A Human Rights based approach for Palliative Care:
Towards Solutions for Public Health Palliative Care

3rd International Research Seminar
AIIHPC and EAPC Reference Group on
Public Health and Palliative Care

EAPC VZW Reference Group
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‘Dying Well at Home; Planning for equity, choice and dignity in end-of -life care’

Dying Well at Home Programme

Marese Damery, Programme Manager

Irish Hospice Foundation

Irish Hospice Foundation is a national charity that addresses dying, death and bereavement in Ireland

Morrison Chambers, 32 Nassau St, Dublin 2, D02 X627

Our Vision

Is an Ireland where people experiencing dying, death and bereavement are provided with the care and support they need

Our Mission

Is to work towards the best end-of-life and bereavement care for all

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Dying, death & bereavement

35,477
deaths were registered in Ireland in 2022

Nearly **100**
people die in Ireland every day

83% of these deaths are people aged 65+

Cancer (31%) and heart-related disease (29%) are the leading causes of death

Up to **10**
people are significantly impacted for every 1 death

Over **350,000**
people are grieving a death every year

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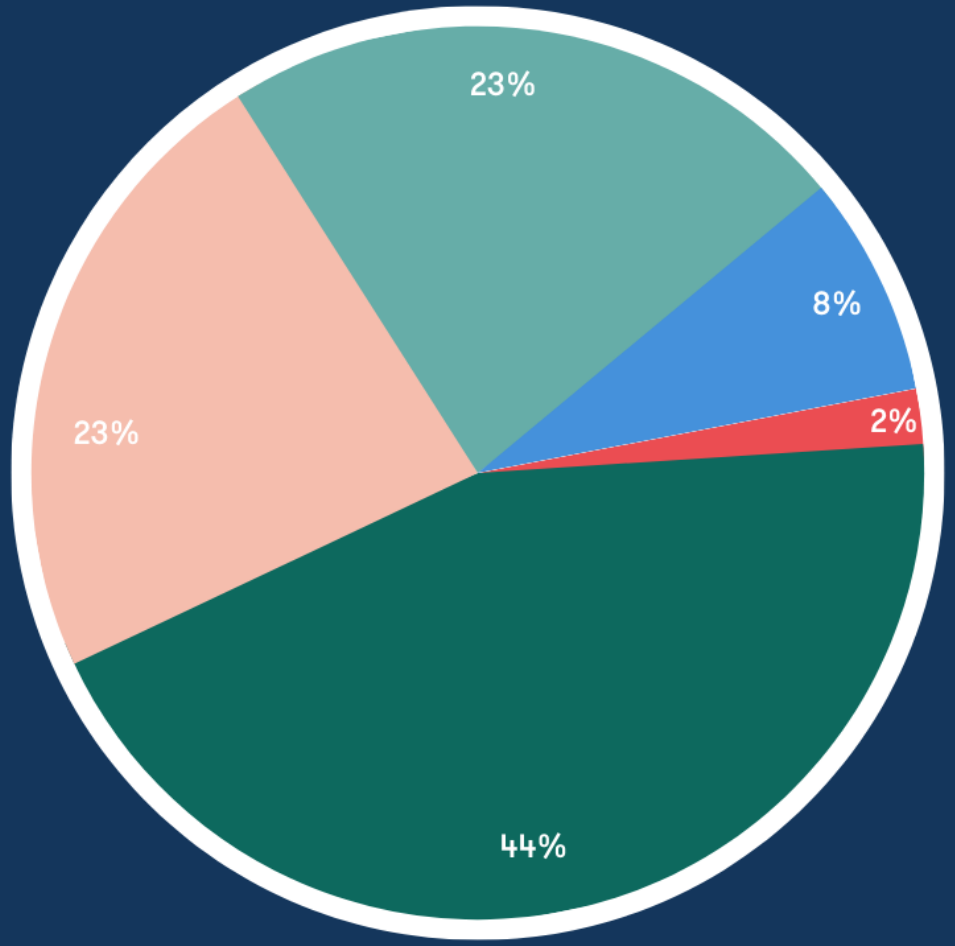

Place of Death - Ireland 2018

- Hospitals
- Nursing Homes
- Home
- Hospices
- Elsewhere

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Dying Well at Home

A new Programme in development to include existing IHF Primary Programmes in place already and other:

- The Primary Palliative Care programme (PPC Steering Committee) brings together Healthcare professionals, Irish College of General Practitioners and IHF colleagues.
- Palliative Care for all - extends to All Life Limiting conditions. Collaboration with Key Stakeholders.
- Nurses for Night Care Service.

