 when compared with the 12 months up to September 2021. While some may not be hit, other households will

experience significant financial challenges, and this may include households where a member has a diagnosis of cancer and who may be receiving palliative care. It was in this context, and in particular with the rising costs of energy and energy hardship from September 2022, that this study was undertaken.

2.2 Cost of Cancer and Life Limiting Conditions

From the day they are diagnosed, people living with cancer are faced with substantial additional costs and Government charges. While most people know that cancer is challenging, both physically and emotionally, many people do not realise that it can cause real financial hardship. A report commissioned by the Irish Cancer Society, 'The Real Cost of Cancer' in 2019, identified that the financial cost of having cancer has a major effect on individuals and families already struggling to come to terms with the disease itself (Irish Cancer Society, 2019).

The findings of this national survey of cancer patients and their carers looking at the financial cost associated with a cancer diagnosis revealed that the average additional cost is €756 per month, with many facing additional outgoings of up to €1,000 per month, According to the survey. there is an average drop in the income of cancer patients of €1,527 per month, equivalent to €18,323 per annum. One in three changed their employment status, while one in four changed their approach to work. Employment was affected for 45% of carers. Cancer patients also face increased costs of medicines, consultations, and parking at the hospital.

The Irish Cancer Society 2019 report also identified that households where there was a person with cancer faced additional bills at home. One in two had additional heating, electricity and telecom bills, and a quarter had increased food and drink costs. One in eight also had additional childcare costs. Over half spent more on personal care and clothing because of having cancer. Two in five patients had a medical card at the time of their diagnosis, more patients received a medical card following diagnosis, but 17% of those who applied for a medical card were unsuccessful.

It is important to note that since this report was published in 2019, living costs have continued to rise, as per section 2.1. Therefore, the above cancer-related costs will also have continued to rise, creating increased financial burdens on families.
The National President of the St Vincent de Paul (SVP) Society, Rose McGowan, said in January 2022 that the SVP had received 1,400 requests for help since 2019 from people struggling financially because of a cancer diagnosis, unable to cover heating bills for their homes or transport costs for treatment (Fegan, 2022). She also

acknowledged that this is likely to underestimate the real need and that SVP would receive many requests from people who have extra heating costs during their cancer treatment and are struggling to keep their homes warm. In 2021/22, Marie Curie UK answered 16,589 calls and web chats through their support line and 13% of these were regarding benefits or money issues. Since April 2022, this percentage has risen to 16.5%. The Irish Cancer Society Support Line does not keep specific information on the focus of the calls. However, when they receive calls regarding practical and financial issues they ask the caller if they wish a referral to be sent to the Practical and Financial team in the Irish Cancer Society.

It is not just people living with cancer who can experience this financial hardship associated with illness. It would seem reasonable to assume that people living with other life limiting conditions also experience increased financial costs and possible hardship. However, it seems there is no empirical evidence from an Irish context, similar to the Irish Cancer Society study, available for other life limiting conditions.

2.3 Understanding the term 'energy hardship' and measurement

The challenge of energy hardship in Ireland was set out starkly in Barrett et al.'s (2022) report, which identified that up to 43 per cent of households could be at risk if energy price hikes continue and bills increase by a further 25 per cent. This report undertaken by the Economic and Social Research Institute (ESRI) suggests that energy poverty in Ireland has increased from 13% in 2015/2016 to 29% in mid-2022 (Barrett et al., 2022).

Many of the papers mentioned in this report use either the term 'energy poverty' or 'fuel poverty'. Spandagos et al. (2023) argue that it is now common for the terms 'energy poverty' and 'fuel poverty' interchangeably even though they had been defined differently in the past. The difference between the terms, according to Bouzarovski and Petrova (2015), is that traditionally, 'energy poverty' concerns the lack of access to modern energy services in developing countries, while 'fuel poverty' refers to the affordability of such services in developed countries. In practice, however, 'energy poverty' is gradually becoming a common term for describing the situation of households not being able to meet their energy needs in developed countries as well. Most official Irish and EU policy documents and recent directives employ the term 'energy poverty'.

However, for the remainder of this report the term 'energy hardship' will be used as the umbrella term to broadly define when households cannot afford energy use or access energy services (Brabo-Catala et al., 2023a, Brabo-Catala et al., 2023b) and

encompasses, therefore, energy poverty and fuel poverty. The reason for this is, that in going out to research this sensitive topic with people with advanced cancer and palliative care needs, family carers and health professionals, the project steering committee suggested use of the term energy hardship as this was viewed as less stigmatising, particularly when recruiting people for the study.

Energy hardship is an issue which impacts both developed and developing countries (Halkos and Gkampoura, 2021). Energy hardship may *'manifest itself in a high percentage of income spent covering energy bills'* (Cong et al., 2022, p.2). It may be caused by rising energy prices, low income, and inefficient housing and appliances (Halkos and Gkampoura, 2021; de Vries and Blane, 2012; Recalde et al., 2019; Jones, 2016; Kyprianou et al., 2019).

Energy hardship concerns both the availability and affordability of different energy supplies (Fairburn, 2019) and may also mean that not only are households unable to afford heating, but also not able to *'afford to cook hot meals or have reliable hot water for baths and washing clothes or run essential domestic appliances'* (Jones 2016, p. 21-22).

For an adequate standard of temperature and warmth, the World Health Organization (WHO) suggests that 18°C is a *'safe and well-balanced indoor temperature to protect the health of general populations during cold seasons'* (WHO 2018, p. xvii) for countries with temperate or colder climates, although *'a higher minimum indoor temperature than 18°C may be necessary for vulnerable people including older people, children, and those with chronic illnesses, particularly cardiorespiratory diseases'* (WHO 2018, p. 3). The Health Information and Quality Authority (HIQA; 2016) has recommended that temperature in bedroom areas (in residential homes for older adults) should be at a minimum 18°C (65°F) and 21°C (70°F) in day areas and that internal heating systems should also take into account external temperatures and adjust accordingly. The HSE, in their review of energy hardship, advocated a minimum home temperature threshold for health in winter as 18°C and recognise that people with medical vulnerabilities may benefit from a slightly higher temperature (Cooney et al., 2022). No specific guidance was located for housing temperatures for those receiving palliative care at home.

There is no universally accepted standard for determining whether an individual (or a household) is energy-poor (Roberts et al., 2015). Instead, a range of measures can be utilised. Cong et al. (2022) identify these energy hardship metrics as primary or secondary and relative or absolute. Primary metrics directly employ consumer-

level information, while secondary metrics use weighted scoring of specific indices and aggregated information from utilities. Absolute metrics measure energy hardship via strict thresholds, while relative metrics provide comparative information across multiple households, countries, or regions. Energy hardship metrics can also be categorised as subjective and objective. Information on energy hardship from households is commonly used and is therefore an example of a primary-relative and subjective metrics.

The most common example of an objective and primary-absolute metric concerns the percentage of income that should not be exceeded for paying for energy services. Research from the UK has set the maximum acceptable threshold for this purpose to be 10% of the available income (the so-called '10% rule') (Dogan et al., 2022). Another objective metric is the Low-income High cost (LIHC) indicator (Robinson et al., 2018), which classifies households as energy-poor when their energy expenditure is higher than the median in their country, and at the same time, their income after that expenditure falls below the country's poverty line (Siksnelyte-Butkiene et al., 2021). In Ireland, from a policy perspective, households are currently defined as energy-poor if they spend more than 10% of their disposable income on energy costs in any one year. Severe energy poverty refers to spending more than 15%, while in extreme energy poverty, the household is spending more than 20% of their disposable income (Department of Communications, Energy and Natural Resources, 2011). However, Tovar Reaños and Lynch (2022) have noted that fuel poverty affects a considerably larger proportion of households than just the income poor, and hence, criteria to assess vulnerability to energy poverty should be broader with specific cohorts of people targeted based on the distinct type of energy hardship experienced by them.

2.4 Energy Hardship Scoping Review

As part of the study, a scoping review was undertaken to examine the current literature on energy hardship and health, with a particular focus on the impacts on those with a life-limiting cancer diagnosis receiving palliative care at home. The objective was to examine what the academic and professional literature has uncovered on the subject so far and what gaps might still exist that may need further investigation to provide a fuller understanding of the complexities of the effects of energy hardship on health in general and on the health of palliative care patients and their families.

2.4.1. Methodology

Scoping reviews have been increasingly used in health and social sciences (Pollock et al., 2021). The scoping review framework, which was first proposed by Arksey and O'Malley (2005), aims *'to map the existing literature in a field of interest in terms of the volume, nature, and characteristics'* (Pham *et al.* 2014, p. 371). A scoping review is beneficial when literature about a research topic has been poorly defined or has not yet been extensively reviewed (Grant and Booth, 2009), as well as in identifying research gaps within the existing literature, and is *'commonly undertaken to examine the extent, range, and nature of research activity in a topic area'* (Pham *et al*., 2014, p. 371).

2.4.2 Search Strategy and Selection Process

The scoping review search was conducted from March to April 2023 and used Arksey and O'Malley's (2005) framework. The review was prompted by the following research questions: what is known about energy poverty and palliative care in the existing literature, and what is known on the impact of energy poverty on health. The decision was taken to broaden the search and review to palliative care, including cancer, as it was felt that this would provide a more comprehensive view of the issue of energy hardship among those receiving palliative care at home.

A scoping review protocol was developed for the specific topic of study so as to guide the search process. The following twelve electronic databases were used: CINAHL, The Cochrane Library, OVID SP, JSTOR, PsycArticles, ScienceDirect, Web of Science, Academic Search Complete, BASE Digital Collections, DOAJ – Directory of Open Access Journals, PubMed, Wiley Online. The review was also complemented with a search on Google and Google Scholar.

Five keywords were used for searching each database: *'Energy poverty and palliative care', 'Energy poverty and health', 'Energy poverty and cancer', 'Energy poverty and*

end of life', and *'Energy poverty and nursing'*. Literature that mentioned varying terms, such as *'fuel poverty', 'energy hardship', 'household material hardship',* and *'energy affordability'*, were incorporated into the selection process. Searches were made for English-language literature only, published between 2013-2023. According to Arksey and O'Malley, *'decisions have to be made at the outset about the coverage of the review in terms of time span and language'* (2005, p. 23)

In this scoping review, the search for publications was within a ten-year timespan (2013-2023) to better understand recent developments in the subject. This decision was made to account for the increasing concerns regarding climate change and rising energy costs. Inclusion criteria were as follows: Publication focus on energy poverty and palliative care, or energy poverty and health; Energy poverty to include factors such as inadequate indoor temperatures [cold or hot]; the existence of dampness, mould, or related allergens; the absence, misuse, or disuse of hot/cold equipment; the absence of or inadequate thermal insulation; the inability to use light and/or hot water; expenditure-based studies; arrears in utility bills; and health to include physical or mental health. Exclusion criteria included exclusion of editorials, opinions, and conference abstracts.

A total of 5,386 documents were retrieved (5,366 from databases and 20 from other sources), of which 360 were found to be potentially eligible for the review. Among these 360 publications, 182 were found to be duplicates, and with their exclusion, there remained a total of 177 records. These 177 documents were then reviewed by title and abstract. In this phase of the review, literature was screened and excluded based on two criteria: a) the literature was not accessible, b) upon reading the title and abstract, it was found that the literature did not meet the inclusion criteria. A total of 87 publications were excluded based on such criteria, 9 of which were not accessible, and 78 were found not relevant based on the inclusion/ exclusion criteria. After screening, 90 academic papers and grey literature documents were included in the scoping review. Further details on the scoping review can be seen in Appendix 1.

Due to the differences in the definition of 'wellbeing' found in the literature during the selection process, it was decided that only those encompassing 'health' as an aspect of wellbeing would be included in the scoping review. For instance, studies focusing only on wellbeing as life satisfaction, happiness, or welfare were excluded from the scoping review. Furthermore, although some studies found during the selection process appeared relevant to the present study, they were excluded based on the inclusion and exclusion criteria. This was the case, for example, of a study on energy and care work focusing specifically on the cases of Sweden and India (Wågström

and Michael, 2023), which discussed the relevancy of energy for care work but not precisely issues related to energy poverty, of another study on how housing affects end-of-life care and bereavement in low-income communities in the UK (Hansford et al., 2022), which addressed aspects of housing on the end of life care not related to energy hardship, and of a study on physical and mental health, old age, and energy poverty (Oyarzún-Ruiz and Espinoza, 2020), which was published in the Spanish language.

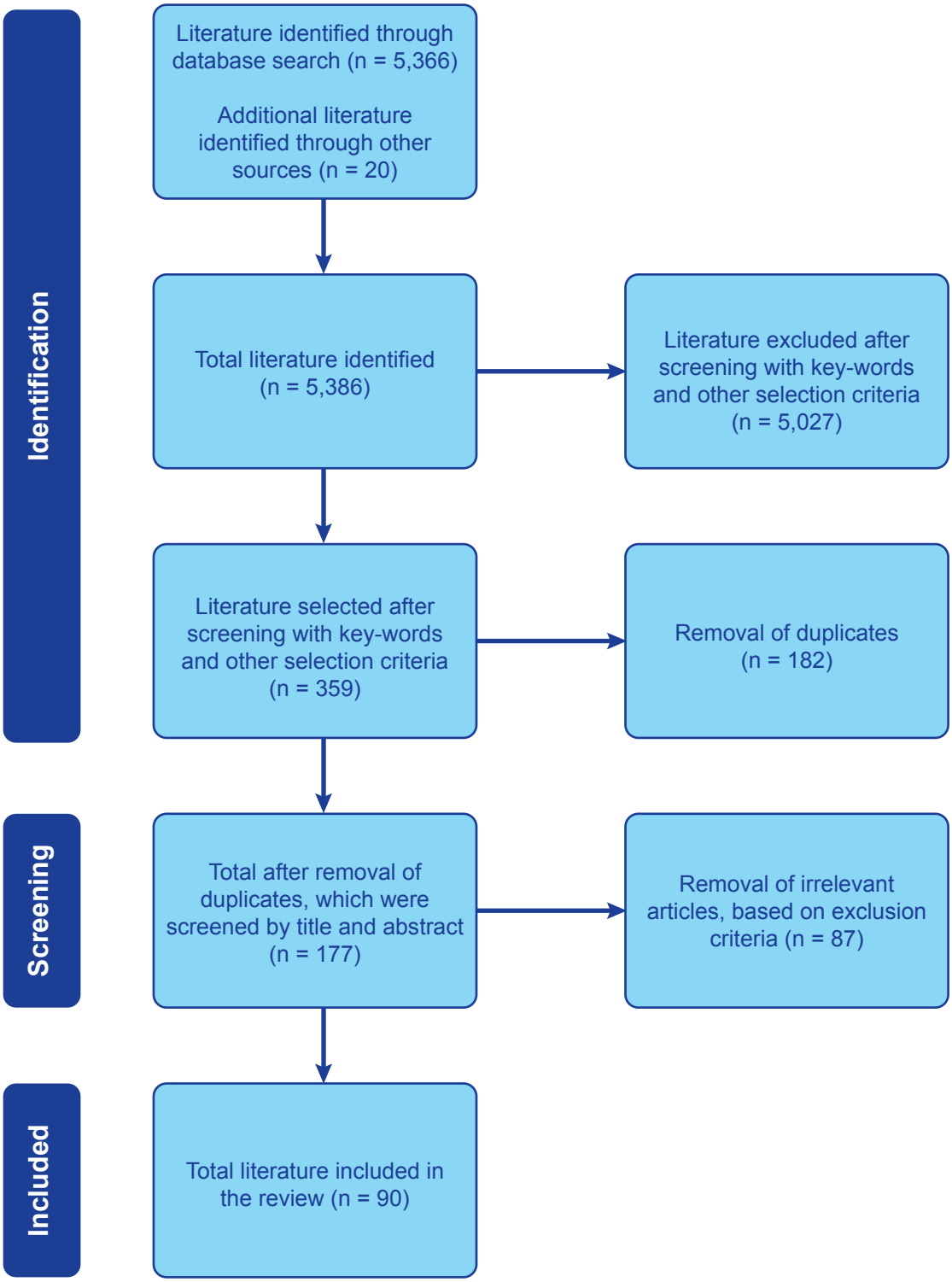


Figure 2.1 Flowchart of the scoping review selection process.

During the selection process, we found a scoping review with similarities to our review (Ballesteros-Arjona et al., 2022), which was incorporated into the final selection. The scoping review by Ballesteros-Arjona et al. (2022) focused on the 'effects of energy poverty and interventions to ameliorate it on people's health and wellbeing'. One should note that this review presented its analysis with an equity lens (gender, ethnicity, social class, etc.). The authors highlighted in their paper that the studies reviewed linked energy poverty to poorer general health, mental health, respiratory health, and worse control of chronic conditions, in addition to higher mortality, use of health services, and exposure to health risks (Ballesteros-Arjona et al., 2022), which was worsened for vulnerable cohorts across dimensions of inequality (Ballesteros-Arjona et al., 2022).

2.4.3. Review Results: Palliative Care

Our review confirmed that literature on energy poverty and palliative care is scarce. Of the literature selected during the scoping review, only three documents were found that presented a direct connection with the topic. Therefore, for the research question *'what is known about energy poverty and palliative care in the existing literature?',* we found that little is known. Of the three literature items found on this topic, the first focused on energy poverty and cancer (Bilodeau et al., 2018), the second on energy poverty and terminal illness (Marie Curie, 2020), and the third on energy poverty and at-home care (Willand, 2022).

Bilodeau et al. (2018) analysed household material hardship, including food, energy, or housing, in families of post-chemotherapy children in the context of the United States. The authors (Bilodeau et al. 2018) noted that among a cohort of newly diagnosed paediatric cancer patient families, household material hardship was experienced by 20%, which increased to 30% following six months of chemotherapy. In conducting a follow-up survey with a sub-cohort of such families, at least one year off therapy, Bilodeau *et al.* (2018) found that 32% reported household material hardship in early survivorship.

Marie Curie UK published a report (Marie Curie, 2020) on fuel poverty and terminal illness, which was based on a survey conducted among Marie Curie's community nurses across the UK. The report underscored the vicious cycle of fuel poverty and terminal illness. That is, due to deteriorating health, patients are compelled to spend more to heat their homes, which may inevitably lead to increased costs for people who must already bear the costs associated with their illnesses. Meanwhile, for such patients, the cold and damp conditions of their homes may yield consequences for their health, leading to the worsening of symptoms, infections, and problems

with mental health and wellbeing, and in some cases, even hastening death (Marie Curie, 2020). Among the findings, the report highlighted that of the nurses who were surveyed, 28% had provided care to a dying patient during the last five years, and they had mentioned that patients were having difficulty with the costs of heating in their home (Marie Curie, 2020). Among those nurses who had cared for patients struggling with heating costs, 38% believed it made the patient's physical health worse, 17% believed it hastened their deterioration, and 40% believed it made their mental health worse (Marie Curie, 2020). Marie Curie reported their response rate to the survey as 11%.

Willand (2022) looked at stakeholders' perceptions of tackling energy poverty and vulnerability among older Australians, particularly for integrating energy assistance with health services for those aged 65 and over. The qualitative investigation used the Australian in-home aged care services as a case study, conducting focus groups and interviews in two care providers' organisations. The study found that the regional distribution of energy assistance may be improved by integrating energy assistance into Australian in-home care. It also found that it may reach those in hidden energy poverty (Willand, 2022). On the other hand, Willand (2022) also highlighted differences of opinion regarding the benefits of this kind of initiative and the need for it to be co-designed by stakeholders. Additionally, it underscored the challenges involved in engaging health policy decision-makers.

Although these three publications have different contexts, approaches, and target populations, they demonstrate that energy hardship may indeed negatively impact those who have a health condition, and as highlighted by the Marie Curie UK report (2020), it can create a vicious cycle, since those in such conditions often spend more on energy costs. Furthermore, they show that energy hardship may impact the health of different segments of vulnerable populations, such as children and elders.