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Dying Well at Home

Development Stage

Marese Damery, Nicole Forster and Siobhán Murphy

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Background

Previous research has shown that 74% of people in Ireland would want to die in their home, however, in 2018 only 23% of individuals in Ireland had home deaths.

The number of at-home deaths in Ireland are expected to increase each year, with 8,444 deaths in the family home setting per year predicted by 2031, and over 12,000 home deaths expected by 2051

Whilst not everyone can die at home, IHF believes that more can be done to enable greater choice about place of care as death approaches, to allow people to be cared for and to allow their preference to die at home if medically and practically possible.

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Focus Group Report

Focus groups and interviews were held with family and carer groups, healthcare professionals from a range of backgrounds and patients' advocacy groups.

This report presents the findings of these discussions, to highlight the challenges of ensuring a good death at home and current gaps in the provision of end-of-life care.

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Focus Group Report- Objectives

To better understand the experience of dying at home in Ireland, we carried out qualitative research with key stakeholders between November 2021 and November 2022

To inform the development of Irish Hospice Foundations new Dying Well at Home programme

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Planning

An IHF project group was set up in 2021- a process for the focus group consultations was developed

A mapping exercise was carried out by the DWAH team to identify points of end-of-life care provision in Ireland

We reached out to prospective groups directly through our existing programmes - Nurses for Nightcare, Primary Palliative Care Steering Committee and Palliative Care for All.

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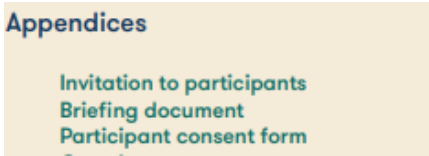
Processes

An initial **briefing document** was sent to groups and organisations describing the scope and goals of the research and they were asked to invite/identify individuals to participate in the focus group discussions and interviews.

- Once participants were identified **invitations** were sent out.
- Opportunities were offered to pose **questions.**
- Informed **consent** was obtained from all participants.
- Following the session all participants were **thanked** and provided information on **bereavement** supports and other resources as required.



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Description of Participants by focus group and interview

Focus group discussion	Participant organisation	Participants per organisation	Total participants per focus group discussion/interview
1	The Alzheimer Society of Ireland	3	5
	Progressive Supranuclear Palsy Association	2	
2	Care Alliance Ireland	2	4
	Family Carers	2	
3	Public Health and Community Nurses	3	3
4	Practice Nurses	2	2
5	Irish Cancer Society Night Nurses (1)	3	3
6	Irish Cancer Society Night Nurses (2)	5	5
7	Community Pharmacists through the Irish Pharmacy Union	5	5
8	Specialist Palliative Care Community Nurses	9	9
9	Traveller Mental Health Services	1	2
	Traveller Primary Healthcare Project	1	
10	Members of Voices4Care	4	4
11	Primary Palliative Care Steering Committee members (1)	3	3
Interviews	Primary Palliative Care Steering Committee member (2)	1	1
	Family Carers Ireland	1	1
	Homeless services staff representative (residential)	1	1
	Homeless services staff representative (clinical)	1	1
		Total	49

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The research questions that guided this work are:

- What constitutes a good death?
- What factors facilitate patients to have a good death at home in Ireland?
- What factors prevent someone from dying at home in Ireland ?
- How has the Covid-19 pandemic affected end-of-life care at home in Ireland?

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Methodology

Online focus group discussions were held with **49** individual participants, from **15** different organisations representing a wide variety of paid and unpaid end-of-life care providers in Ireland.

Semi-structured discussions were recorded with participant consent.

Thematic analysis was used to code responses.

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A note on participants provision of care

Throughout this report, we share the personal experiences of family members and carers in providing informal, unpaid care to patients. Alongside this we share the professional experiences of healthcare workers in providing formal care. However, it is important to note that healthcare workers also drew on their personal experiences in providing unpaid care to family members. Similarly, healthcare workers often must work beyond the scope of their role, sometimes unpaid, in order to cover gaps in the healthcare provision.