2.4.4. Impacts of Energy Hardship on Health

The literature identified in the scoping review on what is known on the impact of energy poverty on health indicates that living in energy poverty may cause significant impacts on the health, mental health, and wellbeing of individuals (O'Meara, 2015; Lee et al., 2022; Llorca et al., 2020; Oliveras et al., 2020; Xu et al., 2022; Tod and Thomson, 2016; Fairburn, 2019; Riva et al., 2023; Brown and Vera-Toscano, 2021), contributing to respiratory illnesses, such as asthma, and circulatory diseases (O'Meara, 2015; WHO, 2018; Recalde et al., 2019), anxiety and depression (Recalde et al., 2019; Bentley et al., 2023), as well as increased morbidity rates and mortality risk (Recalde et al. 2019). These impacts are important to be aware of as palliative

care is accessed by people with chronic illnesses and other co-morbidities. In addition, the literature indicates that certain groups may also be particularly vulnerable to the impacts of energy hardship on health, including the older population, people with disabilities or long-term illnesses, single-parent families, women, and children (Jones, 2016).

The physical impact of energy poverty and health can result from a drop in indoor temperature below 12°C), raising blood pressure in the general population (Näyhä, 2002). Specific health impacts could result from cold indoor temperatures, which place thermal stress on the body and affect the immune, circulatory and cardiovascular systems (Liu et al., 2015). Cold homes also generate mould, damp and dust mites, which can affect respiratory and allergic conditions (Mendell et al., 2011).

It was not possible to locate any studies that investigated the effects of energy hardship on the health of individuals receiving palliative care. However, living in cold temperatures can trigger bronchospasm in those with asthma and chronic obstructive pulmonary disease (COPD) and can lower resistance to respiratory infections (D'Amato et al., 2018). Studies that examined the effects of colder housing have also identified increased winter mortality in women over 85 years (Donaldson et al., 2019), reduced respiratory health and an increase in depressive symptoms in older people (de Vries and Blane, 2013) and an increase in mortality from all causes but most specifically cardiovascular, respiratory, and non-cardio-respiratory causes (Hajat, 2017). A low housing temperature, where high blood pressure could result, along with increased blood viscosity, could increase the risk of stroke and myocardial infarction (Public Health England, 2014). Coronary events in younger age groups (35-64 years) are also more likely to be fatal in colder periods. In addition, cold conditions can exacerbate diabetes, musculoskeletal and rheumatological conditions. Cold homes are also associated with lower strength and dexterity and exacerbated symptoms of arthritis, which can increase the risk of unintentional injury and falls (Public Health England, 2014).

Energy hardship not only directly and indirectly affects health, but it may also burden households with health expenditure (Bukari et al., 2021) and have impacts on public health (Pan et al., 2021). Energy poverty in Europe, for instance, has become an increasing and more pressing issue since the 2008 economic downturn (O'Meara, 2015; Jones, 2016), and with recent increases in energy prices (Menyhért 2022), those most vulnerable may have aggravated impacts on their health. Ireland has relatively high levels of winter deaths, with a strong relationship shown between energy hardship, social class, geographic and demographic patterns (Cooney et al.,

2022). Research from England identified that 10% of winter excess deaths can be attributed to energy hardship (Public Health England, 2014).

In addition to rising costs, climate change may also impact those experiencing energy poverty (Nawaz, 2021; Jessel et al., 2019), as health risks may increase due to climate changes or catastrophic climate events (Nawaz, 2021) and *'as climate change worsens, the demand for more energy services and the strain on existing services will increase'* (Jessel et al., 2019, p. 1).

The scoping review revealed that literature on energy hardship and palliative care is scarce, indicating a need for further research. There has been a steady growth in the number of publications on energy hardship and health over the last ten years, which indicates an increase in interest in the topic. Our findings indicate, however, that most of the studies on energy poverty and health have been secondary, quantitative research, mainly survey analysis of official government or international organisation statistics. Very few studies reviewed have relied on mixed methods, and a meagre number of studies employed qualitative methods, such as interviews. The absence of qualitative methods may reflect the sensitive nature of the topic, per se, and the challenges surrounding the engagement of research participants in any qualitative investigation of the theme. At the very least, the findings of the present scoping review highlight the need for more research which should consider people's perceptions, perspectives, and lived experiences, notwithstanding its inherent difficulties.

2.5 Interventions to Address Energy Hardship

The three major causes of energy hardship are poor energy efficiency of housing and household appliances, low household income and high energy prices. Interventions to address energy hardship, therefore, need to consider all these causes. Measures to improve Irish home energy efficiency will be discussed, followed by consideration of current measures in place to enhance energy affordability through broad and targeted household allowances.

2.5.1 Home Energy Efficiency

Household energy efficiency is a critical preventive measure that can help reduce energy costs and positively influence the health of individuals. Avanzini et al. (2022) found that an intervention, specifically energy retrofitting, may benefit public health, as it helps households save money. Lima et al. (2022) argue that home energy efficiency may be a direct pathway with protective and preventive impact on health, followed by energy affordability as an indirect pathway.

In Ireland, there is a drive toward improving the energy efficiency of housing stock. This is an essential initiative towards relieving energy hardship as the energy hardship prediction model developed by Spandagos et al. (2023) revealed that the condition of a dwelling is one of the most significant household-level predictors of energy poverty. They say that dwelling condition relates, not just to insulation and energy efficiency state, but also to the existence of damage, such as a leaking roof, damp walls or foundations, and rot in window frames or floors.

Most homes in Ireland (70%) were built before 1983 (Future of Rural Energy in Europe (Free), 2020) and consume energy in the form of electricity, gas, and heating fuel. Heating oil and solid fuels are used more prominently in the oldest dwellings, which are typically less energy efficient and harder to upgrade. Irish homes use 7% more energy than the EU average and emit 60% more CO2 (Government of Ireland, 2023). Oil is the predominant heating fuel source utilised in homes in Ireland (38%; FREE, 2020). Furthermore, rural homes in Ireland are typically larger and disconnected from natural gas networks and thus consume higher quantities of oil (65%), as well as solid fuels such as coal and peat, than those of urban housing stock (FREE, 2020).

Improving the energy performance of the housing stock is a core commitment of the Climate Action Plan and the Programme for Government (Government of Ireland, 2023). Improving the energy efficiency of a home permanently decreases the amount of energy required to heat that home to an adequate degree. This reduces greenhouse gas emissions, but it also protects households from the impact of rising energy prices.

The schemes in place to support retrofitting for energy-efficient housing can be broadly grouped into three housing types- local authority housing, social welfare recipients and non-social welfare recipients. For those living in local authority housing, where their house is identified for retrofitting, there is no cost to the householder. Since the programme commenced in 2013, over 75,000 homes have been retrofitted

with a total exchequer spend of €184 million under the scheme. Social Welfare recipients can apply for the 'Better Energy Warmer Home' scheme, also known as 'Free Energy Upgrade'. In this scheme, the homeowner is not charged for work done under this scheme. This scheme is aimed at those on low incomes/certain social welfare recipients and has a wait time of up to 24 months, and thus may have limited potential in its current form as an intervention at the point when someone already has palliative care needs. For non-social welfare recipients, including landlords and owner-occupiers, two grant schemes are available: the One Stop Shop- Better Energy home scheme; and the Individual Energy Grants. Under the One-Stop Shop – Better Energy Home Scheme, homeowners and landlords can apply for approximately 50% of costs incurred. Under the Individual Energy Grants- Better Energy Home Scheme, homeowners and landlords can apply for up to 80% of the costs, paying the total amount to their contractor and then claiming the grant, allowing between 4-6 weeks for payments. This grant allows the homeowners /landlords to manage their own project upgrades.

The National Development Plan commits to investing at least €8bn in residential retrofit to 2030. Through the Warmer Homes Scheme, €133m of this allocation will be used to provide free energy efficiency upgrades to households in, or at risk of, energy poverty.

While these schemes are important from a long-term public health perspective, for someone with cancer or receiving palliative care, the option of a rapid upgrade of housing energy efficiency is unlikely. This is due to the financial outlay if not eligible for 100% funding or living in a local authority home, but also the possible administrative burden of accessing grants and managing upgrade work in the home. There are also long delays currently experienced in both getting a grant towards payment and getting the work completed (Sustainable Energy Authority Ireland (SEAI, 2023). SEAI data (2022) indicated that for homes completed in 2021, the average time from application to completion was approximately 26 months countrywide. Only 35% of applications for home retrofitting as part of the Warmer Homes Scheme had been processed as of the end of May 2023. Out of 15,203 applications received since February 2022, just 5,287 have been fulfilled, leaving the outcomes of over 6 in every 10 applicants uncertain. Therefore, while housing retrofitting, if necessary for a house, may benefit those receiving palliative care at home, the reality is that it is probably not viable due to financial and delay constraints and most importantly impact on quality of life. The impact on the home environment when implementing energy upgrades includes risks from dust, noise, infection, cuts in power and heating, or having to vacate parts of the property. These risks can detrimentally impact the quality of life of a person with palliative care needs.

Another cause of energy hardship can be inappropriate use of energy in the home or inefficient household appliances. An SEAI publication, 'Changing Energy Behaviour- What Works' review (2019) identified multiple studies that show that providing feedback to households on their energy use is effective in reducing energy consumption and, therefore, costs. Feedback is most effective when: it is delivered in real-time with appliance-specific breakdowns by time of use (Asensio & Delmas, 2016); the energy use is communicated in broadly understood units (like euros instead of kWh), along with tips on how to save energy (Schleich, 2013); and households are frequently prompted to check their energy use over a long period.

An Irish study, the 'Irish Smart Meter Trial', undertaken in 2011 by SEAI, CRU and other partners, showed that households saved the most energy when they were provided with in-home displays, enhanced billing frequency, and feedback on how their energy use changed over time. The reported energy savings associated with providing feedback to households ranges from 1% to 13% but is most likely to be closer to 2.9% based on results from the Irish trial.

The SEAI (2019) review, using the example of Alberini and Towe's study (2015), also says that preliminary evidence suggests that providing households with energy audits can reduce their energy use and increase the likelihood that they will invest in energy efficiency measures likely to produce long-term energy savings.

2.5.2 Enhancing Energy Affordability

Research by the ESRI (O'Malley et al., 2020) found that cutting indirect taxes (such as the carbon tax) on energy is ineffective at tackling energy poverty. While energy prices would be lower, about half of the aggregate gains from such tax cuts would go to the highest-income 40% of households compared to less than a third of gains to the lowest-income 40%. Instead, targeted payments to households most affected by rising energy prices result in gain profits that are larger in both cash terms and as a percentage of income.

Similarly, this would concur with the point that a price cap on energy costs does not protect those who cannot afford the cost of keeping warm. Therefore, there needs to be direct government intervention through bill support, social tariffs and home energy efficiency initiatives (see section 2.5.1).

Internal Government analysis using the SWITCH model found that the increases in the carbon tax have been progressive as a result of the increased social protection payments funded by the carbon tax (Department of Public Expenditure and Reform,

2023). An analysis conducted in support of Budget 2023 found that households in the bottom five income group are better off because of the increased spending on social protection made possible by the increases to the carbon tax.

The Department of Social Protection pays out several targeted supports to help people pay their energy bills. The main support, a free electricity allowance or natural gas allowance, falls under the Household Benefits Package (HBP). Those eligible can receive either the electricity allowance or the natural gas allowance. Both payments are €35 per month, paid directly into a bank account. The HBP is not means-tested, but in order to receive it, the person must be aged 70 or over. If under 70 years of age, a person may still qualify if receiving a qualifying social welfare payment.

A winter fuel allowance is also available. This is a means-tested payment under the National Fuel Scheme, and those who qualify receive a weekly payment of €33. The winter fuel allowance season usually starts around September and lasts 28 weeks. It was announced in the Government budget 2023 that households receiving the fuel allowance will also receive an extra lump sum of €400 in November of that year, in addition to their regular weekly payment.

The final support available is an additional needs payment for help with paying bills, such as gas and electricity. This is a single payment to help with an essential, one-off cost that a person could not pay out of their income and is part of the Supplementary Welfare Allowance Scheme. It is also a means-tested payment.

In relation to energy hardship since September 2022, specific interventions have been put in place. The energy regulator, the Commission for Regulation of Utilities (CRU) placed a temporary ban or moratorium on energy disconnections during the winter months of 2022-2023 and 2023-2024. During this period, a household cannot have their gas or electricity supply disconnected for whatever reason.

However, Social Justice Ireland (2023) are critical in their analysis of these electricity credit schemes. They say while one-off measures are welcome, when they are removed, what remains is a skewed distribution of resources that favours those on higher incomes. The CRU's (2023) monitoring data on arrears highlighted the positive impact of the electricity credits on the reduction of arrears for domestic electricity customers. However, the CRU said it had a temporary impact, and debt levels climbed quickly again. If these credits are removed, this will impact those with those receiving palliative care at home.

2.5.3 Potential Benefits of Interventions

From the scoping review, it was seen from studies conducted internationally that addressed interventions or the evaluation of interventions that positive impacts on energy hardship and health can arise from interventions. Such studies have highlighted the effectiveness and positive results of energy efficiency interventions on health (Lawler et al. 2023; O'Sullivan, 2019; Lima et al., 2022; Wang et al., 2022), for illnesses such as asthma, respiratory diseases (Wang et al., 2022), and mental health. No studies were located in relation to cancer or palliative care and interventions.

Regarding wellbeing (Sawyer et al., 2022; Wang et al., 2022), studies have noted the efficacy of energy hardship interventions in reducing stress and isolation (Sawyer et al., 2022). Interventions that have been shown to have positive health impacts on households with energy hardship include more efficient heating and increased thermal insulation (Wang et al., 2022), installation of major heating or insulation measures, such as new boilers and central heating (Sawyer et al., 2022), and simple telemetry for managing chronic health conditions in the winter and helping healthcare systems (Pollard et al., 2019). For instance, Carrere et al. (2022) found that their intervention successfully reduced energy hardships among vulnerable populations in the short term. The pilot intervention studied by Carrere et al. consisted of energy-counselling home visits through an information-based measure (2022).

Specific studies in the Irish context on how measures to either improve home energy efficiency or the impacts of the allowances are limited. No studies were located which assessed the impact of the extended moratorium or the energy credits or allowances. A small numbers of studies were located that examined the potential benefits of housing energy efficiency retrofits on health.

The Warmth and Wellbeing Pilot Scheme was undertaken from 2016 to 2022 as a joint policy initiative with the Department of Communications, Climate Action and Environment, and the Department of Health, and was operated by the Sustainable Energy Authority of Ireland and the Health Service Executive, with an overall budget of €20m. The scheme targeted energy efficiency retrofits in the homes of people living with chronic respiratory conditions and aimed to objectively measure and validate the health and wellbeing impacts of improving the living conditions of vulnerable people living in energy poverty with chronic respiratory conditions. The scheme was expanded to include households with children with respiratory conditions.

The scheme's objectives were to provide 'deep' energy efficiency improvements to the homes of older people with chronic health conditions at risk of, or experiencing,

energy poverty. Energy efficiency upgrades such as attic and wall insulation and ventilation, boiler upgrades with heating controls and window and door replacements were provided free of charge to successful applicants. Over 1,300 homes were upgraded.

The London School of Hygiene and Tropical Medicine undertook an independent evaluation of the associated health benefits of the Warmth and Wellbeing Scheme. The final evaluation report is not yet publicly available. However, an interim presentation (Stanton, 2018) suggested that it was hoped that by the end of the evaluation sufficient evidence would have been collected to carry out a cost-benefit analysis, which will calculate the level of healthcare costs avoided for participants in the scheme and for the state.

A presentation by Stanton (2018) on the Warmth and Wellbeing study outlined the following impacts of retrofitting.

- *Winter indoor temperatures*: Increase in winter indoor temperatures and reduced decline in indoor temperatures when it is very cold.
- *Self-reported – heating related*: Increase in thermal comfort, reduced difficulty in paying fuel bills, improved sense of control over indoor temperatures, and improved social inclusion. *Objective measures-* Improved wellbeing scores on multiple dimensions (e.g. mobility, self-care, pain, emotional wellbeing including anxiety & depression, physical activity and symptoms, social functioning).
- *Use of Health care-* Reduced usage of GP, emergency departments and hospital services and reduced volume of prescribed drugs.
- *Modelled outcomes:* Lower mortality (esp. cardiorespiratory)

It seems the details of how the scheme can inform the Government's approaches to retrofitting, especially with regard to those who are more vulnerable and at risk of energy poverty, will be considered when the final findings of the analysis are available.

In 2018, Wexford County Council completed a deep retrofit of twelve one-bedroom social housing units to units to meet passive house standards (Colclough et al., 2018, Colclough et al., 2022). The development transformed the thermal comfort of the houses, and in at least one case, the improvement in indoor air quality has had a substantial positive impact on the occupant's health.

2.6 Gap in Knowledge of Energy Hardship and Palliative Care

The scoping review highlighted the global prevalence of health issues caused by energy poverty, affecting different racial and ethnic groups. However, the research revealed that some groups are more vulnerable than others. Energy hardship can have a particularly negative impact on the health of certain groups of people. Women, individuals with disabilities, children, and older people are especially vulnerable. This is also true for those living in less developed countries, low-income households, and poor housing conditions.

A particularly vulnerable cohort of the population who may be affected by energy hardship is those receiving palliative care at home. People receiving palliative care are already burdened with high costs associated with their illnesses, are often homebound, and need to maintain a higher minimum indoor temperature. They may also need specific medical equipment that requires electricity such as lifts to help movement, machines to support breathing when sleeping, hospital beds, electric wheelchairs, kidney machines. It is important to note that individuals receiving palliative care at home may also be part of groups characterised as more vulnerable by the literature reviewed, such as women, elderly, and people with disabilities, among others. In this case, palliative care compounds their vulnerability.

However, specific information on energy hardship in a Republic of Ireland context was not available, hence the need for this study to try understanding the possible extent of the issue and the impacts it was having on people's lives, as well as looking at measures which could help alleviate energy hardship for people receiving palliative care at home.

Chapter 3
Methodology and Methods

This chapter begins with an outline of the study's aim and objectives (3.1) and the role of the Steering Committee (3.2). The study design (3.3), population and sample (3.4), recruitment strategies (3.5) data collection tools (3.6), and data analysis (3.7) are then described. Ethical considerations for the study are outlined in section 3.8, and section 3.9 describes the patient-public involvement in the study.

3.1 Study Aim and Objectives

This study aimed to examine and address the evidence gap in energy poverty for people receiving palliative care at home and to make informed recommendations that will be shared with 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.

The study objectives were to:

1. Examine home energy usage and needs of people receiving palliative home care by exploring the views of home care nurses, energy providers, and the energy regulator and patients and family carers, patients;
2. Make informed recommendations and share the project results with policymakers and energy providers to influence fairer policy decisions and measures to address the home energy needs of those receiving palliative care at home.

3.2 Steering Committee

The project was overseen by a Steering Group including academic researchers, clinicians, representatives from the All-Ireland Institute of Hospice and Palliative Care (AIIHPC) and Patients-Public Involvement (PPI) from the AIIHPC Voices4Care group. The clinicians represented palliative care services taking part in the study. The academic researchers came from a range of universities and backgrounds, bringing together research, clinical and economic expertise. AIIHPC provided support and expertise on palliative care research, policy, practice, engagement, and dissemination. The PPI representatives provided advice and support in relation to the study design and recruitment strategy, reviewing documentation including study information sheets, and reviewing the interim and final report, including the recommendations.

3.3 Study Design

This study used a cross-sectional mixed methods design consisting of three elements:

- An online survey with Palliative Home Care Nurses.
- Structured individual interviews or questionnaires with the Irish energy providers
- Semi-structured individual or group interviews with patients receiving palliative home care or family carers of someone who is receiving or received palliative home care.

3.4 Population and Sample

The three populations of interest in this study were palliative care nurses, energy providers and the energy regulator, and people receiving palliative care and family carers.

Palliative Home Care Nurses: The sample consisted of nurses working with the Irish Cancer Society national night nursing service providing palliative care to patients with a life-limiting cancer diagnosis or with palliative homecare teams in the south-east and mid-west of Ireland. Home care nurses were chosen as they have lived experience of interacting with this vulnerable population in their home over 24 hours. The inclusion criteria also required the person to have worked in their role for at least 1 year.