The experiences shared by formal and informal carers in these focus group discussions were complimentary and provide a more complete view of the combination of paid and unpaid work that is fundamental to the current functioning of the Irish medical system. For this reason, and to ensure anonymity of respondents, this report where possible will not delineate whether observations shared came from informal or formal workers.

Providing care for a loved one at end-of-life is a common but underreported experience for people in Ireland. Promoting honest, open and supportive conversations about experiences of dying, death and bereavement in Ireland is a central goal of Irish Hospice Foundation.

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Data Analysis

- The research team used thematic analysis to review and analyse the focus group recordings.
- All focus group discussions and interviews were initially analysed separately by three team members for initial emergent themes.
- Researchers then categorised the discussion into themes and subthemes together, based on the research questions.
- Recordings were subsequently reviewed for selection of appropriate quotes for the themes and sub-themes

Results: global themes and organising themes

Global Themes	Conceptualising a good death	Enabling a good death at home	Barriers to dying well at home	Future resources for dying well at home	Effects of Covid-19 on providing home palliative care	Other themes
Organising themes	End-of-life wishes fulfilled	Appropriate support for family and carers	Insufficient information and support for families & carers	Information and education resources for families, carers, and patients	Negative effects	The role of housing in dying well at home
	Patients, families, and carers are suitably informed	Specific forms of palliative care	Inadequate access to care	Education and training for healthcare workers		Building community for care providers
	Patients, families, and carers have good access to care	Good access to care	Poor coordination of care	Dedicated palliative care	Positive effects	The Irish health system
	Patients, families, and carers have ongoing, sustained support	Coordination of care	Insufficient resources to provide care	Essential resources (staffing, hours)		
	Patients receive individualised, appropriate care	Other factors	Care is unsuitable for individual or community	Other resources /supports		
			Lack of other social support	Tools and services		

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1. Conceptualising a good death

A good death was described as one where the patient's individual medical needs were met. Specifically, most groups highlighted the importance of a patient's freedom from pain and suffering.

"...we had a lovely few weeks before he died, it was lovely. He had everybody that he wanted in around the house, it was a great death."

"When [end-of-life home care] works, families are often so relieved, and they can't believe that they did it. There's a sense of satisfaction that they gave their loved one their wish."

1. Conceptualising a good death

A good death was also conceptualised as including open, compassionate and informative discussions between patients, their family/carers and healthcare teams, specifically in clarity about division of roles and expert advice on care provision, such as pain relief.

“I think sometimes they need help in identifying who does what, they may never have had any interface with healthcare services and suddenly they have the [public health nurses, specialist palliative care, community intervention team and night nurses] and they can be quite bothered about who does what.”

2. Enabling a good death at home

Suitably informed families and carers

Family/carers can facilitate a good death when they are provided with support, adequately informed on end-of-life care, understand their role in relation to healthcare teams, understand the stages of dying and understand the worst-case scenarios of dying at home.

“It’s about having the support. [Family and carers] want the person to come home, but obviously there’s an element of fear about their ability to care for them adequately at home. [It’s important] having that home support and access to home support.”

2. Enabling a good death at home

Supportive environment

Participants noted having strong existing support structures in place and positive dynamic, such as family, friends and carers working together, are foundational for good end-of-life care

“I would feel the enablers are the support structures that are around the family or a particular circumstance that allow [the patient] to be at home. Whether it’s right down to your carers, PHN, Night Nurse, GP, palliative care team, it all allows it to develop as it should.”

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3. Barriers to dying well at home