Energy Providers / Energy Regulator: The sample consisted of all energy companies providing a household energy service in the Republic of Ireland and the energy regulator (the Commission for the Regulation of Utilities). All were invited to participate in the study with either a structured interview or a questionnaire. The inclusion criteria required the person to be employed by an energy provider or regulator, to be involved in some respect with customer care and to have been working in this role for at least one year.

Patients/ Family Carers: The sample was patients/ family carers attending Palliative Care Services in the Republic of Ireland. The inclusion criteria required the person to be aged 18 years or older.

3.5 Study Recruitment

A recruitment strategy was implemented for each of the sample groups in the following manner. For the nurse sample, a Gatekeeper was identified from each of the services (ICS Night Nurses, Milford Care Centre, Limerick, and South East Palliative Care, Waterford). The Gatekeeper was responsible for distributing the information leaflet and the link to the online survey to all palliative home care nurses and inviting them to participate in the online survey.

Energy Providers/ Regulator Sample: Contact was made with all energy providers/ regulator via phone calls and follow up e-mail to invite them to participate in the study and requesting that they identify an appropriate person to take part in a research interview or for that person to complete the questionnaire. The companies were provided with the interview schedule /questionnaire, an information sheet and a consent form. If someone from the company was willing to participate in the study, they contacted the research team.

Patient/ Family Carers Sample: Patient/ family carers were invited via the AIIHPC Voices4care group platform to attend a webinar event to discuss the results of the nurse sample survey and their views on these findings. The webinar was arranged on two separate occasions. As only five participants registered, these people were invited to take part in a research interview. An information sheet and consent form were provided to all those who expressed an interest in in taking part in a research interview. In addition to the webinars, patients/family carers attending Palliative Care Services in the South East and Mid-West were invited to participate in individual or group interviews to discuss the results of phase 1 and their views on these. This invitation was extended through gatekeepers at each of the services. Posters/ information leaflets inviting those interested in taking part in interviews were distributed inviting potential participants to contact the researchers. Those interested in being interviewed were then provided with the study's topic guide, information sheet and consent form. The invitation was later extended nationwide via the Irish Cancer Society and AIIHPC media platforms. Those interested in participating in the study were invited to contact the research team and were then provided with the study interview topic guide, information sheet and consent form. Patients and family caregivers were given the option of attending either an individual or group interview, based on their convenience. The interview could be conducted either in person or online, depending on their preference.

3.6 Data Collection Tools

The data collection tools comprised an online survey tool for the nurse sample, an interview schedule/ questionnaire for the energy providers/ regulators and an interview topic guide for the patients/ family carers. The nurse online survey tool, hosted by Survey Monkey, was an 18-item, self-report online questionnaire containing closed and open questions. Marie Curie UK undertook a similar study with palliative home care nurses previously, and permission was received to adapt their tool (Marie Curie, 2020). Items covered included information about the houses where care was provided, energy fuel used in the homes, and views on the possible identification of energy/ financial hardship. The tool can be seen in Appendix 2. The energy provider/ regulator interview schedule can be seen in Appendix 3.The question areas focused on measures currently in place and the awareness and use of these measures. Energy providers were offered the option of completing the structured interview schedule as a questionnaire and returning their responses to the research team. The patient/ family carer interview topic guide can be seen in Appendix 4. The question areas included their views on energy hardship and how might affect a patient/ household, available supports and additional measures which might be needed.

3.7 Data Analysis

Quantitative data from the online survey was analysed using descriptive tests on the SPSS v.24 platform. Qualitative data from the open-ended questions on the survey tool and the interviews with patient/ family carers, and interviews/ questionnaires with energy providers/regulators were analysed using thematic analysis (Braun and Clarke, 2006, Braun and Clarke 2021). Phase 1 involved becoming familiar with the data, which included iteratively reading the entire dataset, transcribing it, and identifying initial patterns. In Phase 2, initial codes were generated through a thorough analysis of each line. Phase 3 consisted of interpretation of the relationships among the identified codes, resulting in the development of subthemes and overarching main themes throughout the dataset. This process culminated in the development of an initial thematic map. Phase 4 entailed the refinement of themes on two levels: examining and revising the coded excerpts for cohesiveness and verifying the themes' accuracy in representing the entire dataset in relation to the research question. In Phase 5, the main themes were given clear and descriptive titles to capture the audience's attention while accurately conveying the study's overarching findings.

3.8 Ethical Considerations

Ethical approval for the study was obtained from the relevant University Ethics Committee and the Health Service Research Ethics Committees. The ethical issues considered were anonymity/ confidentiality, informed consent, and risk of distress. The Research Team ensured that all confidentiality procedures were adhered to in relation to any personal data collected. The information sheet provided to those attending the interviews made it clear that, while their participation was known to the research team, their data would be reported to ensure that no individual is identifiable in any way in any reports/ presentation. This information was included on the information sheet and consent form, and participants were reminded of this at the beginning of the interview.

To support informed consent all participants were provided with information sheets. These information sheets can be seen in appendices 5 (nurse information sheet), 6 (patient/ family carer information sheet) and 7 (energy provider/ regulator information sheet). These consent forms can be seen in appendix 8 (patient/ family carer consent form) and appendix 9 (energy provider/ regulator consent form). Nurses were asked at the beginning of the anonymous online survey if they were happy to complete same and completion of same was taken to signiy consent.

The research team was very cognisant of the vulnerability of the groups involved in the project and the sensitive nature of the topic being discussed. Steps were taken to minimise the risk of distress and to deal with it, should it occur, including careful consideration of the survey, topic guide and interview schedule. The ethical principle of beneficence was expressed in the researcher's responsibility to minimise risks of harm, distress or discomfort to participants, with a distress protocol in place, which included how to manage the situation should someone become distressed and information on supports available.

3.9 Public and Patient Involvement

A PPI plan was developed and implemented as part of this project to ensure that people with palliative care needs, family carers and the public were involved at all stages of the project and that their voices were heard. The PPI plan aimed put in place supports for PPI contributors throughout the study, including information on the option to withdraw at any point should they so wish.

The involvement plan included the following actions:

1. Voices4Care, AIIHPC's PPI group of people with palliative care needs, family carers and interested citizens, were consulted during the project planning phase,

and reviewed the project plan. Feedback was received which supported the need for the project.

2. Voices4Care, clinicians and academic researchers were represented on the project's steering committee. Six steering group meetings were scheduled, one in-person meeting and the other online. All members of the steering group were accorded equal membership. This committee oversaw the project design, data collection and interpretation of results, and identification of appropriate dissemination.

3. PPI contributors will participate in the launch event in February 2024, being asked to present and participate in a panel discussion.

4. Patients/family carers will also be invited to the report launch event, which will take place in person in February 2024 where the research team will present the project findings to key stakeholders and policymakers. A recording of the launch will also be circulated after the event.

Chapter 4
Study Findings

This chapter presents the study findings. Section 1 outlines the results from the nurses' providing night nursing and palliative care to people with palliative care needs. The results from the energy provider/ regulator can be seen in section 4.2 and section 4.3 outlines the results from the patient/ family carer individual and group interviews.

4.1 Night nurses and palliative home care nurses

The nurse sample results are divided into two sections, which focus on descriptive data and then provide information on the families finances. All percentages are based on the total number of nurses who answered the question, and therefore, results are expressed as numbers and valid percentages.

4.1.1 Descriptive data

Night nurses and palliative homecare nurses working across 25 counties participated in the survey (Table 4.1). The majority of the respondents work in Limerick (n=19, 33%), followed by Cork (n=16, 28%), Tipperary (n=14, 24%) and Dublin (n=11, 19%). Kerry, Kildare, Offaly, Roscommon, Waterford, Wicklow were grouped and totalled 12% of the sample.

Table 4.1 Counties where respondents worked (n=58)

County	No. of Nurses	%
Limerick	19	33
Cork	16	28
Tipperary	14	24
Dublin	11	19
Clare	9	16
Galway, Laois	8	14
Kerry, Kildare, Offaly, Roscommon, Waterford, Wicklow	7	12
Kerry, Meath, Westmeath	6	10
Carlow, Louth, Mayo, Sligo	5	9
Leitrim	4	7
Cavan, Longford	3	5
Kilkenny, Wexford	2	3

A total of 56 (92%) of the sample identified that they have worked in a rural town or village. Forty-seven (77%) of the respondents have worked in an urban city and 47 (77%) also noted that they have provided support in a rural area with no neighbours in proximity. Therefore, all geographical settings were represented in the survey results with nurses working across a diversity of locations including urban, rural, large, and small towns, and cities.

Most nurses (>80%) reported that they worked in more traditional housing types such as bungalows and houses. Apartments and flats accounted for a much smaller portion of nurses work places (64%), with log cabins, convents, sheltered accommodation, and caravans being the least common properties (2-3%) attended.

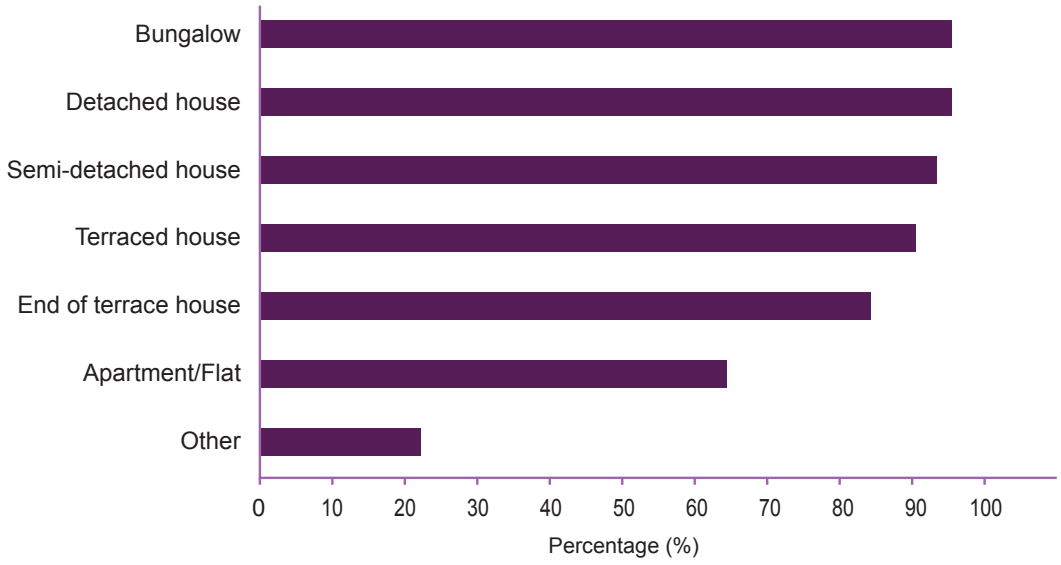


Figure 4.1 Properties where respondents worked.

The following results suggest that energy hardship is an issue which palliative home care nurses have seen in the course of their work. Respondents were asked to indicate if all the homes where they have worked have a central heating system (Figure 4.2). Nearly half of the respondents (n=28; 46%) reported that not all homes had a central heating system, with 18 (30%) indicating they did not know. Respondents were asked to estimate the percentage of homes that have a central heating system. Twenty-seven (44%) indicated they did not know, while the remaining participants stated an average answer of 83% and a range from 10% to 100%.

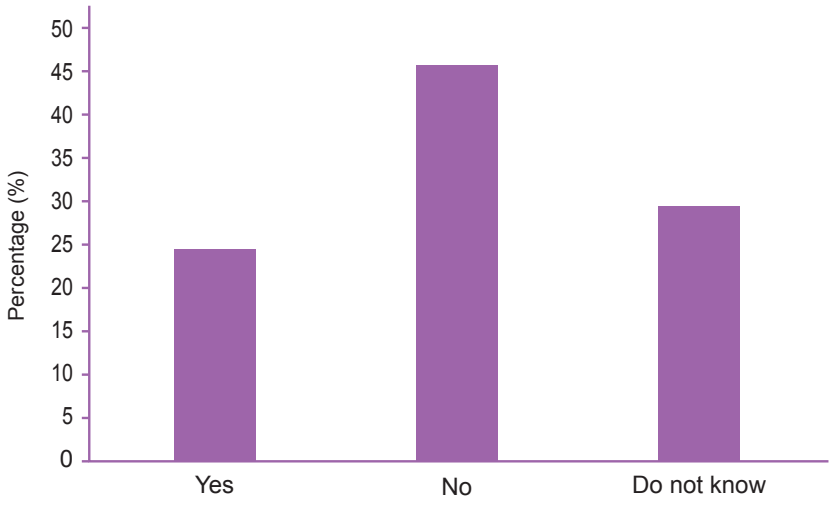


Figure 4.2 Nurses' knowledge on central heating system in home.

In a question related to types of fuels, respondents were asked to indicate if they knew in advance or during a care episode what types of energy-providing fuels are being used in the home (Figure 4.3). Thirty-six (59%) reported that they never knew, followed by 17 (28%) indicating 'some of the time', 7 (11%) stating 'most of the time' and 1 (2%) reporting they always knew the type of fuels.

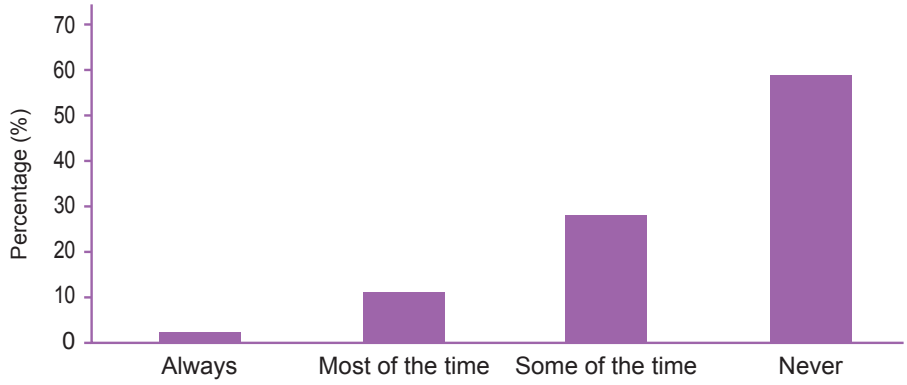


Figure 4.3 Nurses' knowledge of energy-providing fuels in the home.

While, as reported above, types of fuel used was not something most nurses reliably knew, when asked what fuels they had seen used, 57 (93%) nurses ticked 'oil'. Fifty-four (89%) respondents reported that homes were fuelled by solid fuel. Forty-six (75%) reported electricity, 31 (51%) reported gas and 9 (15%) identified LPG/bottled gas as a heating source they had seen used. Solar energy was reported by only 1 respondent (Figure 4.4).

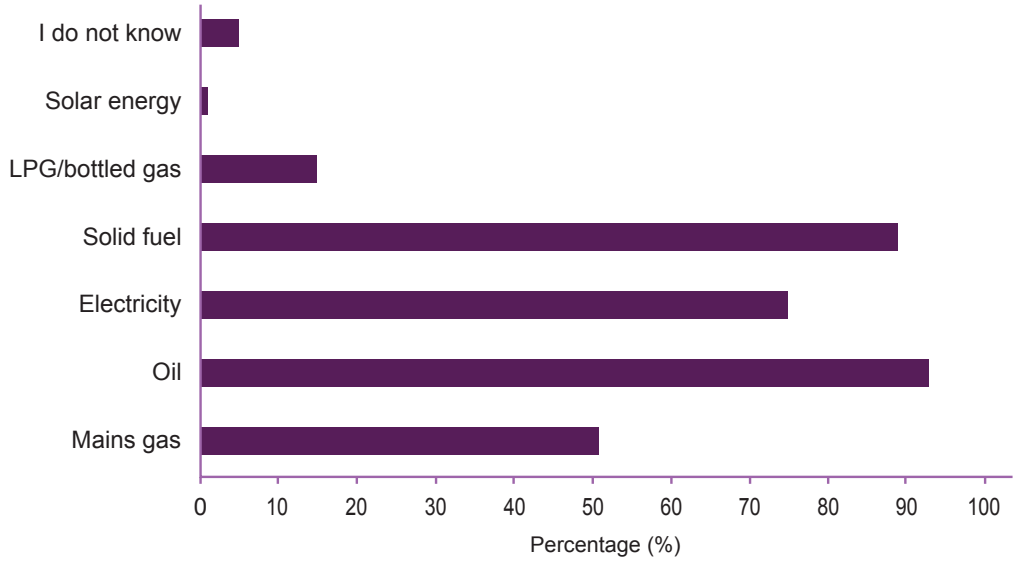


Figure 4.4 Nurses' knowledge on types of fuels used in homes.

Respondents were invited to indicate were any of the following fuel types used to help heat the home including bottled gas, electric storage heaters, electric plug-in heaters and solid fuels,. Most nurses identified solid fuel (n=56; 92%). Electric plug-in heaters and electric storage heaters were reported by 44 (72%) and 34 (56%) of the nurses respectively. Bottled gas was reported as helping to heat the home aby 11 (18%) of the nurses and 4 (7%) reported they did not know.

4.1.2 Main results: Views on housing and finances

Regarding whether homes are adequately warm at the time of support visits, 53 (87%) of nurses reported 'sometimes' and 8 (13%) reported 'always'. Instances of patients having to do without heating were reported by 20 (33%) of the respondents; 32 (53%) reported that they had not experienced a patient having to do without heating and 9 (15%) stated they did not know. When asked, 'What percentage of the patients that you have or are caring for are experiencing this hardship?', the average answer was 18% and ranged from 2% to 50%.

Respondents were invited to indicate, when working in a house with two floors, did they see a difference in the level of heat between upstairs and downstairs. Most respondents felt that there was a difference (n=37; 63%), and 22 (37%) felt there was no difference. In relation to this question, 27 (71%) of the nurses identified downstairs as being the warmest. Housing issues identified by the nurses included draughts (n=52; 93%), condensation (n=39; 70%), damp (n=36; 64%) and mould (n= 28; 50%) being evident in many homes (Figure 4.5).

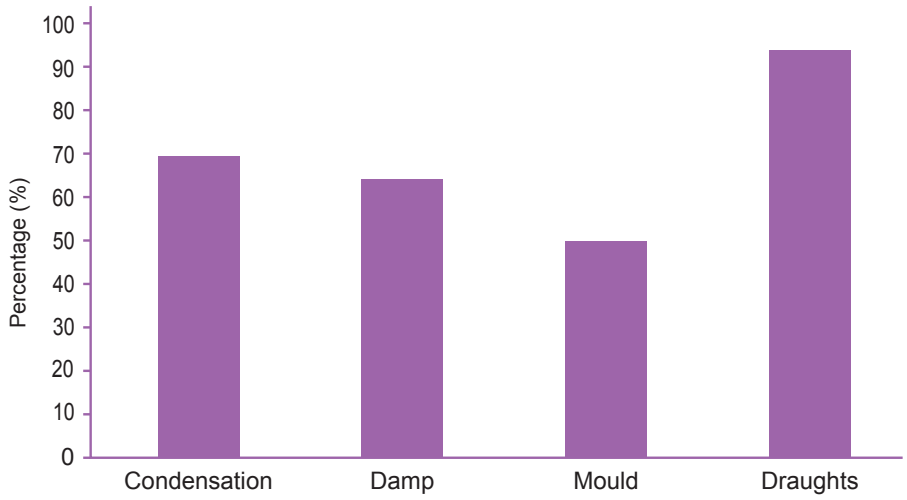


Figure 4.5 Issues evident in homes where care is provided.

When asked, 'Do you believe a patient (s) you were/ are caring for struggle to make ends meet financially?'; almost half of the nurses (n=30, 49%) reported seeing evidence of financial struggles, with only 4 (7%) nurses reporting they had not witnessed any evidence and 27 (44%) stating 'I do not know' (Figure 4.6). When asked to give an approximate percentage of patients who were struggling financially, out of 22 responses, the average answer was 25%, ranging from 5% to 70%.