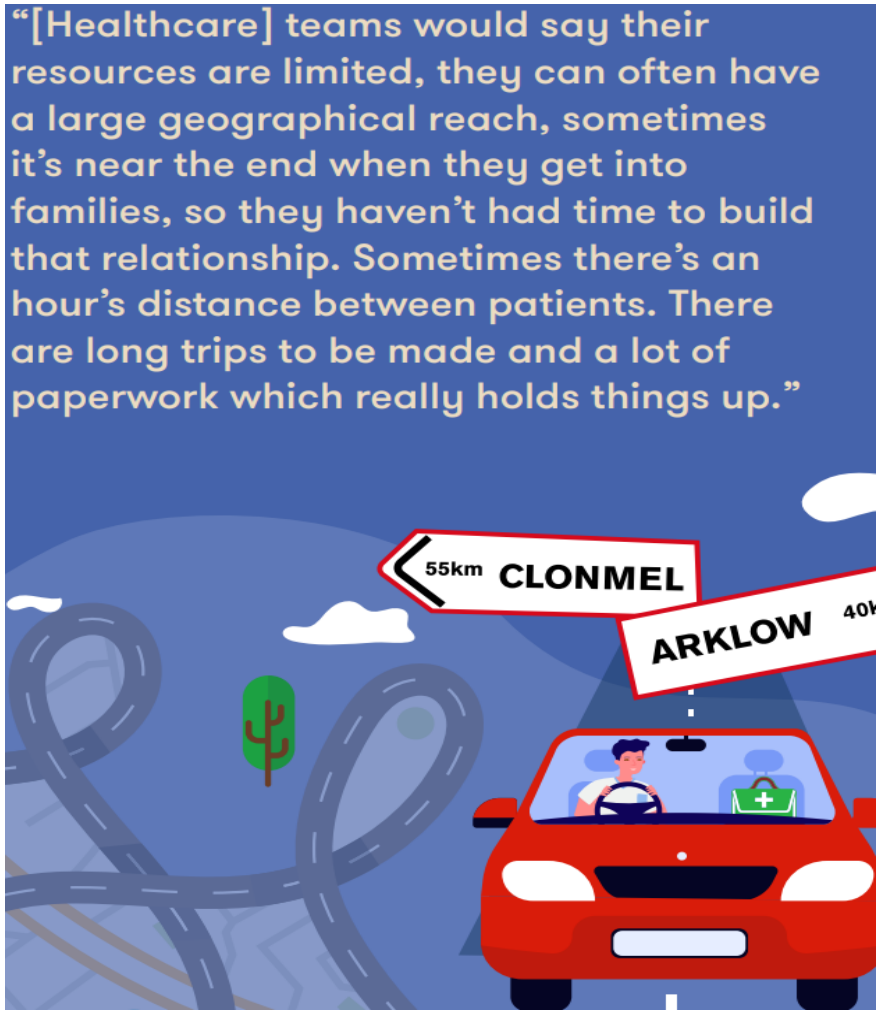
- The discussion of barriers to dying well at home were in-depth across all focus group discussions and interviews, drawing on participants' personal and professional experiences.
- They included practitioners' observations of gaps in care provision, family/carers' experiences of being unable to access support and marginalised groups' experiences that barriers to home care reflected their wider general experiences of exclusion from the health service.

3. Barriers to dying well at home

Insufficient resources to provide care.

“It took 10 days for the bed to arrive, sometimes the length of time it takes to get equipment can be prohibitive…sometimes the equipment provision is just not fast enough.”

“I sometimes wish that there was a catheter pack brought when the syringe box comes because a lot of people do end up having catheterisation, sometimes there’s a delay which can cause discomfort.”



3. Barriers to dying well at home

Inadequate access to care

*"Because there is **no access to 24-hour care**, some patients are ending up in **A&E** inappropriately."*

*"We seemed to run into a **crisis late on Fridays or a Bank Holiday weekend**, and you are left with very limited backup support. It's all left on you, as a carer...there was no coordination of services. It's very frustrating. To have a parent in severe pain, and trying to get the meds right and stuff, if there could be quicker access to supports – timely phone support from a palliative doctor/nurse, it would ease the carers burden and the distress of their loved one."*

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Marginalised groups/services

"Certainly, in the residential [homeless accommodation] home all of them wanted to die but we were not equipped to look after them when they were coming to end-of-life. All of them had written those wishes down but we had no nursing staff, no GP input, no one to come out after hours, so inevitably they couldn't die at home."

"Within the Traveller community family is a huge thing, as faith is and community and that would be a huge gathering around where the family member might want to die at home but can't die at home and then the family have to go to the hospice or the hospital and then that separates them. It should be a personal thing."

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4. Future resources for dying well at home

All participants highlighted the importance of easily accessible and understandable information resources on end-of-life care, so that patients and carers could be empowered to make informed decision

"[There should be information on] oral care, eye care, hygiene in general, how to move a patient in the bed, if family want to do that type of thing."

"There should be something in the community for somebody who's going to be minding someone at home, even if it's an hour tutorial or something online of how to handle somebody in bed, the position, what to look out for."

"A booklet would be very valuable, a signpost or somebody to signpost on where to go, what to do next, people don't know how to access a death cert, have they a living alone allowance."