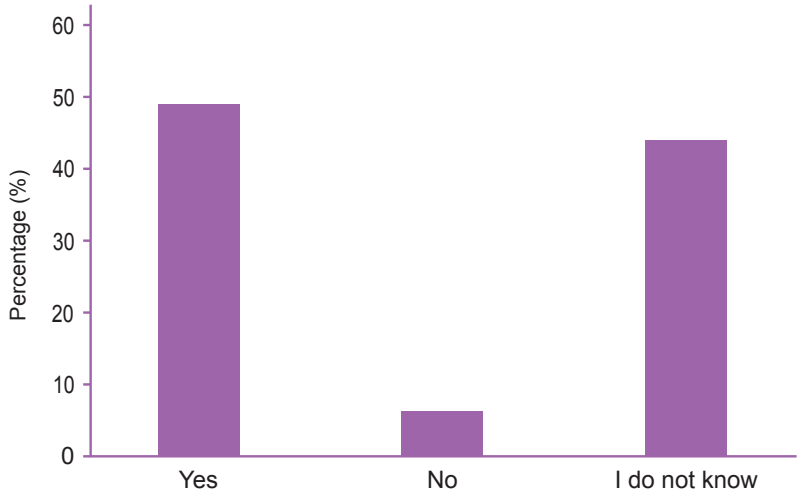


Figure 4.6 Nurse believed a patient struggling to make ends meet financially.

When asked if any patient/ family had initiated any conversations around the subject of energy hardship, 31% (19) reported that conversations about energy hardship had been initiated by patients/families. The impacts of financial struggles were seen with difficulties observed by 43 nurses including: affording suitable food (n= 8; 19%); affording to heat their home (n= 29; 67%); paying for their housing costs (e.g. other utilities, mortgage or rent payments etc.), (n= 26; 60%) ; and affording social activities (n= 13; 30%), (Figure 3.7). Running medical equipment and the increase energy requirement/ costs associated with this were raised with nurses (n= 17; 28%).

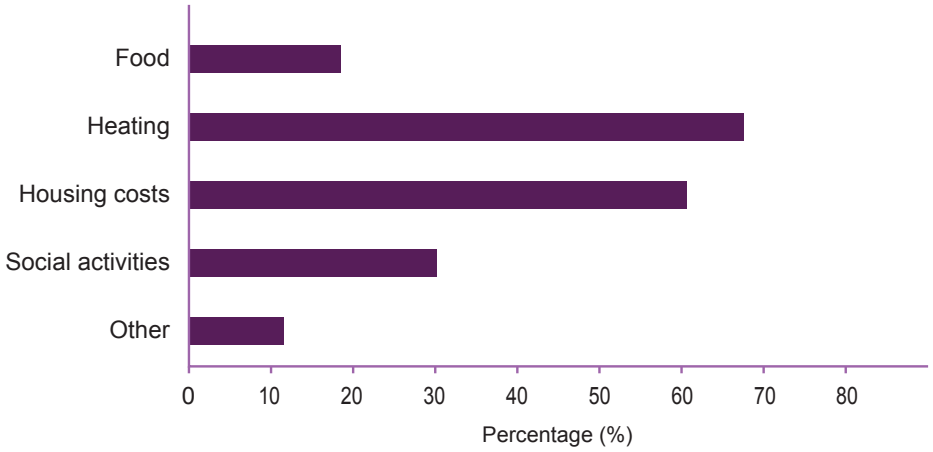


Figure 4.7 Difficulties observed related to financial struggles.

In a question related to the impact of financial struggles, half of the nurses who answered the question (n=42) believed that energy poverty negatively impacted their patient's physical (n = 21; 50%) and mental (n = 28; 66.67%) health and increased their social isolation (n=13; 31%). Six (14%) reported that they felt it hastened the deterioration of the patient's condition, and 6% reported no impact from financial struggles (Figure 3.8).

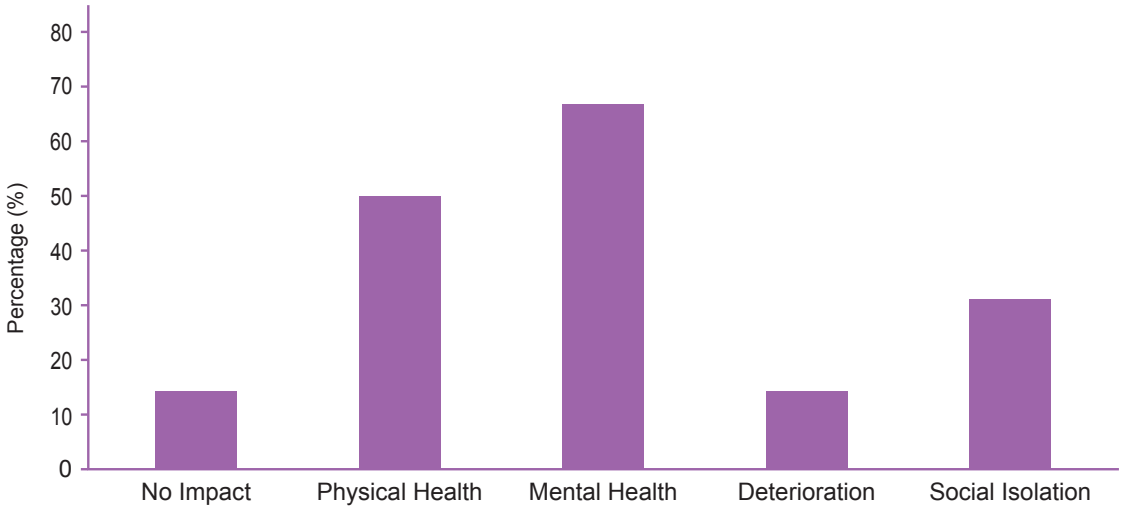


Figure 4.8 Impacts related to financial struggles.

Nurses were invited to write about any stories or experiences related to energy hardship that they would like to share in an open-ended question. Responses noted patients struggling to heat their homes and commented on homes being cold in general:

> 'I believe people will pull out all the stops…. However, I feel that some people just don't realise how cold it gets in the dead of the night …'

> 'Worked with a family that Mum and 3 children and myself in bedroom for night with blow heater and no heat in rest of house.'

> 'Numerous people stay in bed as it's warmer and cheaper than turning on heating or lighting fire.'

> 'One family….didn't have fuel for their stove for their loved one's dying days. Most people in my experience, pull together for family and friends, and fill up baskets with fuel etc...It will be different in time with folk genuinely unable to pay, due to high rents...'

> 'I have noticed in the last two years where I would not notice a house to be a cold previously I feel physically cold ….. patients are usually wrapped up in more blankets or using hot water bottles …. Heating turned off in parts of the house….. I have been in homes where children have still had no dinner late in the evening ….. no evidence of a meal being planned …..'

Nurses also commented on the worry financial struggles place on patients, family members and loved ones/ carers as they struggle to provide heat and comfort. They reported advising patients and carers in relation to supports available to them:

> 'I have been to homes that a patient was living in dire conditions but with a good network of carers so was cared for well, with emotional, nutritional and physical needs beautifully cared for …….But as I said ,I have seen a percentage of people who are cared for in less than desirable conditions.'

> 'Elderly patients who have electric plug-in heaters on 24/7 to heat the one room of the house they live in; fuel bills cause huge financial worry for a cohort of patients living off a pension or sometimes family members paying their bills'
> 'Relatives tend to worry about the loss of earnings on the passing of a loved one'

‘Concerns have been voiced regarding the increasing cost of electricity where a family has cared for their loved one for a long time……These families are more aware of the cost of electricity and running equipment e.g. electric bed, hoist, oxygen, nebuliser machines.’

‘I have directed families towards SVDP [charitable organisation], and community supports …. I have also advised citizens information and social worker in hospitals’

‘The odd time I link in with palliative care and medical social worker regarding extra financial support.’

4.2 Energy Provider-Regulator Results

All the home energy provider companies (n =10) operating in the Republic of Ireland as of May 2023 were invited via email to participate in an interview or complete a detailed questionnaire (see Appendix 4). Two staff from the Commission for the Regulation of Utilities also participated in the study.

This resulted in an 80% response rate (n = 9), with seven interested participants opting to complete the questionnaire and two to be interviewed. Key themes identified from these questionnaires/interviews included:

- The role of the Commission for Regulation of Utilities and the Energy Engage Code
- Considerations for Medically Vulnerable Customers
- Considerations for Financially Vulnerable Customers
- Additional Measures for Winters 2022-2024

4.2.1 Commission for Regulation of Utilities and Energy Engage Code

The Commission for Regulation of Utilities (CRU) is Ireland’s independent energy and water regulator (CRU) and operates within a policy and statutory framework set by the Government to benefit all customers. All suppliers identified that they work within the requirements of the Commission for Regulation of Utilities. The work of the CRU aims to ensure that energy and water supplies are safe, secure, and sustainable.

Under its legal mandate, the CRU is responsible for implementing energy-specific customer protection measures. This is carried out through the development of requirements and guidelines for energy suppliers and network companies, reflected in several documents, including Standard Terms and Conditions of Supply, Codes of Practice and Customer Charters, as detailed in the Electricity and Gas Suppliers’

Handbook (the Handbook), gas and electricity supply licences and market design rules. The Handbook sets out minimum service requirements that suppliers must adhere to in their dealings with energy customers. These rules are in place to ensure that customers experience a high standard of protection when interacting with energy suppliers.

The CRU require companies to have in a place an 'Energy Engage Code' and all suppliers confirmed this was in place. This Code outlines how suppliers will work with domestic customers, both in arrears and at risk of disconnection. The Code seeks to ensures that there is engagement between the supplier and customer and that suppliers must agree that disconnection will only be used as a last resort after all other measures are exhausted and commit to never disconnecting an engaging customer. The Code describes enhanced measures being integrated into all suppliers' debt management processes including improved communications with customers and support agencies and a range of debt management and repayment options.

This Energy Engage Code highlights that, within the debt management process, suppliers must also:

1. Never disconnect a vulnerable customer during winter months (for reasons of advanced age or physical, sensory, intellectual or mental health);
2. Never disconnect a customer who is critically dependent on electrically powered equipment, which shall include but is not limited to life-protecting devices, assistive technologies to support independent living and medical equipment;
3. Prioritise the reconnection of a customer who is found to be vulnerable after disconnection;
4. Ensure the Vulnerable Customer Register is properly maintained; and
5. Ensure that customers are notified annually of the Vulnerable Customer Register.

The CRU also deals with customer complaints about electricity suppliers and issues regular reports on these complaints. However, CRU iterated that it is not possible from these reports to determine the vulnerability status or otherwise of those making complaints. Such information is not recorded when complaints are received.

The CRU stated they are keenly aware of the significantly negative impacts on customers from high electricity and gas prices in 2022 and 2023. The CRU provides information for consumers considering changing electricity suppliers on their webpage and is supportive of the need for consumers to be aware of how to change suppliers as price is an important factor for a customer in determining which energy supplier will be best suited to their needs. The CRU provides reports on consumers and rates of switching energy suppliers.

The CRU also has a quarterly forum where they meet with various community groups who in ensuring issues can be addressed with the CRU and, therefore, energy suppliers. There is no representation from a specific palliative care perspective on this forum.

4.2.2. Considerations for Medically Vulnerable Customers

The CRU requires suppliers to have protective measures in place for registered vulnerable customers. These measures include rules around how suppliers must treat and protect such customers, communication with vulnerable customers and further protections around disconnection for non-payment of accounts.

Suppliers generally have two registers in place- a priority services register where a customer is critically dependent on electrically powered equipment, which includes, but is not limited to, life-protecting devices and assistive technologies to support independent living or medical equipment. The other, a special services register, is for those customers considered vulnerable due to advanced age or physical, sensory, intellectual, or mental health reasons.

Details on registered vulnerable customers are sent to ESB networks for inclusion in the industry register or to the Gas Point Register Operator (GPRO). For such vulnerable customers, planned disconnections are minimised, with the electricity or gas network supplier giving at least three days advance notice of the planned interruption, and in the event of an unplanned interruption to supply, these customers are prioritised for reconnection.

To be registered as a vulnerable customer with an energy supplier or network operator, the customer needs to self-register. Information on this need to self-register is provided on sign up with the supplier, and reminders are sent on an annual basis and all bills and on energy companies webpages.

However, it was the view of the CRU and several suppliers 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.

4.2.3 Financial Vulnerability Measures

All suppliers interviewed confirmed they deal with customers who are in any difficulties, including financial. Customer service teams are trained in how to deal with customers who are experiencing any problems, including financial ones. These customer service teams must be familiar with the additional services available to vulnerable customers and be able to facilitate sign-posting customers to other relevant supports such as Money Advisory Budgeting Service (MABS).

For financial vulnerability, the advice from the CRU, and therefore applied by the energy supply companies regarding difficulties in paying energy supply bills is always to contact the supplier. Energy companies are required to provide customers who have difficulty paying their bills with options to avoid disconnection.

The actions that can be taken include (where appropriate):

- Assisting the customer in making a payment plan. Suppliers are required to consider the customer's ability to pay when agreeing to any repayment arrangement, by credit or prepayment meter and confirm that arrangements are manageable.
- The supplier engaging with a money advisor acting on a customer's behalf, for example, the Money Advisory and Budgetary Service (MABS), a recognised charity, such as St Vincent de Paul Society (SVdP), Alone, or a third party.
- Some suppliers are offering, where suitable, a prepayment meter.
- Some suppliers also confirmed that they do not put someone who needs medical equipment on 'pay as you go' to avoid risk of self-disconnection.

In addition, it seems some companies have instigated a hardship fund since 2022 due to the cost-of-living crisis, which they operate in conjunction with MABS or identified charities. This is an internal voluntary measure beyond regulatory obligation. However, this is only used where a customer is engaging through the MABS or a registered charity. It seems there is a concern to ensure that this hardship fund is provided to those most in need, and hence, the MABS or a charity generally undertakes a household means assessment before the fund can be accessed. Further information on this was not available to the research team- for example, the funds available or spent or the categories of those who have benefitted from these funds.

4.2.4 Additional Measures Winters 2022-2024

Due to the increased energy cost in 2022, a moratorium against disconnection was announced in August 2022, which covered the winter period 2022-2023 and was introduced again for the winter of 2023-2024. This moratorium meant that for ordinary domestic customers (not those registered as vulnerable), the moratorium was extended from what is normally only three weeks over Christmas to now be in place from December 1, 2023, until the end of January 2024. The moratorium for customers registered as being particularly vulnerable to winter disconnections was extended in August 2022 to cover six months from 1 October 2022 until 31 March 2023, and the same applied over the winter period 2023-2024.

Additional measures were also introduced in August 2022. These included:

- Extended debt repayments for customers to allow for a minimum of 24 months to repay accumulated debt;
- All customers with a financial hardship meter were required 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.

Suppliers were also required to be fully committed to working with vulnerable Customers and to have a separate Code of Practice on Vulnerable Customers setting out the full information on services available. All suppliers in the study confirmed that this was in place, and that this information was available on their websites.

In addition, the CRU required all suppliers to provide them with a report of the actions they took to encourage their customers to reduce demand/ increasing energy efficiency.

4.3 Result from Patient- Family Carer Interviews

The views of people receiving palliative care (patients) and family carers were sought through several different methods, including webinars and individual and group interviews.

In August and September 2023, two webinar events were planned and advertised through the AIIHPC Voices4Care group. Only two people registered for the August event, and three people registered for the September event. Due to the low level of response, it was agreed that the webinars would not go ahead. Those registered were contacted and asked if they would be interested in an individual interview with a research team member. Two of those registered agreed to be interviewed. One interview took place over the telephone and the other over Zoom. Both had been carers of family members who had received palliative care for cancer in their homes. Another patient receiving palliative care for advanced cancer agreed to be interviewed over the telephone about their views on energy hardship and palliative care.

Posters were also displayed to advertise an in-person focus group for patients/ family carers in cancer centres, one in the south-east and the other in the mid-west of the country. There were no attendees for the south-east event, but four patients receiving palliative care attended the mid-west group interview. As this was a group interview, the condition for which these people were accessing palliative care was not ascertained but confirmation was provided by them that they were accessing the palliative care services.

A research participant request also went through the Irish Cancer Society social media channels. This resulted in one further family carer participant contacting the research team and a telephone interview undertaken with this person.

Therefore, the study results in this section are based on five patients and three family carers interview. The gender balance was four men, all patients, four women, one patient and three family carers. The results of all interviews were analysed using a thematic analysis, and the following themes were developed.

4.3.1 Impact of illness on energy needs and costs

Participants' homes were heated by various methods, including wood-burning stoves, coal fires with back burners, electric heaters or an oil burner. All participants agreed that energy hardship was an issue for palliative care patients at home.

All participants said that either they, as a patient, or their family member if they were a carer, were at home more than previously due to their illness/ treatment and that they felt the cold more when on treatment-

'I needed the fire on all day and felt very cold on chemo' (P5) – or when receiving palliative care.

All participants spoke of the increased cost of heating their homes, regardless of the fuel used. One patient, an older palliative care patient said their electricity cost had doubled and had *'gone sky high' (P4).* Another participant spoke about the cost of buying bags of coal and cost increase of over 50% in two years. This was a particular issue for them as

'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).

All participants, patients and family carers spoke of the need to keep the house warm. During the day, it was not just the living room area, but also bedrooms had to be kept warm as the person receiving care may have been using the bedroom during the day to rest. A participant spoke about the need to use an electric heater in the bedroom at night because the fire with the backburner would have gone out, leaving the radiator and, therefore, the room cold. Another participant described how

*'All the rooms had to be kept heated - as *** went to rest in bed during the day and I needed to keep that room warm. I also had to keep downstairs rooms heated, as *** liked to vary the rooms *** sat in - so the heating was on all day and even in the night, as he sometimes was awake and sitting up in his bedroom' (P8).*

A family carer spoke of the fact that visitors coming to see the patient meant that other living areas had to be heated and that there were associated hospitality expenses. This participant (P7) said their household costs and financial pressures went down when their relative went into hospice care. When discussing this, the participant was distressed and said that they found the move of their relative to hospice care very upsetting and added *' I wonder if I should have kept ** (relative) at home and if I agreed to use the hospice because it would reduce bills'* . In the interview, this family carer reported some relief from stress and financial costs when the person went into in patient hospice care.

This reported increase in the cost of heating a home when receiving treatment for cancer was on top of other everyday living cost increases. One family carer who had been driving their family member to medical appointments and cancer treatment said the *'cost of putting petrol in the car and parking at hospital was eating up money all the time' (P8).*

One participant voiced a view that the current housing challenge which has meant that more adult children are remaining living at home could also raise household energy costs, raising energy demands in a situation where household income may also have reduced due to reduction/ ceasing employment due to illness/ caring responsibilities (P6).

A view was expressed by an older participant and supported by the other three participants in the group interview, who were also older adults, that *'there is a big difference between a younger person and an older person getting a big (energy) bill. Older people are more vulnerable mentally and physically and are frightened by big bills. Younger people have more possibility to pay these bills with salaries and to get loans if they need to' (P3).*

It was felt that it was this fear of getting a large bill that meant that older adults might be reluctant to heat their homes and that this was *'a bad thing' (P2*) as older adults need their homes kept warm.

Several of the participants mentioned the energy efficiency of their housing, and said they were living in old, poorly insulated houses. One participant said their house was over 100 years old, and that they had *'got the ceiling insulated in two rooms, was too expensive to insulate the whole house' (P4).* Another participant said they lived in an old house, so there was no wall insulation (stone walls), but they had insulation in the roof space (P5). A third participant noted *'that grants only cover a quarter of retrofitting. Grants are given to upgrade heating but doesn't cover full cost. You still have to pay VAT. Government not in touch with full cost' (P4).* This cost was considered prohibitive, and this person had decided they could not do any housing retrofit to improve energy efficiency.

Regarding the impact of energy hardship, all in the group interview said financial pressures to pay bills would have a huge impact mentally, and one participant also noted that energy hardship can also impact people physically.

At another interview a family care participant said *'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 ** died- I ended up not sleeping and had to get sleeping tablets from my GP. A lot of this stress was financial' (P8).*

4.3.2 Dealing with Energy Companies

The theme has three subthemes, changing supplier, dealing with energy supply company when in payment difficulties and registering as a vulnerable customer.

Changing Supplier

Participants were not asked directly which supplier they were with at the time of the interview; however a range of different current suppliers were mentioned by participants in the course of the discussion. Only one of the participants, in the group interview, said they had changed supplier in the past five years. They, or rather their spouse, had moved from a bill pay to a pre- payment meter company. The reason given for this was that it was *'a means of keeping control of the bills'* (energy costs) (P1). This was also the view of a participant in a separate interview who suggested that *'perhaps a 'pay as you go' energy meter' might be of help to control energy costs'* (P6).

However, when other participants were asked if they had considered changing suppliers, one participant, a person in their 30's, said, *'No, as it seems like too much bother'* (P8). For two other older adult participants, the fact that this change seemed to be something that needed to be done online meant it was not something they considered, as they were not online at all. *'Online applications are an issue as I am not comfortable doing this administration in the digital format'* (P4). These two group participants felt that they were not alone in thinking this, as, in their view, most older people would struggle to change supplier. This was also the view of another individual interview participant: *'if this change had to be done online, older people would not think of looking online or may not have access'* (P5). Another participant, when asked if they had considered changing provider, said *'this is a problem as it can be hard to understand contracts and compare terms. I stay with the usual provider out of frustration'* (P1).

Payment Difficulties and Energy Supply Company

Of the eight participants, only one person spoke of contacting an energy supplier and the reason for this was to set up a payment plan as they went into financial arrears. As described by the participant,

> *'I ended up getting into arrears with the heating company. I had to set up a payment plan to keep on top of the bills with both the oil and electricity company' (P8).*

They expressed that '****(their relative) would have hated anyone knowing we were struggling. We didn't even tell my brother and sister, as (relative) didn't want them to know. (relative) said they had enough bills of their own. 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).* This was six months after the death of their relative.

The participant who had linked with the energy provider in financial hardship said they *'found the company very helpful'.* The energy supply company suggested to the participant to involve the Irish Money Advice and Budgeting Service (MABS), but this person felt that their relative would have found such a MABS intervention demeaning and hence declined this suggestion.

Registering as a Vulnerable Customer

Only one participant volunteered that *'It would be good to contact the electricity supply company and register as a 'vulnerable customer' when caring for someone receiving palliative care at home' (P6).* This person was also aware that registering helps ensure their house will be prioritised if an energy fault occurs and that registration

is important, particularly if medical equipment requires a continuous connection. However, only one of the other seven participants were aware that someone could register if medically vulnerable, even though two of the participants, who were not registered as vulnerable, were dependent on medical devices. In the group interview, where only one participant had registered as medically vulnerable (P4), the reason they gave was their age, not their palliative care condition; the remaining three participants were unaware of this possibility and asked what the advantages of this would be to them.

4.3.3 Awareness and use of measures/ interventions

This theme, 'awareness and use of measures/ interventions to address rising energy costs', includes the subthemes 'energy use advertising', 'government measures and interventions' and the 'role of charities'.

Energy Use Advertising

One participant, who seemed to have good awareness of energy-saving measures, viewed the current advertising, which suggested reducing the thermostat as unhelpful in a home where someone had palliative care needs as *'a home where someone has palliative care needs must be kept warm'(P6)*. The advice that people look at ways to reduce energy usage was also seen as not particularly helpful as this person believed that *'most people were already energy use conscious and hence cannot take any more steps to reduce usage' (P6).*

The current advertising on reducing the thermostat was raised in the group interview. A participant said, *'if you have an old thermostat, this might not be possible and it would cost money to have this replaced' (P3).* It was also expressed that *'maybe you get sick if you turn down the thermostat' (P2).*

A participant also had an issue with current advertising on energy hardship, which suggests linking with Energy Providers if there are any issues with paying bills (P6). This participant felt that such advertising could raise people's expectations as it might suggest that the energy company would waive bills instead of the actual outcome of such contacts that a payment schedule would be put in place for the costs outstanding and not relieve the financial pressure as the costs remain and continue to be incurred. In the group interview, three participants were not aware that they could ring electricity companies if they could not afford to pay bills. One said that a penalty is charged for overdue payments and that this is not helpful to someone is already struggling to pay bills (P2).

Government Measures/ Interventions to Support energy costs

Participants were asked about their awareness of measure to support energy costs. Two participants in the group interview mentioned the Winter Fuel Allowance and felt that *'this should be given to people with healthcare needs without means testing' (P1).* The other participant said that they had applied for Winter Fuel Allowance but were refused it because it was means tested *(P4)*.

Another participant, a family carer, believed that the government could do more to help with energy costs when caring for someone with palliative needs: *'I had a look online, but all the allowances are means tested, … we wouldn't have qualified. To be honest, I didn't even bother trying- it wasn't worth the hassle if we were going to be told no' (P8).*

The Government energy credit scheme was mentioned by four participants, with the credit acknowledged as *'making a massive impact on energy bills last year' (P2)* and the planned winter 2023-2024 credit was also welcome. As one participant said, *'Without the €200 X 3, it would have been worse' (P5)* and suggested *'it would be good if continued for people with palliative care needs – could be linked to illness in some way'.*

Participants were not aware of any other energy-related allowances. One participant mentioned the Irish Cancer Society Travel grant which they availed of when receiving treatment *(P6).*

Energy Companies

No participants were aware that electricity companies would direct customers towards MABS/ charities if they could not pay energy bills. One participant said *'corporate is corporate and has to answer to shareholders and needs to make a profit. While I feel they could do something, perhaps a fund, but I don't see the energy companies doing anything' (P5),* to help relieve energy hardship. No participant was aware that some energy companies may have hardship funds available.

Role of Charities in Energy Hardship

One participant was receiving help from a charity to pay fuel bills (P5). They only became aware of this help through a poster displayed in a community health centre. They said they only take this if absolutely necessary as they feel there are others who are more needy. They also felt there is a stigma of accessing this charity help, but that the charity is very discrete, and this is important. The person articulated that stigma might be a barrier to asking for help. Another participant *(P1)* felt it should not be the responsibility of charities to provide this energy cost support as *'It shouldn't be up to them',* while another participant said this support was likely being provided privately, '*as people mightn't want it known they needed this help' (P7).*

A family carer participant said, *'I know we could have gone to SVP, and they might have helped ….- but (relative) was very proud and we would never have needed this help before- and I also thought that at least we could still stay on top of the bills and that other people might have needed SVdP help more' (P8).*

Chapter 5
Discussion and Recommendations

This Irish Cancer Society funded study sought to examine and address the evidence gap in energy poverty for people receiving palliative care and home, where people with a life-limiting cancer diagnosis were a group of particular interest within this wider population. The study included a range of perspectives, comprising ICS night nurses, palliative home care nurses, patients/ family carers and energy supply companies and regulators.

There is little recognition that people receiving palliative care are vulnerable to energy hardship. By way of examples of this, a comprehensive review of energy poverty and deprivation in Ireland undertaken by Barrett et al. (2022) did not consider this cohort of people, and similarly, the HSE report on energy poverty (Cooney et al., 2022) did not include this group in their list of vulnerable population groups. This is a significant oversight when one considers the Marie Curie UK (2020) report which identified that, for terminally ill patients, cold and damp conditions of homes may yield consequences for health, leading to the worsening of symptoms, infections, and problems with mental health and wellbeing, and in some cases, even hastening death.

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

The CRU have a quarterly forum which includes representatives from community groups. The purpose of the forum is to enable raising of awareness of issues related to home energy supply and measures needed.

Recommendation 2:
There should be representation from a palliative care perspective on the CRU community representation forum.

The scoping review (see section 2.4) undertaken as part of this study demonstrated that energy hardship in palliative care at home was an issue about which little is known nationally and internationally with only three papers located which considered the issue. This present study replicated in part the Marie Curie UK 2020 study in that it utilised an amended tool, i.e. extended, version of the data collection tool from the Marie Curie study (Marie Curie, 2020). The scoping review undertaken as part

of the current study highlighted the absence of qualitative methods being used to examine energy hardship. This study therefore sought to also include the viewpoints of patients/ family carers and energy supply companies / regulator, capturing these through a qualitative lens.

The study results suggest that energy hardship is an issue that night nurses and palliative home care nurses have witnessed in the course of their work. Instances of patients having to do without heating were reported by 33% of the respondents. When asked about the percentage of patients who were experiencing energy hardship, the average answer from the nurses was 18% based on whom they had or were currently caring for. In addition, 49% of respondents reported seeing evidence of financial struggles. When asked to give an approximate percentage of patients struggling financially, out of 22 responses, the average answer was 25%.

Comparing our survey results in the current study to the Marie Curie UK study, they said their report sought to shed light on the scale of the problems among the people cared for by Marie Curie. When they surveyed their community nursing workforce, among those who responded, just under a third (28%) had provided care to a dying patient during the last five years who said they were struggling with the costs of heating their home.

Marie Curie said of their study that it is not to suggest that this proportion of all terminally ill people is fuel-poor but that it provides an interesting insight in lieu of wider data. The response rate to their study was 11%. The current study sample was 61 palliative home care nurses (a 23% response rate) using a purposive, non-randomised sampling frame. Therefore, the results are not generalisable. However, even accepting this, the results of the current study paint a picture wherein energy hardship is an issue in some households where patients receive palliative care, including end-of-life care.

Marie Curie in their report suggest it is likely that actual rates of fuel poverty among terminally ill people are even higher than their data suggests, as some households may feel embarrassed that they are struggling with heating costs, creating a reluctance to raise or acknowledge the problem. The absence of qualitative papers in this current study scoping review may also reflect the sensitive nature of the topic and the challenges surrounding the engagement of research participants on any qualitative investigation of the theme of energy hardship.

In the current study, the issue of embarrassment was raised in all the interviews with patients and family carers. For example, the person who said that their relative who was receiving palliative care *'would have hated anyone knowing we were struggling. We didn't even tell my brother and sister, as *** didn't want them to know. Another participant speaking more generally about the issue of energy hardship said, 'People mightn't want it known they needed this help'.*

Despite several methods being utilised to try to build up the sample size and access patients/ family carers, including offering online, in-person, individual and group interviews, there were challenges in accessing a sample for the study. The final sample was only eight participants, five patients and three family carers. The initial sample strategy was to use the palliative care services, with posters on display and health care professionals informing patients (who were in sufficiently good health to take part) and family carers about the study, particularly if conversations with the patient/ family carer had suggested that there may be an issue with energy hardship. However, this recruitment method did not lead to the recruitment of any patients/ family carers to the study.

A small number of the research team met with palliative care team members to discuss the study recruitment. While this meeting did not form part of the study data, it was noteworthy that the palliative care team members expressed that discussing the issue of energy hardship with patients and family carers was exceedingly difficult. It seemed they were not sure how to introduce the topic and felt the patients could feel very demeaned if it was suggested that they were in energy hardship. In the nurse survey sample, 44% responded that they didn't know when asked 'do you believe a patient being cared for may be struggling to make ends meet financially?'. This could reflect that they didn't know but could reflect also that many just did not feel comfortable acknowledging this hardship due to the stigma (even though they were not talking about specific houses). This is an important point, as it is unlikely to be dealt with unless the issue is being identified.

The European Commission Energy Poverty Advisory Hub (2023) held a mini-conference in March 2023 on 'Engaging All Stakeholders For A Comprehensive Approach To Energy Poverty'. At this event, a speaker (Marine Cornelis from Next Energy Consumer) discussed the role of stakeholders who hold relevant information on the risks related to vulnerability and/or energy poverty, and the importance of these stakeholders working together identifying where there is energy hardship to ensure measures can be put in place.

In the UK and other jurisdictions, training is offered to organisations/ services aimed at front-line staff, volunteers, community workers, councillors etc, who support communities/households who may be at risk of energy hardship is offered. For example, the National Energy Action (NEA) in the UK offers a range of training programmes relevant to health and social care professionals (NEA, 2024) .

The Director of Public Health Leadership Group (Cooney et al., 2022) provided a report to the Executive of the HSE in October 2022, a point in time where energy prices had rapidly escalated. This report identified the need to increase awareness among all HSE staff about the issue of energy hardship, with information on populations at risk, the adverse health impact and available interventions. The extent to which this has been undertaken is not visible to the research team.

This raising of awareness and knowledge on how to identify, raise and provide information on interventions available is essential also for other health and social care/ early childhood professionals, and governmental and non-governmental agencies who may be linking with patients/ family carers of people receiving palliative care at home.

Training could include suggesting ways to initiate conversations on energy hardship, such as focusing on the 'medical' aspect and talking about it being particularly important for medical/physical health reasons for the person to stay warm, and thus help being available, and signposting to supports, because of their health situation. This then shifts the focus from a possible stigmatising approach to a rights-based approach where the person perceives they have a right to this type of support similar to all those in their health situation. It is recognised however that such additional training could be challenging to deliver where there are other training programmes to be delivered to staff within services.

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.

While information to support those experiencing energy hardship is available, there is no standardised information pack available nationally. It appears that services and health professionals, including medical social workers, have developed their own local resources.

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.

There are a range of social welfare allowances currently in place to help with energy costs, as seen in section 2.5.2. It is essential that palliative care patients and their carers know of these allowances. It seemed from the patient/family carers interviews that there are several barriers to accessing these including means testing, which may deter people from even applying for such allowances. In the findings from this study, one family carer when speaking of financial hardship described how they had not been able to access additional social welfare supports as these were means tested. It is known that cancer, and other long-term/ terminal illnesses, result in financial hardship. The Irish Cancer Society's Real Cost of Cancer work, as seen in section 2.2, showed that many households lose on average €1,500 in income per month following a cancer diagnosis. At the same time, people face additional expenses, including medication, personal care items and utilities bills (for electricity and heating).

The ESRI report (Spandagos et al., 2023), suggests that social welfare systems and their typical criteria should not be the only channels for identifying recipients of energy poverty programs. They say if that happens, a considerable number of energy-poor households in need of assistance might be excluded from energy hardship programmes, limiting the fair character of schemes. This is very much the situation for households where a person has cancer/is receiving palliative care and where schemes based on income thresholds can lead to exclusion. Therefore, defining criteria for energy assistance provision should include additional characteristics to determine the energy vulnerability status more accurately and equitably. The routine assessment of means is used to determine eligibility for many services including

for example medical card, Fair Deal and social welfare supports. This could be considered in relation to the provision of care and support services for people receiving palliative care and their families, where such an assessment of means could be built into routine care and follow up as needed with a suitably skilled person, for example a medical social worker.

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

Leave no one behind' is the central premise of the United Nation's 2030 Agenda for Sustainable Development. It represents the commitment of all UN members to eradicate poverty in all forms, end discrimination and exclusion and reduce the inequalities and vulnerabilities that leave people behind and undermine the potential of individuals. Over the last 10 years, technological innovations have seen a vast upsurge. Over the last 15 years, Irish society has seen a massive drive by organisations to deliver services to the public in an online capacity. Most services, particularly financial, health, retail and those involving social interaction, are now carried out online. This works well for digitally connected people, but these challenges can be daunting for more marginalised communities, including older adults. Findings from this study confirm this, as digital literacy was cited as a reason for not applying for allowances or not changing electricity suppliers and may therefore be contributing to energy hardship.

Research from the Central Statistics Office (CSO, 2022) and the Irish Longitudinal Study on Ageing (TILDA, 2020) identified that 230,000+ Irish citizens over 70 never used internet, which is 46% of that demographic group. Digital adoption remains a significant challenge for many older adults and, consequently, this has limited the effectiveness of the public and commercial sectors that endeavour to serve them. Therefore, where application processes for interventions or allowances that may assist in alleviating energy hardship are solely online, this may be a deterrent to those with poor digital literacy skills or limited access to digital platforms.

Information and applications should be provided in a format that is accessible to those with palliative care needs or their carers who are not online.

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.

The CRU requires energy companies to inform their customers of the facility to register as vulnerable customers. From the study findings from the energy suppliers, this information is provided by the energy companies to customers and is also publicly available on their websites as required by the CRU.

The raising of awareness of the 'Vulnerable Customer Register' appears to be working in that the number of people registering as vulnerable for electricity supply has increased from 48,464 in August 2022 to 74,032 (an increase of 52%) in March 2023, and an increase was also seen in gas customers registering as vulnerable from 15,544 in August 2023 to 20,284 in March 2023 (30% increase).

However, most of the patients/family carers in this study had not registered their medical vulnerability. This is perhaps not surprising when one considers the study finding where energy providers and regulators acknowledge that while the numbers registering were increasing, there were likely many eligible vulnerable people not registering. Health professionals should therefore encourage palliative care patients to register as medically vulnerable. Being on the 'Vulnerable Customer Register' helps reduce the risk of disconnection, or ensure rapid re-connection in the event of disconnection, particularly important if the patient needs an energy supply for medical equipment.

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.

It is not clear from the information on all supplier's websites that physical health needs are a criterion for registration as being a vulnerable customer, although the CRU does include physical health as a criterion. This needs to be made more explicit on all supplier's websites and application forms.

Vulnerable customers on the priority services register are recognised by energy supply companies as being critically dependent on electrically powered assistive devices and cannot be disconnected for reasons of non-payment at any time (CRU, 2023). This group is considered as having extreme vulnerability in terms of energy supply. However, this restriction from disconnection may not cover someone being cared for at home with palliative care needs who does not have an energy powered medical device but needs to be cared for in a warm environment. Palliative care in this instance includes those receiving specialist and non-specialist palliative care input, and it should be considered that an energy supply to keep their home is an essential requirement for those receiving palliative care at home.

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.

Economically, it seems applying a price cap on energy prices, whether that is the wholesale rate or customer supply rate is contentious. It is recommended however to ensure there is a strong competitive energy supply market as high levels of consumer switching rates are deemed a desirable characteristic of well-functioning energy markets, as they reflect consumer ability to choose from a wide variety of available options (Harold et al., 2019). It seems that switching rates remain small in Europe (Spandagos et al., 2023).

The findings from the energy provider /regulator illustrate that while consumers are encouraged to consider switching energy providers, the number of consumers in Ireland who change suppliers is low. This energy company switching data is captured in the CRU reports. Their 2023 report (CRU 2023b) showed that just 4,070 households changed their supplier in April 2023, down from over 24,000 in the same month a year earlier, and overall figures remained down on the previous year. The suggested reason for this small number was that retail energy prices remained high after several price increases in 2022 with no cheaper competitive alternatives available. In addition, the final Government electricity credit was provided to customers in March 2023 and may have been a factor in influencing a customer's decision not to switch to another supplier until the credit has been given to them.

Consumers, including households where someone is receiving palliative care, should seek to ensure that they are paying for energy at competitive rates. However, the findings from the patient and family carer interviews found a lack of awareness and a reluctance to change energy supply providers due to a perception of it being a complex process and being done online, which is not accessible to all.

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.

Housing energy efficiency in an issue for Irish households, as seen in section 2.5.1. There are Government and Local Government supports and grant schemes in place, and an ambitious national plan to carry out 500,000 home retrofits to a B2 Building Energy Rating (BER) and is to install 400,000 heat pumps to replace older, less efficient heating systems by 2030 (Department of the Environment, Climate and Communications, 2021), in line with European policy, and in particular, Section 2.1.4 of the EU Green Deal which calls for a 'Renovation Wave' (European Commission, 2020) across Europe.

Where a person is receiving palliative care at home, be that specialist palliative care input or non- specialist, in an energy inefficient house with a low BER rating, they may not be able to have retrofitting works undertaken due to the impact on the home environment and subsequent impact on quality of life due to, for example, dust, noise, infection risk during work, supply disruption). However, even if they wish to retrofit

to make their house more comfortable and energy efficient, they may still not be in a position to do so for financial and time delay reasons.

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.

Marie Curie UK sought funding in collaboration with four UK Gas Distribution networks for an innovative scheme to help support palliative care patients in energy hardship- 'Marie Curie – Energy safeguarding and tackling fuel poverty for terminally ill people' (Marie Curie, 2022).

Their project aims to identify and support terminally ill people and their families that are suffering from fuel poverty with dedicated support and advice. There are four main areas that Marie Curie aims to address through this partnership. These include:

1. Improving information and support for people affected by fuel poverty;
2. Promoting the use of the Priority Services Register;
3. Identifying households in fuel poverty and providing them with support;
4. Reaching out to groups that are most likely to be affected by fuel poverty.

The project , funded in collaboration with energy providers in the UK, involves upskilling the Marie Curie Support Line team and the charity's frontline teams, including volunteers, we can direct people living with a terminal illness to any additional help they need around energy and financial issues.