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Resources

"It would be great to have a **map,** search for support' it is the things like the bed, were to get it' things like if you want an air mattress, where do you get it from? Hover on the map, where would you actually find these things?"

The was a need for **an appointed contact liaison** for patients in order to facilitate greater coordination between health services and to prevent referrals being lost. A right for patients to be seen in person was also suggested as a means of reducing barriers in access to care

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Discussion

- Strength of the report
  - The **variety** of voices and experiences included
  - A **wide array** of groups providing care in Ireland

- Limitations
  - The groups included are **not a full representation of all groups** affected by home care and further work needs to be done to include the experiences of rural communities, economically deprived communities, migrant communities, and disabled communities
  - **Does not** represent the **direct experiences** of those receiving care.

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Findings

Huge gaps were noted in our healthcare system

- **Gaps** in the system, difficulties in knowing how and where to access appropriate care and delays in getting this care
- Fears about what to do or how to cope out of regular provision care hours, **outside the 9am - 5pm** Monday to Friday
- **Stressful** situations for both healthcare professionals trying to contact each other through the different teams and for families/carers trying to access support, pain management and further help

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Conclusion

- **Inconsistencies** in the provision of end-of-life care was very apparent throughout the sessions.
- **Pressures** placed on both families, carers, and healthcare professionals' results from not only a lack of resources but failures in the system.
- **Information** on how to access care needs to be transparent, inequity of services across all regions needs to be addressed.
- Care systems need to be **mapped** out clearly.
- **Out of hours** services need to be reviewed.

Every death matters, and we only have one chance to get it right.

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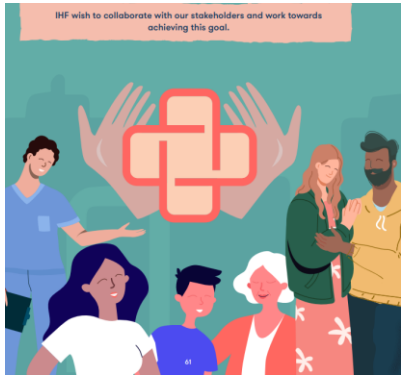
Recommendations



1. **To scope and develop an Information and Support Line.** The report identified a need for signposting to services, a key theme in the study related to insufficient information and support for families and carers. We would envisage that the Information and Support Line will respond to enquiries and provide signposting to appropriate services. This resource when established will further inform IHF about current gaps in end-of-life information and services being experienced in the community.

2. **Create an easily accessible map with information resources and current services for supporting end-of-life care.** The map will signpost care options for patients, families, and carers.

3. **Support and scope further research to identify the barriers and inform the development of resources and co-ordination required to better support dying well at home. All of which were prevalent themes in the study.**

Considerations for this research should include:

- A system mapping of what regional and local palliative and end of life supports are available for people in the community.
- Identify what gaps exist in services.
- Establish how individuals are referred and signposted to services.
- Explore the option for end-of-life co-ordinator roles in the community.

4. **Conduct a review of existing resources and training with a view to making these accessible to the community.** Participants in the focus group discussions highlighted the need for more accessible dedicated, educational end-of-life and bereavement resources and also the need to broaden the availability of standardised training support for carers and healthcare professionals. We would also seek to develop further information and educational resources through stakeholder engagement and partnership with service providers.

5. **Identify best practice community-based end of life models of care, which are socially and culturally appropriate to address the specific barriers to care faced by underserved groups to support dying well within their communities.** The discussions identified that further research into the **health inequalities** faced by historically underserved communities is needed. This includes low socioeconomic status groups, migrants, Traveller communities, rural communities, disabled groups, and people who are homeless.

6. **Strengthen our advocacy for primary palliative care supports that help people remain in their community and die at home if this is their wish and is possible.** It will include advocating for continued improvements in homecare and supports for family carers.

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Dying Well at Home

https://hospicefoundation.ie/healthcare/dying-well-at-home-report/

Irish Hospice Foundation

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Thank you

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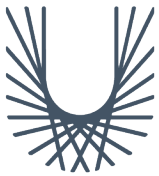
Irish Cancer Society



SETU
Ollscoil Teicneolaíochta an Oirdheiscirt
South East Technological University

Exploring Energy Hardship in Palliative Care at Home: The Nurse Perspective

Dr. Pilar Luz Rodrigues

School of Humanities, South East Technological University (SETU)

setu.ie
INSPIRING FUTURES

Context

- Vulnerability of people with life-limiting cancer diagnosis to cold
- Struggles in affording heating for their homes
- Consideration of the needs of this group by energy companies, regulators or government policy.
- Importance of this study.