The project is currently underway and is set to run from 2022 to 2025, with funding from energy supply companies. This project and the report generated from it could provide valuable guidance for similar projects in Ireland. In the Irish context, government departments, Health and Environment, Climate and Communications, the HSE and the Irish Cancer Society, along with energy supply companies could support similar initiatives in the future. For such a study with an intervention, it is also important that it be co-designed by stakeholders, including people with palliative care needs and their carers.

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.

Study Limitations

A limitation of the study was the sample size. For the energy providers, the response rate was 80%, which was a good response rate with data saturation reached. For the patients/ family carers, the sample was eight, with three carers and five patients. The data from the interviews revealed rich data. Vasileiou et al. (2018) discuss the issue of data adequacy in relation to sample size in qualitative research. Despite the richness of the data, the authors note that saturation cannot be claimed to have been achieved. Hence, further research is needed to ensure a diverse range of views are represented and that data saturation is reached. It is important to carefully consider the challenges of reaching participants, as demonstrated by the difficulties encountered in obtaining a sample for the current study. The sample for the nurse survey only had a 23% response rate and the results cannot be generalised due to the lack of sample randomization. It is therefore necessary to conduct further research with this group, considering how to achieve a sample that would be representative.

Conclusion

Energy hardship occurs when households cannot achieve an adequate standard of warmth and lack access to sufficient energy services at an affordable cost. 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.

The results from our primary research identified that energy hardship is an issue witnessed by night nurses and palliative home care nurses in their line of work. A third of the respondents reported incidents where patients had to go without heating, while just under a third reported that patients/families-initiated conversations about energy hardship. The financial struggle of patients was evident through reported difficulties in affording suitable food (19%), heating their homes (67.44%), paying for their housing costs (e.g. other utilities, mortgage or rent payments, etc.) (60.47%), and affording social activities (30.23%). The nurses who participated in the survey also raised concerns about running medical equipment and the increase in energy requirements/ costs associated with it, which was reported by 27.87% of them. Almost half (46%) of the nurses stated that some homes where they provided nursing care did not have a central heating system. Moreover, the survey identified housing issues such as draughts (93%), condensation (70%), damp (64%), and mould (50%) being evident in many homes. The nurses believed that energy hardship had a negative impact on their patient's physical (50%) and mental (66.67%) health and that it increased their social isolation (30.95%).

The findings from the patients and family carers confirmed that keeping their homes warm was a major issue for many of them, and the rising costs of energy, and other living costs, has posed challenges and caused significant stress to some participants. There was limited awareness of the opportunity available to register as medically vulnerable with their energy supplier despite the fact some participants were dependent on medical devices. The energy efficiency of some of the participants houses was also identified as an issue, but the cost associated with addressing this was a deterrent to some participants. Comparing energy supply rates between suppliers was not something most participants were willing to do as it was seen as cumbersome, and that it was likely an online process also deterred some participants. Not all participants qualified for social welfare energy cost supports, and the application of means testing meant that some participants were ineligible to

receive energy related social welfare payments even if they were experiencing energy hardship. There were some individuals who needed financial assistance from charities to pay their bills. However, many participants felt that asking for help would hurt their pride and believed that there were others who needed the support more than they did. The CRU requires energy suppliers to put in place measures to support consumers in managing their energy consumption, including addressing difficulties in paying bills. However, these measures may not be fully meeting the needs of individuals receiving palliative care at home. Moreover, people with palliative care needs and their carers have expressed a lack of awareness of these measures available to them.

The study is proposing recommendations to tackle energy hardship, which is a complex and multi-dimensional problem. A coordinated and multi-sectoral approach is required to address this issue effectively, by implementing a combination of supports including, but not limited to, clear information and streamlined processes to register palliative care patients as medically vulnerable, rapid access to energy hardship social welfare payments and home retrofitting upgrades, and energy hardship educational packages aimed at upskilling frontline staff in meeting the energy hardship related needs of this vulnerable group. The recommendations are broad and will require the involvement of multiple agencies in a collective effort. It is crucial that these agencies collaborate to address this complex problem, which is having a significant impact on a highly vulnerable group, that is those receiving palliative care at home.

References

Alzehr, A., Hulme, C., Spencer, A. & Morgan-Trimmer, S. (2022) The economic impact of a cancer diagnosis to individuals and their families: a systematic review. *Supportive Cancer Care,* 30(8), 6385-6404.

Arksey, H. & O'Malley, L. (2005) Scoping Studies: Towards a Methodological Framework. *International Journal of Social Research Methodology: Theory & Practice*, 8(1), 19–32.

Avanzini, M., Pinheiro, M.D., Gomes, R. & Rolim, C. (2022) Energy retrofit as an answer to public health costs of fuel poverty in Lisbon social housing. *Energy Policy,* 160, 1-13.

Ballesteros-Arjona, V., Oliveras, L., Muñoz, J. B., Lima, A.O.L., Carrere, J., Ruiz, E.M., Peralta, A., León, A. C., Rodríguez, I. M., Daponte-Codina, A. & Marí-Dell'Olmo, M. (2022) What are the effects of energy poverty and interventions to ameliorate it on people's health and wellbeing?: A scoping review with an equity lens. *Energy Research & Social Science,* 87, 1-19.

Barrett, M., Farrell, N. & Roantree, A. (2022) Energy Poverty And Deprivation In Ireland. *Research Series Number 144*. Economic and Social Research Institute. Available at https://www.esri.ie/system/files/publications/RS144.pdf. Accessed 1-1-2024

Bentley, R., Daniel, L., Li, Y., Baker, E. & Li, A. (2023) The effect of energy poverty on mental health, cardiovascular disease and respiratory health: a longitudinal analysis, *The Lancet Regional Health – Western Pacific,* 35, 1-13.

Bilodeau, M., Ma, C., Al-Sayegh, H., Wolfe, J. & Bona, K. (2018) Household material hardship in families of children post-chemotherapy. *Pediatric Blood & Cancer,* 65(1), 1-8.

Bouzarovski, S. & Petrova, S. (2015). A global perspective on domestic energy deprivation: Overcoming the energy poverty- fuel poverty binary. *Energy Research & Social Science* 10: 31–40.

Brabo-Catala, L., Cernic, A., Collins, E. & Barton, B. (2023a) The heat goes on: Simplifying the identification of energy hardship. *Heliyon,* 9(8). doi.org/10.1016/j.heliyon.2023.e19087;

Brabo-Catala, L., Collins, E. & Barton, B. (2023b) Fuel Poverty of Energy Hardship: Analysing the literature, the proposed official definition and the views of experts in Aotearoa New Zealand. *Policy Quarterly,* 18(4).

Braun, V, & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Reseach in Psychology* 3(2), 77-101.

Braun, V. & Clarke, V. (2021) Can I use TA? Should I use TA? Should I not use TA? Comparing Reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Couns Psychother Res*. 21(1),37–47.

Brown, H. & Vera-Toscano, E. (2021) Energy poverty and its relationship with health: empirical evidence on the dynamics of energy poverty and poor health in Australia. *SN Business & Economics,* 139: 1-34.

Bukari, C., Broermann, S. & Okai, D. (2021) Energy poverty and health expenditure: evidence from Ghana'. *Energy Economics,* 103, 1-10.

Carrere, J., Belvis, F., Peralta, A., Marí-Dell'Olmo, M., López, M.J., Benach, J. & Novoa, A.M. (2022) 'Effectiveness of an energy-counselling intervention in reducing energy poverty: evidence from a quasi-experimental study in a southern European city. *Journal of Urban Health,* 99, 549-561.

Central Statistics Office (2022) Census of Population 2022 - Summary Results. Available at: https://www.cso.ie/en/releasesandpublications/ep/p-cpsr/censusofpopulation2022-summaryresults// . Accessed 28-12-2023.
Central Statistics Office (2023) Consumer Price Index.
Consumer Price Index May 2023 - CSO - Central Statistics Office
Accessed 28-12-2023

Colclough, S., Kinnane, O., Hewitt, N. & Griffiths, P. (2018), Investigation of nZEB social housing built to the Passive House standard. Energy and Buildings, 179, 344-359, ISSN 0378- 7788,

Colclough, S., Hegarty, R.O., Murray, M., Lennon, D., Rieux, E., Colclough, M. & Kinnane, O. (2022) Post occupancy evaluation of 12 retrofit nZEB dwellings: The impact of occupants and high in-use interior temperatures on the predictive accuracy of the nZEB energy standard. *Energy and Buildings,* 254,111-563, ISSN 0378-7788, https://doi.org/10.1016/j.enbuild.2021.111563

Commission for Regulation of Utilities (2023) Decision on Additional Customer Protection Measures for Household Electricity and Gas Customers 2023/24. Available at Additional Customer Protection Measures Decision Paper . Accessed 15-10-2023

Commission for Regulation of Utilities (2023b) CRU Report on Retail Energy Markets September 2023. Available at https://cruie-live-96ca64acab2247eca8a850a7e54b-5b34f62.divio-media.com/documents/CRU_Report_on_Retail_Energy_Markets_September_2023_1_1.pdf Accessed 3-1-2024

Cong, S., Nock, D., Qiu, Y. & Xing, B., (2022) Unveiling hidden energy poverty using the energy equity gap. *Nature Communications* 13, 2456. https://doi.org/10.1038/s41467-022-30146-5

Cooney, F., Brennan, K., Carney, P., Carroll, C., Kearney, P., Lawlor, C., Lynch, C., Murray A.M., O'Callaghan, N. & Smith L (2022) Rapid Report on Energy Poverty for the HSE EMT from the Area Director of Public Health Leadership Group (ADPHLG). HSE. Available at https://www.lenus.ie/bitstream/handle/10147/634784/Rapid%20report%20on%20energy%20poverty%20ADPHLG%2019%20Oct%202022.pdf?sequence=1&isAllowed=y . Accessed 3-1-2023

D'Amato, M., Molino, A., Calabrese, G. Cecchi, L., Annesi-Maesano, I. & D'Amat, G. (2018)_The impact of cold on the respiratory tract and its consequences to respiratory health. *Clin Transl Allergy* 8, 20. https://doi.org/10.1186/s13601-018-0208-9

Department of the Environment, Climate and Communications (2021) National Climate Action Plan. Available at https://www.gov.ie/en/publication/7bd8c-climate-action-plan-2023/ Accessed 12-12-2023

de Vries, R. & Blane, D. (2012) Fuel poverty and the health of older people: the role of local climate. *Journal of Public Health* 35(3), 361-366. https://doi.org/10.1093/pubmed/fds094

Dogan, E., Madaleno, M., Inglesi-Lotz, R. & Taskin, D. (2022) Race and energy poverty: Evidence from African-American households. *Energy Economics* 108. https://doi.org/10.1016/j.eneco.2022.105908

Department of Communications, Energy and Natural Resources (2011) *Warmer Homes – A Strategy for Affordable Energy in Ireland.* Dublin: Government of Ireland

Department of Public Expenditure and Reform (2023) *Budget 2023 The Use of Carbon Tax Funds 2023.* Government of Ireland. Available at https://assets.gov.ie. Accessed 29-12-2023

Donaldson, G.C., Witt, C. & Näyhä, S. (2019) Changes in cold-related mortalities between 1995 and 2016 in South East England. *Public Healt*h 169, 36–40. Available at https://doi.org/10.1016/j.puhe.2019.01.008

Energy Poverty Advisory Hub (2023) *Energy Poverty Advisory Hub Lunch Talk #5* - takeaways - Engaging all stakeholders for a comprehensive approach on energy poverty. European Commission. Available at https://energy-poverty.ec.europa.eu/about-us/news/epah-lunch-talk-5-takeaways-engaging-all-stakeholders-comprehensive-approach-energy-poverty-2023-03-17_en

European Commission (2020) A Renovation Wave for Europe - greening our buildings, creating jobs, improving lives. Available at https://eur-lex.europa.eu/legal-content/EN/TXT/?qid=1603122220757&uri=CELEX:52020DC0662 .Accessed 6-3-2023

Fairburn, F. (2019) Inequalities in energy poverty. In. WHO, *Environmental health inequalities in Europe: second assessment report*, Copenhagen:.World Health Organization (WHO) Regional Office in Europe

Fegan , J. (2022) The cost of living with cancer - 'It ripped my life apart'. Irish Times. Available at https://www.irishexaminer.com/news/spotlight/arid-40778085.html Accessed 30-1-2024

Future of Rural Energy in Europe (2020) Ireland - Rural Energy Data. Available at https://www.rural-energy.eu/wp-content/uploads/2020/12/FREE-CountrySheet_A4-IRELAND_V04-09112020-approved.pdf. Accessed 3-1-2023

Government of Ireland (2023) Climate Action Plan 2023. Available at https://www.gov.ie/en/publication/7bd8c-climate-action-plan-2023/. Accessed 28-12-2023

Grant, M.J. and Booth, A. (2009) A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Information and Libraries Journal,* 26(2), 91-108

Hajat, S. (2017) Health effects of milder winters: a review of evidence from the United Kingdom. *Environmental Health* 16(1), 109. Available at https://doi.org/10.1186/s12940-017-0323-4

Halkos, G.E. & Gkampoura, E.C. (2021) Evaluating the effect of economic crisis on energy poverty in Europe. *Renewable and Sustainable Energy Reviews,* 144, 1-11

Hansford, L., Thomas, F., & Wyatt, K. (2022) How does housing affect end-of-life care and bereavement in low-income communities? A qualitative study of the experiences of bereaved individuals and service providers in the United Kingdom. *Palliative Care & Social Practice,* 16, 1-13

Harold, J., Cullinan, J. & Lyons, S. (2019) Consumer switching in European retail markets. *Oxford Economic Papers* 1–19. Available at https://doi.org/10.1093/oep/gpz044

Health Information and Quality Authority (2016) National Standards for Residential Care Settings for Older People in Ireland. Available at https://www.hiqa.ie/sites/default/files/2017-01/National-Standards-for-Older-People.pdf Accessed 15-1-2024

Irish Cancer Society (2019) The Real Cost of Cancer. Irish Cancer Society: Dublin. Available at https://www.cancer.ie/sites/default/files/2020-01/Real%20Cost%20of%20Cancer%202019%20report.pdf . Accessed 30-1-2024

Jessel, S., Sawyer, S. & Hernández, D. (2019) Energy, poverty, and health in climate change: a comprehensive review of an emerging literature. *Frontiers in Public Health,* 7, 1-19

Jones, S (2016) Social causes and consequences of energy poverty, pp. 21-39. In Csiba, K. & Meszerics, T., (eds.) *Energy Poverty Handbook.* European Parliament: Brussels

Kyprianou, I., Serghides, D.K., Varo, A., Gouveia, J.P., Kopeva, D. & Murauskaite, L. (2019) Energy poverty policies and measures in 5 EU countries: a comparative study. *Energy & Buildings,* 196, 46-60

Lawler, C., Sherriff, G., Brown, P., Butler, D., Gibbons, A., Martin, P. & Probin, M. (2023) Homes and health in the Outer Hebrides: a social prescribing framework for addressing fuel poverty and the social determinants of health. *Health and Place,* 79, 1-10

Lee, A., Sinha, I., Boyce, T., Allen, J. & Goldblatt, P. (2022) *Fuel poverty, cold homes and health inequalities.* London: Institute of Health Equity

Lima, F., Ferreira, P. & Leal, V. (2022) The role of energy affordability in the relationship between poor housing and health status. *Sustainability,* 14, 1-17

Liu, C., Yavar, Z. & Sun Q. (2015) Cardiovascular response to thermoregulatory challenges. Am J *Physiol Heart Circ Physiol.* 309(11):H1793-812. doi: 10.1152/ajpheart.00199.2015.

Llorca, M., Rodriguez-Alvarez, A. &Jamasb, T. (2020) Objective vs. subjective fuel poverty and self-assessed health. *Energy Economics,* 87, 1-13
Marie Curie (2020) *The vicious cycle of fuel poverty and terminal illness.* Marie Curie. Available at https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2020/fuel-poverty-andterminal-illness.pdf. Accessed 10 December 2023

Marie Curie (2022) GDN Collaborative Vulnerability & Carbon Monoxide Allowance (VCMA) Project Eligibility Assessment (PEA) Marie Curie – Energy safeguarding and tackling fuel poverty for terminally ill people Available at https://www.sgn.co.uk/sites/default/files/media-entities/documents/2022-08/GDN-Collaborative-VCMA-PEA-Marie-Curie-Energy-Safeguarding-Fuel-Poverty.pdf
Accessed 3-1-2023

Mendell, M.J., Mirer, A.G., Cheung, K., Tong, M. & Douwes J. (2011) Respiratory and allergic health effects of dampness, mould, and dampness-related agents: a review of the epidemiologic evidence. *Environ Health Perspect.*119(6):748-56. doi: 10.1289/ehp.1002410

Menyhért, B. (2022) *The effect of rising energy and consumer prices on household finances, poverty, and social exclusion in the EU: a preliminary empirical analysis*, JRC Science for Policy Report, Joint Research Centre (JRC): Brussels

National Energy Action (2024) Training and Assessment. Available at https://www.nea.org.uk/training/. Accessed 30-1-2024

Nawaz, S. (2021) Energy poverty, climate shocks, and health deprivations. *Energy Economics,* 100, 1-16

Näyhä, S. (2002) Cold and the risk of cardiovascular diseases. A review. *International Journal of Circumpolar Health.* 61:4, 373-380, DOI: 10.3402/ijch.v61i4.17495

O'Malley, S., Roantree, B. & Curtis J (2020) *Carbon Taxes, Poverty And Compensation Options. Esri Survey And Statistical Report.* Series Number 98. Available at https://www.esri.ie/publications/carbon-taxes-poverty-and-compensation-options. Accessed 30-12-2023

O'Meara, G. (2015) A review of the literature on fuel poverty with a focus on Ireland. *Social Indicators Research,* 128, 285-303

O'Sullivan, K.C. (2019) Health impacts of energy poverty and cold indoor temperature', in. Nriagu, J., ed., *Encyclopedia of environmental health,* 2nd Edition, Elsevier: Amsterdam, Oxford, and Cambridge, 436-443.

Oliveras, L., Artazcoz, L., Borrell, C., Palència, L., López, J., Gotsens, M., Peralta, A. & Marí-Dell'Olmo, M. (2020) The association of energy poverty with health, health care utilisation and medication use in southern Europe. SSM – *Population Health*, 12, 1-8

Oyarzún-Ruiz, T. & Espinoza, A. (2020) 'Salud física y mental, vejez y pobreza energética: una revision de la literatura', *Revista Sul Americana de Psicología,* 8(1), 33-56

Pan, L., Biru, A. & Lettu, S. (2021) Energy poverty and public health: global evidence. *Energy Economics*, 101, 1-14

Pham, M.T., Rajić, Greig, J.D., Sargeant, J.M., Papadopoulos, A. & McEwen, S.A. (2014) A scoping review of scoping reviews: advancing the approach and enhancing the consistency. *Research Synthesis Methods*, 5(4), 371-385

Pollard, A., Jones, T., Sherratt, S. &Sharpe, R.A. (2019) Use of simple telemetry to reduce the health impacts of fuel poverty and living in cold homes. *International Journal of Environmental Research and Public Health,* 16, 1-15

Pollock, D., Davies, E.L., Peters, M.D.J., Tricco, A.C., Alexander, L., McInerney, P., Godfrey, C.M., Khalil, H. & Munn, Z. (2021) Undertaking a scoping review: a practical guide for nursing and midwifery students, clinicians, researchers, and academics. *JAN – Leading Global Nursing Research,* 77(4), 2102-2113

Pope, C. (2023) Energy costs bite: 'I don't know how anyone is expected to pay a bill that big' Irish Times. Available at https://www.irishtimes.com/your-money/2023/02/04/inflation-becomes-reality-as-energy-bills-hit-the-doormats/ Accessed 30-1-2024

Press, V. (2003) *Fuel poverty and health: a guide for primary care organisations, and public health and primary care professionals,* London: The National Heart Forum

Public Health England (2014) *Fuel poverty and cold home-related health problems.* London: Public Health England, Inequity UIoH UCL Institute of Health Inequity.