Objective

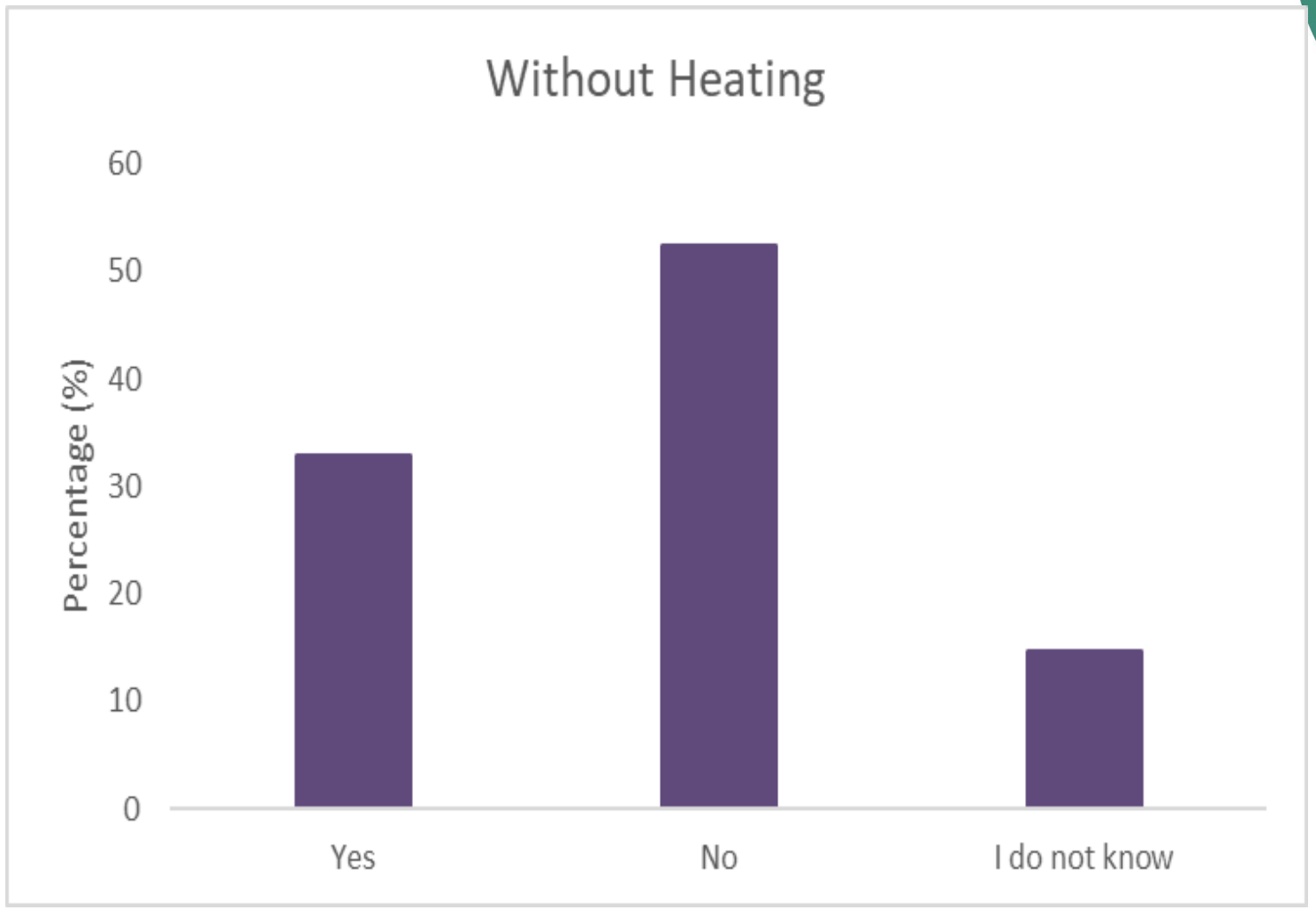
- This study aims to address the evidence gap on energy hardship among people with a life limiting cancer diagnosis.