Recalde, M., Peralta, A., Oliveras, L., Tirado-Herrero, S., Borrell, C., Palència, L., Gotsens, M., Artazcoz, L. & Marí-Dell'Olmo, M. (2019) 'Structural energy poverty vulnerability and excess winter mortality in the European Union: exploring the association between structural determinants and health. *Energy Policy,* 133, 1-18

Residential Tenancies Board (2023) *Rent Index- Quarter 1 2023.*
Rent Index - Residential Tenancies Board Accessed 28-12-2024

Riva, M., Makasi, S.K., O'Sullivan, K.C., Das, R.R., Dufresne, P., Kaiser, D. & Breau, S. (2023) Energy poverty: an overlooked determinant of health and climate resilience in Canada. *Canadian Journal of Public Health,* 114, 422-431

Roberts, D., Vera-Toscano, E. & Phimister, E. (2015) Fuel poverty in the UK: Is there a difference between rural and urban areas? *Energy Policy* 87, 216–223

Robinson, C., Bouzarovski, S. & Lindley, S. (2018) Getting the measure of fuel poverty: The geography of fuel poverty indicators in England. *Energy Research & Social Science* 36, 79– 93. https://doi.org/10.1016/j.erss.2017.09.035

Sawyer, A., Sherriff, N., Bishop, D., Darking, M. & Huber, J.W. (2022) It's changed my life not to have the continual worry of being warm'' – health and wellbeing impacts of a local fuel poverty programme: a mixed-methods evaluation. *BMC Public Health,* 22, 1-16

Siksnelyte-Butkiene, I., Streimikiene, D., Lekavicius, V. & Balezentis, T. (2021) Energy poverty indicators: A systematic literature review and comprehensive analysis of integrity. *Sustainable Cities and Society* 67. https://doi.org/10.1016/j.scs.2021.102756

Social Justice Ireland (2023) *Budget 2023 Analysis & Critique.* Available at. https://www.socialjustice.ie/system/files/file-uploads/2022- 09/Budget%202023%20Analysis%20-%20Full%20Document.pdf. Accessed 3-1-2024

Spandagos., C, Tovar Reaños. M,A, & Lynch MÁ (2023) ESRI Working Paper No. 762. *Energy poverty prediction and effective targeting for just transitions with machine learning.* Available at https://www.esri.ie/publications/energy-poverty-prediction-and-effective-targeting-for-just-transitions-with-machine. Accessed 29-12-2023

Stanton, G. (2018) *Healthy Ireland and the Warmth and Wellbeing Pilot Scheme.* Energy Action. European Energy Poverty Conference 2018. https://slideplayer.com/slide/14386296/ Accessed 31-7-2023

Sustainable Energy Authority Ireland (2022) *National Retrofit Plan Quarterly Progress Report Full Year 2022.* Available at https://www.seai.ie/publications/SEAI-Retrofit-Annual-Report-2022.pdf. Accessed 15-1-2024

Sustainable Energy Authority Ireland (2023) *Promoting retrofitting among homeowners in Ireland through a behavioural lens. Evidence review and policy recommendations.* Available at https://www.seai.ie/publications/Promoting-retrofitting-among-homeowners-in-Ireland-through-a-behavioural-lens.pdf. Accessed 15-1-2024

The Irish Longitudinal Study on Ageing (2020) *Internet access and use among adults aged 50 and over in Ireland: Results from Wave 5 of The Irish Longitudinal Study on Ageing.* Available at https://tilda.tcd.ie/news-events/2020/2016-%20covid19-techhabits/. Accessed 28-12-2023

Tod, A. &Thomson, H. (2016) Health impacts of cold housing and energy poverty', 39-56, in Csiba, K. and Meszerics, T., eds., *Energy Poverty Handbook,* European Parliament: Brussels.

Tovar Reaños, M.A. & Lynch, M.A. (2022) *The benefits of action on implementing carbon taxation in Ireland,* Economic and Social Research Institute (ESRI), ESRI Research Bulletin, ESRI: Dublin.

Trading Economics (2023) Ireland Food Inflation.
Ireland Food Inflation - *Trading Economics* Accessed 30-12-2024

United Nations (2016) *Principle 2 - Leave no one behind.* Available at https://unsdg.un.org/2030-agenda/universal-values/leave-no-one-behind Accessed 2--1-2024

Vasileiou, K., Barnett, J., Thorpe, S. &Young T. (2018) Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Med Res Methodol* 18, 148. https://doi.org/10.1186/s12874-018-0594-7

Wågström, A. & Michael, K. (2023) Caring for energy, energy to care: exploring the energy-care nexus through examples from Sweden and India. *Energy Research & Social Science,* 99, 1-5

Wang, C., Wang, J. & Norbäck, D. (2022) A systematic review of associations between energy use, fuel poverty, energy efficiency improvements and health. *International Journal of Environmental Research and Public Healt*h, 19, 1-29

World Health Organisation (2018) *WHO housing and health guidelines,* World Health Organization (WHO): Geneva.

Willand, N. (2022) Opportunity, ideal or distraction? Exploring stakeholder perceptions of tackling energy poverty and vulnerability among older Australians. *Energy Research & Social Science,* 94, 1-11

Xu, W., Xie, B., Lou, B., Wang, W. & Wang, Y. (2022) Assessing the effect of energy poverty on the mental and physical health in China – evidence from the China family panel studies. *Frontiers in Energy Research,* 10, 1-17

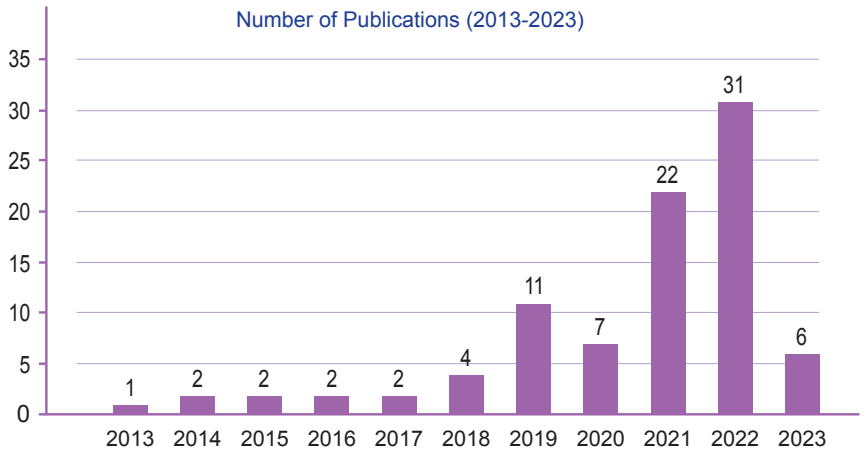
Appendices
Appendix 1

Additional Results from Scoping Review

Topics of Focus of the Literature in Relation to Health	n (%)
General Health	58 (48.3%)
Mental Health / Depression / Anxiety	14 (11.7%)
Wellbeing	13 (10.8%)
Disability / Long-Term Illness	5 (4.2%)
Public Health	4 (3.3%)
Health Service / Healthcare Facilities	4 (3.3%)
Respiratory Health / Condition / Infection	4 (3.3%)
Health Expenditure	3 (2.5%)
Mortality	2 (1.7%)
Comfort / Quality of Life	2 (1.7%)
Injuries / Accidents / Poisoning	2 (1.7%)
Obesity	1 (0.8%)
Cancer	1 (0.8%)
Terminal Illness	1 (0.8%)
At Home Care	1 (0.8%)
Lung Function	1 (0.8%)
Stunting	1 (0.8%)
Diarrhoea	1 (0.8%)
COVID-19	1 (0.8%)
Cardiovascular Disease	1 (0.8%)

Table 1: Topics of focus of the literature in relation to health.

The scoping review also revealed that there seems to have been a steady growth over the last 10 years of literature focusing on energy poverty and health, which may indicate an increase in interest on the topic, as shown in Graph 2. Note that our database search took place between March and April 2023, which explains why the number of publications for 2023 is low.



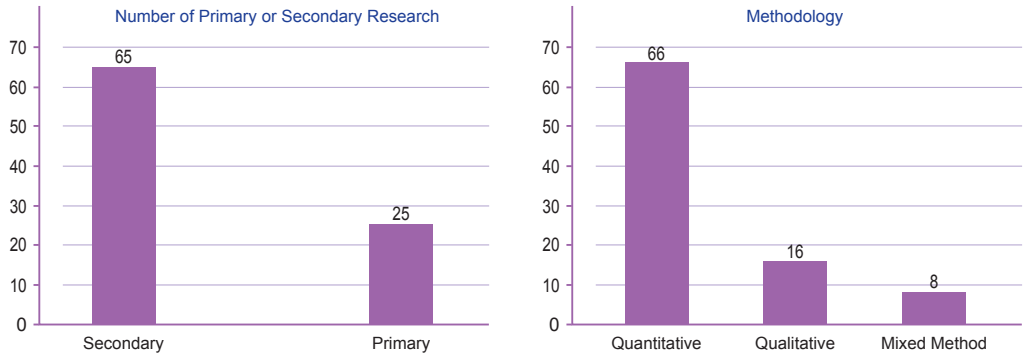
Graph 1: Number of works published per year between 2013 and 2023 focusing on energy poverty and health.

In relation to the types of studies in the literature featured in the present scoping review, the overwhelming majority were academic papers, accounting for 82.2%. Other types of publications included reports, book chapters, encyclopaedia articles, editorials, discussion papers, article summaries, conference papers, protocols, and glossaries. Literature which was not accessible was excluded during the screening process. Pre-print academic papers which had not been peer reviewed or yet accepted for publication were not included, neither were conference paper abstracts.

Type of Publication	n (%)
Academic Paper	74 (82.2%)
Report	7 (7.8%)
Chapter	2 (2.2%)
Encyclopedia Article	1 (1.1%)
Editorial	1 (1.1%)
Discussion Paper	1 (1.1%)
Article Summary	1 (1.1%)
Conference Paper	1 (1.1%)
Protocol	1 (1.1%)
Glossary	1 (1.1%)

Table 2: Type of publication.

Most of the works reviewed were secondary research, precisely 72.2% (n=65), while primary research made up 27.8% (n=25) of the literature. With regards to methodology employed in the literature, the majority was comprised of quantitative works, that is 73.3% (n=66). Only 17.8% (n=16) used qualitative methods and 8.9% (n=8) were mixed method.



Graph 2 and 3: Number of Primary or Secondary Research and Methodology.

Survey analysis accounted for 56.7% of the works found, followed by studies that had used multiple methods (17.8%), and surveys (11.1%). Other methods included literature review, systematic review, interviews, legal analysis, and scoping review. Studies which utilised multiple methods included controlled trials, interviews, focus groups, survey, survey analysis, comparative analysis, case studies, evaluations, narrative reviews, systematic reviews, literature reviews, and pilot studies.

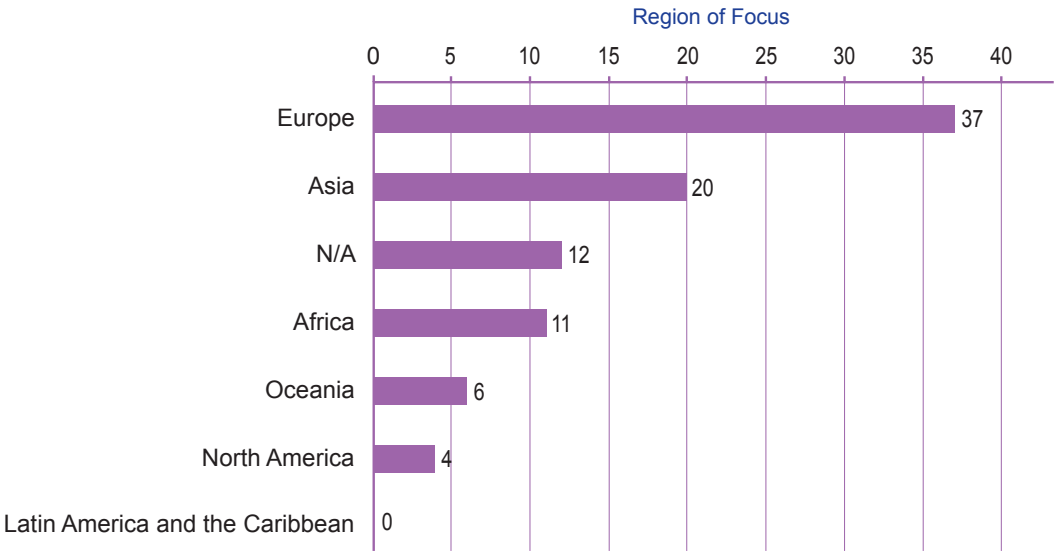
Methods Used	n (%)
Survey Analysis	51 (56.7%)
Multiple Methods	16 (17.8%)
Survey	10 (11.1%)
Literature Review	7 (7.8%)
Systematic Review	1 (1.1%)
Interviews	1 (1.1%)
Legal Analysis	1 (1.1%)
Scoping Review	1 (1.1%)

Table 3: Methods used in the literature.

With respect to geographical focus, most studies have focused specifically on Europe (n= 37, 41.1%), followed by Asia (n=20, 22.2%). Studies which either had a global focus, a focus on developed or developing countries, or that did not focus on any specific region accounted for 13.3% (n=12) (labelled in Graph 4 as 'NA'). Of the European countries featured in the literature, the United Kingdom (UK) was the most studied, followed by Spain and Ireland. In Asia, most of the works in the literature focused specifically on China. The literature on Oceania focused exclusively on Australia, and the literature on North America included mostly studies on the United States. The literature on the African region focused on different countries, including Ghana, Kenya, Uganda, Cameroon, Nigeria, South Africa, and Senegal. Literature focusing on Latin America and the Caribbean was not found. However, this does not mean that literature on the topic focusing on this specific region does not exist. Perhaps this was a result of the scoping review criteria, which limited our analysis to publications in the English language only.

Groups	Children
	Gender /Women
	The Elderly
	Parents / Families
Group Characteristics	Vulnerable
	Rural
	Community
	Students
Aspects of Energy Hardship	Measuring Energy Hardship
	Definition
	Multidimensional Aspect
Intervention and Evaluation	Reducing Energy Hardship / Energy Efficiency Measures
	Evaluation of Intervention
Impacts of Energy Hardship	Labour Market Participation
	Food Insecurity / Nutrition
	Education
	Individual Development
Housing	Affordable Housing
	Private Rented Accommodation
	Public / Social Housing
	Housing Conditions / Temperature
Economy / Policy / Legal Aspects	Energy Prices
	Economic Crisis
	Transport Poverty
	Inequality
	Policy
	Legal Aspect
Climate Change	Climate Change / Climate Shocks

Table 4: Other topics of focus of the literature.



Graph 4: Region of focus of publications. (N/A - this includes the literature which either had a global focus, a focus on developed or developing countries, or that did not focus on any specific region)*

Appendix 2
Palliative Home Care Nurses Survey

Study: Energy hardship - Understanding issues for people with palliative care needs at home and promoting actions

We would be grateful if you could please complete the below survey.

Information about the households in which you provide care

1. Please tick all that apply. Are you working and providing support in:

☐ an urban city or suburbs
☐ a rural town or village
☐ a rural area with no neighbours close

2. Please state the county/ counties you work in

_____

3. What types of property do you provide support in? Please tick all that apply.

☐ Apartment/ Flat
☐ End of terrace house
☐ Terraced house
☐ Semi-detached house
☐ Detached house
☐ Bungalow
☐ Other. Please specify: _____

Information on the fuels used in the home

4. Do all of the homes where you work have a central heating system?

☐ Yes
☐ No
☐ Do not know

Of the homes where you work, what % do you estimate have a central heating system?

_____%
☐ Do not know

5. Do you know in advance or during a care episode, what type of energy-providing fuels are being used in the homes where you provide care?
☐ Always
☐ Most of the time
☐ Some of the time
☐ Never

6. Which type of fuel or fuels have you seen used in the homes where you provide care? Tick all that apply.

☐ Mains gas
☐ Oil
☐ Electricity
☐ Solid fuel
☐ LPG/bottled gas/gas tand
☐ Other. Please specify: _____
☐ I Do not know

7. Are any of the following used to help heat the home? Tick all that apply.

☐ Bottled gas
☐ Electric storage heaters
☐ Electric plug-in heater
☐ Solid fuels (wood, coal, turf)
☐ Other. Please specify: _____
☐ None of these
☐ Do not know

Information on the household and finances

8. Do you think the homes where you are providing support are adequately warm:

☐ Always
☐ Sometimes
☐ Never
☐ Do not know

9. Have you experienced a case where you felt that the patients had to go without heating?

☐ Yes
☐ No
☐ I Do not know

If yes, in your opinion, what % of the patients you have / are caring for are experiencing this hardship
_____%

10. In a house with two floors, do you see a difference in the level of heat between upstairs and downstairs

☐ Yes
☐ No

11. If so, which is warmest?

☐ Upstairs
☐ Downstairs

12. Have you seen these problems evident in the homes where you provide care. Tick all that apply.

☐ Condensation
☐ Damp
☐ Mould
☐ Draughts
☐ Other. Please specify: _____

13. Do you believe a patient (s) you were/ are caring for struggle (d) to make ends meet financially?

☐ Yes
☐ No
☐ I Do not know

If yes, could you give an approximate percentage _____%

14. Did any patient/ family initiate any conversations around the subject of energy hardship?

☐ Yes
☐ No

15. If you believe the patient is struggling to make ends meet financially, which of the following difficulties have you observed related to this? Tick all that apply.

☐ Affording suitable food
☐ Affording to heat their home
☐ Paying for their housing costs (e.g. other utilities, mortgage or rent payments etc.)
☐ Affording social activities
☐ Other. Please specify: _____

16. If you are aware that a patient has struggled financially in relation to energy costs, which of the following impacts have you observed? Tick all that apply.

☐ No impact
☐ Made their physical health and wellbeing worse
☐ Made their mental health and wellbeing worse
☐ Hastened the deterioration of their condition
☐ Increased their social isolation
☐ Other. Please specify: _____

17. Has any patient/ family carer discussed increased energy consumption/costs as a consequence of increasing need for equipment such as oxygen, c-pap machine

☐ Yes
☐ No

18. Are there any stories or experiences you have had that are related to these issues and that you would like to share with us? Please describe them below

Please respect patient and family confidentiality if responding to this question. You should not provide any information that could identify a particular patient or someone close to them.

Appendix 3
Energy Provider / Regulator Interview Schedule / Questionnaire

Energy Hardship in Palliative Care at Home:
Understanding Issues and Promoting Actions

Welcome to this interview. We want to thank you for joining us today and we really appreciate your participation in this first study in Ireland exploring energy hardship in palliative care.

The topics we will explore are as follows

1. What are the measures currently in place at your company for vulnerable customers?

2. What criteria do customers need to meet to avail of these measures?

3. How do you raise awareness of these available measure among your customers?

4. What percentage of your customers avail of these measures?

5. Has your company adapted or changed measures for vulnerable customers as a response to the current cost of living crisis?

6. Are there plans to develop/expand on these measures in the near, medium or long term future?

Appendix 4
Patient/ Family Carer Semi-structured Interview Schedule

We hope to get your views on the following questions.

Energy Hardship

1. Do you think energy hardship is an issue for people receiving palliative care at home?

2. How might this energy hardship affect those in the household?

3. Are you aware of any support measure which may help with energy hardship?

4. Are you aware of any support from energy providers?

Energy Hardship and Quality of Life

5. Quality of life is the degree to which an individual is healthy, comfortable, and able to participate in or enjoy life events. How might energy hardship affect quality of life?

Possible Measures Needed to Help Address Energy Hardship

6. What could the government implement to help overcome energy hardship for those affected by palliative care?

7. What do you think energy companies could implement to help overcome energy hardship for those affected by palliative care?

8. In what way should or could charities be involved in helping overcome energy hardship for those affected by palliative care?

9. Can you identify anything else that could help with energy hardship?

Sample Poster Patient Family Carer Invitation

Are you a palliative care patient or family caregiver?

Our research team would love to hear from you to understand the impact of rising energy and heating costs on your life.

Why is this study important?
With home heating costs soaring, we aim to address and promote actions to help those in need.

What we've done so far:
Our survey with palliative home care nurses has revealed valuable insights. Now we want to hear from you!

Join us for a group conversation
Tea and coffee provided!

When: 13 December 2023, at 2:00pm – 3:00PM
Where: Palliative Day Care Unit, Milford Care Centre, Plassey Park Rd.., Sreelane, Castleroy, Co. Limerick

SETU Ollscoil Teicneolaíochta an Oirdheiscirt South East Technological University
AIIHPC All Ireland Institute of Hospice and Palliative Care
DCU
Irish Cancer Society
Milford Care Centre (Under the auspices of Little Company of Mary)

For more information, please contact: pilar.luzrodrigues@setu.ie

Appendix 5
Information Sheet Nurse Participants

Study title: Energy Hardship in Palliative Care at Home: Understanding Issues and Promoting Actions to Improve Quality of Life

Principal Investigator's name:	Dr Suzanne Denieffe
Principal Investigator's title:	Head of School of Humanities
Telephone number of Principal Investigator:	051-302250
Data Controller's/Joint Controller's identity:	Dr Suzanne Denieffe
Data Controller's/Joint Controller's contact details:	As above
Data Protection Officer's identity:	Corina Power
Data Protection Officer's contact details:	Room TL2.54, Tourism and Leisure Building, South East Technological University, Waterford Campus 051 302608; dataprotection@wit.ie

You are being invited to take part in a research study to be carried out by a Team of researchers led by Dr Suzanne Denieffe, South East Technological University in partnership with the All Ireland Institute for Hospice and Palliative Care and Dublin City University.

Before you decide whether or not you wish to take part, you should read the information provided below carefully and, if you wish, discuss it with your family and friends. Take time to ask questions – Do not feel rushed and Do not feel under pressure to make a quick decision.

You should clearly understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. This process is known as 'Informed Consent'.

You Do not have to take part in this study.

Why is this study being done?

This research study is taking place to find out if people with a life limiting cancer diagnosis, who are receiving palliative care at home experience energy hardship. Energy hardship is when some one is not able to achieve a good level of warmth and comfort, and supply of energy in their home at an affordable price.

This research study has three parts. In this first part, we are asking you, a nurse who cares for people with a life limiting illness, what their experiences are when caring for these people who are at home in terms of energy hardship. The researchers will also interview energy companies to find out their experiences of supplying energy to people who have palliative care needs and will hold interviews with patients/ family carers.

This part of the research study is the part where we would like you to complete an online survey to get you views and experiences if you have seen energy hardship in the people who require palliative care and their families.

Who is organising and funding this study?

Dr Suzanne Denieffe, from South East Technological University is the lead researcher of this research study. A team of researchers will be helping with this study. The research study is funded by the Irish Cancer Society through a research grant.

Why am I being asked to take part?

You are being asked to take part in this study because you are working in palliative home care.

How will the study be carried out?

This research will take place online with a survey available to you via a link.

What will happen to me if I agree to take part?

If you decide to participate in this research study, you will be asked to compete the survey. The survey will take approximately 15 minutes to complete. You will not be able to be identified. We ask that you Do not give us any information that will enable either you or the people you care for to be identified. Should this occur, the research team will delete this data prior to the data analysis stage.

What are the benefits?

You may not benefit directly from taking part in this study. You will be providing information that will help to inform the researchers about the experiences of energy hardship for people who are receiving palliative care. This may help people in a similar situation in the future.

What are the risks?

There are minimal risks to you when taking part in this study. You may feel upset at some of the frustrations felt around energy hardship.

What if something goes wrong when I'm taking part in this study?

If you get upset or frustrated in relation to the subject of the survey, we suggest you talk to a friend or a colleague, or avail of the support services within your organisation.

Will it cost me anything to take part?

There are no costs to take part in the *survey.*

Is the study confidential?

Yes, You cannot be identified from your survey responses. Should you include any identifiable information, this will be deleted by the research team prior to inclusion in the data set for analysis.

The information gathered from the survey will be used in a final Research Report. This report will be published. The research study results will also be presented at national and international conferences and published in medical journals. There will be no way of identifying individuals from the results presented or published.

Data Protection

We will not have access to any personal information about you- as your participation is anonymous.

The data is being processed for the purpose of scientific research (General Data Protection Regulation 2016, Article 9(2)(j))

Only the members of the research team will have access to the data from the study.
The survey data will be stored for 10 years and will then be destroyed by shredding.

A data breach would not result in any harm to you as you would not be identifiable in any way.

Completing the survey online indicates that you are consenting to take part in the study. As the survey is anonymous, we will not be able to identify you should you wish to withdraw from the study after completing the online survey.

You have a right to lodge a complaint with the Data Protection Commissioner.

Where can I get further information?

If you need any further information now or at any time in the future, please contact:

Name Dr Suzanne Denieffe
Address: Head of School of Humanities
South East Technological University
College Street Campus
Cork Road
Waterford.
Phone No: 051-302250
Email- Suzanne.denieffe@setu.ie

Thank you for taking time to read this Research Information Sheet.

Appendix 6
Patients/ Family Carer Information Sheet

Study title: Energy Hardship in Palliative Care at Home: Understanding Issues and Promoting Actions to Improve Quality of Life

Principal Investigator's name:	Dr Suzanne Denieffe
Principal Investigator's title:	Head of School of Humanities
Telephone number of Principal Investigator:	051-302250
Data Controller's/Joint Controller's identity:	Dr Suzanne Denieffe
Data Controller's/Joint Controller's contact details:	As above
Data Protection Officer's identity:	Corina Power
Data Protection Officer's contact details:	Room TL2.54, Tourism and Leisure Building, South East Technological University, Waterford Campus 051 302608; dataprotection@wit.ie

You are being invited to take part in a research study to be carried out at Milford Care Centre, Limerick / Palliative Care Unit, University Hospital Waterford by Dr Suzanne Denieffe.

Before you decide whether or not you wish to take part, you should read the information provided below carefully and, if you wish, discuss it with your family, friends or medical team. Take time to ask questions – Do not feel rushed and Do not feel under pressure to make a quick decision.

You should clearly understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. This process is known as 'Informed Consent'.

You do not have to take part in this study. If you decide not to take part, it won't affect your future medical care.

You can change your mind about taking part in the study any time you like. Even if the study has started, you can still opt out. You Do not have to give us a reason. If you do opt out, rest assured it won't affect the quality of treatment you get in the future

Why is this study being done?

This research study is taking place to find out if people with a life limiting cancer diagnosis, who are receiving palliative care at home experience energy hardship. Energy hardship is when you are not able to achieve a good level of warmth and comfort, and supply of energy in your home at an affordable price.

This research study has three parts. In the first part, we asked nurses who care for people with a life limiting illness what their experiences are when caring for these people who are at home in terms of energy hardship. The researchers will also interview energy companies to find out their experiences of supplying energy to people who have palliative care needs.

This part of the research study is the part where we would like to hear the views and experiences of energy hardship from people who require palliative care and their families. In order to hear the views and experiences of people who require palliative care, we are inviting you to take part in an individual interview where we will ask questions about energy hardship.

Who is organising and funding this study?

Dr Suzanne Denieffe, from South East Technological University is the lead researcher of this research study. A team of researchers will be helping with this study. The research study is funded by the Irish Cancer Society through a research grant

Why am I being asked to take part?

You are being asked to take part in this study because you are receiving palliative care, or a family member is receiving palliative care.

How will the study be carried out?

This research will take place in a room, in the Milford Care Centre, Limerick or the Palliative Care Unit at University Hospital Waterford or a location that you would like. The research will take place in June 2023. In total, we will be gathering information from up to 12 people who receive palliative care and their families. We will gather information by asking you questions. We will give you information on the specific question areas we would like to ask you. An experienced person from the research team will do the interview with you.

What will happen to me if I agree to take part?

If you decide to participate in this research study, you will be asked to attend an interview at either Milford Care Centre, Limerick or The Palliative Care Unit at University Hospital Waterford or a location of your choice.

During the interview , the interviewer, who is one of the research team will ask questions to you about views and experiences of energy hardship. All of the people who agree to be interviewed will be asked the same questions. We will give you these questions prior to the interview. There will also be two of the research team taking notes of the conversation. This is to ensure that we have an accurate account of the conversation.

The interview will take up to 45 minutes. You Do not have to provide any medical information and the researchers will not have any access to your medical notes.

Video/and or Audio recordings?

There are no video or audio recordings being taken in this study.
Notes will be taken during the interview. These notes will be provided to you if you wish to read them after the interview. You will be able to request changes to be made to these if you see they are inaccurate. These changes can be made within one month of the interview.

What are the benefits?

You may not benefit directly from taking part in this study. You will be providing information that will help to inform the researchers about the personal experiences of energy hardship for people who are receiving palliative care. This may help people in a similar situation in the future.

What are the risks?

There are minimal risks to you when taking part in this study. You may feel tired during or after the interview as this will take up to 45 minutes. You may feel upset at some of the frustrations felt around energy hardship. Support is available if you are upset from the Irish Cancer Society Support line - Phone number 1 800 200 700

What if something goes wrong when I'm taking part in this study?

If you get upset, unwell or frustrated during the interview, we will pause the interview. You can choose to stop the interview completely, begin again if you like or re-schedule or withdraw from the study.

We would also encourage you to use the Irish Cancer Society Support line if you do feel upset.

Will it cost me anything to take part?

There are no specific costs to take part in the interview. There is no reimbursement available.

Is the study confidential?

This interview with you will gather information which will be recorded in note form by the researchers. No personal identifiable information will be documented during this time. The notes from the interview will be kept in a secure place, a locked filing cabinet, by the research team in South East Technological University. The notes will not use your name but instead will use a pseudonym. The key code to these pseudonyms will always be kept separate to the notes. The code will only be available to the research team members who attended the interview.

Should you wish to withdraw from the study, you may do so up to one month following the interview by contacting Dr Pilar Rodrigues (email… .) or Dr Suzanne Denieffe, details as below. After this time the information gathered during the interview, will be analysed and categorised into themes. It will not then be possible to remove your data. There will be no way to identify any individual.

The information gathered from the interview will be used in a final Research Report. This report will be published. The research study results will also be presented at national and international conferences and published in medical journals. There will be no way of identifying individuals from the results presented or published.

Data Protection

We will be using your personal information in our research to help us study energy hardship. This personal information will come from your consent form and the notes taken at the interview.

The data is being processed for the purpose of scientific research (General Data Protection Regulation 2016, Article 9(2)(j))

Only the members of the research team attending the interview will have access to your consent form and the interview notes.

The data, your consent form, will be stored for 10 years and will then be destroyed by shredding. The notes and key code to pseudonyms will also be stored for 10 years and then destroyed by shredding.

Your data will be securely stored. If there is a data breach, this would mean that people outside the research team would know you took part in the interview.

You have the right to withdraw consent. You can withdraw your consent to take part in this research up to one month following the interview by contacting Dr Suzanne Denieffe, at 051-302250 or Suzanne.denieffe@setu.ie. In this time period, your data can be removed. After this time, your data from the interview will be merged with other data and so cannot be removed.

You have a right to lodge a complaint with the Data Protection Commissioner.

You have a right to request access to your data from the interview up to one month after the interview. You have a right to request access to your consent form up to 10 years after the study.

You will have the opportunity to read the notes from the interview within the month after the interview and so have any inaccurate information corrected or deleted.

You have the right to data portability, meaning you can move your data, that is your consent form one controller to another in a readable format.

Where can I get further information?

If you have any further questions about the study or if you want to opt out of the study, you can rest assured it won't affect the quality of treatment you get in the future.

If you need any further information now or at any time in the future, please contact:

Name Dr Suzanne Denieffe
Address: Head of School of Humanities
South East Technological University
College Street Campus
Cork Road
Waterford.

Phone No: 051-302250
Email- Suzanne.denieffe@setu.ie

Thank you for taking time to read this Research Information Sheet.

Appendix 7
Information Leaflet Energy Providers

Study title: Energy Hardship in Palliative Care at Home: Understanding Issues and Promoting Actions

Principal Investigator's name:	Dr Suzanne Denieffe
Principal Investigator's title:	Dean of the Faculty of Humanities, South East Technological University, Waterford
Telephone number of Principal Investigator:	051-302250
Data Controller's/Joint Controller's identity:	Dr Suzanne Denieffe
Data Controller's/Joint Controller's contact details:	Email: sdenieffe@wit.ie Telephone: 051-302250
Data Protection Officer's identity:	Ms Corina Power
Data Protection Officer's contact details:	cspower@wit.ie

Why is this study being done?

People with palliative care needs and their carers are often unable to afford to heat their homes as they may not be able to work following a diagnosis. They are often more vulnerable to the cold because of their treatment and condition. Living in a cold home adversely impacts their physical health and mental wellbeing at a time of crisis in their lives. In Ireland, we Do not know the energy usage and needs of people with palliative care needs and their carers.

In this study we will examine home energy usage and needs of people with palliative care needs and their carers, getting the views of home care nurses and families, and energy providers and regulators, to increase awareness among key stakeholders and decision-makers of the home energy needs of people with palliative care needs and make recommendations to policymakers on measures that could address the energy needs of those receiving palliative care at home.

Who is organising and funding this study?

This research study is being undertaken by South East Technological University. It is funded by the Irish Cancer Society.

Why am I being asked to take part?

This study on energy hardship among those with palliative care needs is inviting energy companies to participate that have measures currently in place to accommodate vulnerable customers. You are being asked to participate in this study in order to share the measures and processes now in place in your company as well as any plans to develop or expand these measures further in response to the current cost of living crisis. Therefore, your participation in this study would offer useful information and insight regarding the current options available to people with palliative care needs experiencing energy poverty and would inform our recommendations to policy makers on how and why these current measures could be developed further.

How will the study be carried out?

This study involves surveys with home care nurses working with people with palliative care needs, interviews with family carers and people with palliative care needs and interviews with energy companies about the measures in place for vulnerable customers. Energy companies will be contacted by the research team at SETU to conduct an interview about the measures for vulnerable customers. As well as being asked about the measures now in place you will be asked about any plans to develop these in the near, medium and long term. You are being asked to take part in one interview with the research team from SETU.

What will happen to me if I agree to take part?

If you agree to take part in the intervention study, your contact details will be shared with the research team based at SETU. You will be asked to take part in an interview with a research team member. This interview can be conducted by phone, teleconferencing or in person.

A note taker will also be at the interview. Detailed notes will be taken but your name and personal details will all be removed and replaces with an ID number and a pseudonym. The results of the study will be published but will not identify any of the research participants.

What are the benefits?

Your involvement will help us to identify the measures and processes currently in place by energy companies to accommodate vulnerable customers and to evaluate whether the measures can be developed further.

What are the risks?

No risk exists to you other than the potential for distress caused by the completion of the interview. If you become distressed at any time during this process please let the research team know and they can assist you.You can end the interview at any time if you feel distressed and wish not to continue

Is the study confidential?

This study is confidential. The Research Team at SETU will treat all information with strict confidentiality and will adhere to all data protection guidelines. The research team will code all information which is being analysed. The results of the study will be published but no personally identifiable information will appear in these publications as they will be replaced by codes and pseudonyms. We will not be keeping any information for use in future research studies.

Data Protection

You will asked to provide SETU about the measures and processes for vulnerable customers currently in place at your energy company. We will be using this information to increase awareness among key stakeholders and decision-makers of the home energy needs of people with palliative care needs and to make recommendations to policymakers on further measures that could address the energy needs of those receiving palliative care at home.

The data is being processed for the purpose of scientific research (General Data Protection Regulation 2016, Article 9(2)(j))

The research team at SETU will have access to your own personal and contact details, but will replace all personally identifiable information during the transcription of interview notes prior to data analysis and publication of evaluation findings.

As per the Data Protection Regulation (2018) and the SETU Data Retention Schedule (2020) all information will be kept only for the purposes of this study and will be held for up to ten years in anonymised format after study completion.

Once collected the data will be pseudonymised – each participant will be given a random number so that their interview transcripts can be analysed. This data will be stored on a secure online storage system at South East Technological University accessible only to the research team.

You have the right to withdraw consent to your data being used in this research project up to one month after the interview by contacting the Principal Investigator at SETU Dr Suzanne Denieffe. After this time, the data findings will be merged and it will not be possible to remove data from your interview.

You have the right to lodge a complaint with the Data Protection Commissioner.

You have a right to have your data collected but not processed as part of this research up to one month after the interview.

The notes of the interview will be shared with you if you wish. You have a right to request any inaccurate information be corrected or deleted up to one month after the interview.

Your data will not be used for profiling or moved to any other service.

Where can I get further information?

If you have any further questions, please feel free to contact the Principal Investigator at South East Technological University, contact details below:

Dr Suzanne Denieffe
(Research Team SETU)
sdenieffe@wit.ie
Phone: 051302250

Thank you for taking time to read this Research Information Sheet.

Appendix 8
Consent Form Patient/ Family Carer

Patient/ Family Carer Consent Form: Interview

Study Title: Energy hardship - Understanding issues for people with palliative care needs at home and promoting actions

I _____ am aware that I am being invited to participate in the intervention study being conducted by South East Technological University in conjunction with other partners and funded by the Irish Cancer Society, to examine the impact of energy hardship on people with palliative care needs

Please insert a ✓ in the box provided if happy to do so.

I have read and understood the **Information Leaflet** about this research project. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	☐
I understand that I do not have to take part in this study and that I can opt out at any time. I understand that I do not have to give a reason for opting out and I understand that opting out won't affect my future medical care.	☐
I am aware of the potential risks and benefits of this research study.	☐
I am aware that I will participate in an interview	☐
I have been given a copy of the Information Leaflet and this completed consent form for my records.	☐
I consent to take part in this research study having been fully informed of the risks, benefits and alternatives.	☐

I give informed explicit consent to have my data processed as part of this research study.	☐
I consent to be contacted by researchers as part of this research study.	☐

Patient Name (Block Capitals) Patient Signature Date

To be completed by the Principal Investigator or nominee.

I, the undersigned, have taken the time to fully explain to the above patient/ family carer the nature and purpose of this study in a way that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

Name (Block Capitals) Qualifications Signature Date

2 copies to be made: 1 for patient/family carer *and* 1 for PI.

Appendix 9
Consent Form Energy Provider/ Regulator

Study Title: Energy hardship - Understanding issues for people with palliative care needs at home and promoting actions

I _____ am aware that I am being invited to participate in the intervention study being conducted by South East Technological University in conjunction with other partners and funded by the Irish Cancer Society, to examine the impact of energy hardship on people with palliative care needs

Please insert a ✓ in the box provided if happy to do so.

I have read and understood the **Information Leaflet** about this research project. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	☐
I understand that I Do not have to take part in this study and that I can opt out at any time. I understand that I Do not have to give a reason for opting out and I understand that opting out won't affect my ability to refer patients to this intervention.	☐
I am aware of the potential risks, benefits and alternatives of this research study.	☐
I understand that this research evaluation is being carried out by South East Technological University and is funded by The Irish Cancer Society.	☐
I understand that all information I provide for this research will be treated confidentially.	☐
I understand that the results of this research may be published and that in any report on the results of this research my identity will remain anonymous. This will be done by assigning a code and no details will be provided by the research team that may reveal my identity	☐

I understand that under Freedom of information legislation I am entitled to access the information I have provided at any time while it is in storage with South East Technological University	☐
I understand that I am free to contact the research team to seek further clarification and information.	☐
I understand that under the Data Protection Regulation (2018) and the South East Technological University Data Retention Schedule (2020) all information will be kept only for the purposes of this study and will be held for up to ten years in anonymised format after study completion.	☐
I am aware that I can request a break at any time during the interview and that the interview can be stopped and re-started at another time, or cancelled completely, if I become distressed.	☐
I understand that by signing this form I am giving my consent to participate in the above study that I am aware that my data will be analysed by South East Technological University.	☐
I consent to take part in this research study having been fully informed of the risks, benefits and alternatives.	☐
I give informed explicit consent to have my data processed as part of this research study.	☐
I consent to be contacted by researchers as part of this research study.	☐

Patient Name (Block Capitals) Patient Signature Date

To be completed by the Principal Investigator or nominee.

I, the undersigned, have taken the time to fully explain to the above patient/ family carer the nature and purpose of this study in a way that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

Name (Block Capitals) Qualifications Signature Date

2 copies to be made: 1 for patient/family carer *and* 1 for PI.