Method

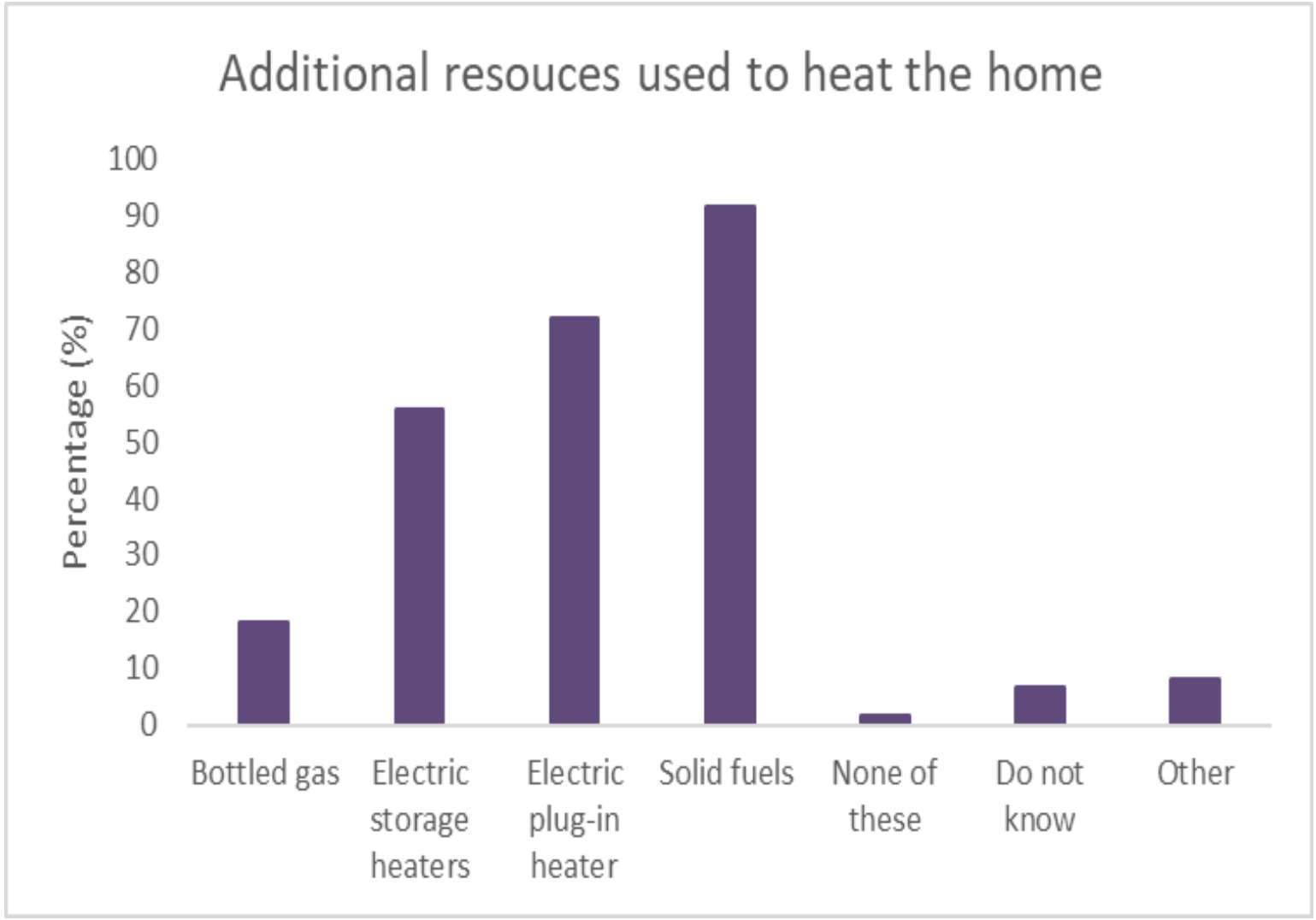
- QUESTIONNAIRE
- CROSS SECTIONAL DESIGN
- PALLIATIVE HOME CARE NURSES (n=61)
- RESPONDENTS COMPLETED QUESTIONNAIRES
- STATISTICAL ANALYSIS OF DATA – SPSS V.25
- OPEN ENDED QUESTIONS

Results

Energy Poverty Indicators



Energy Poverty Indicators



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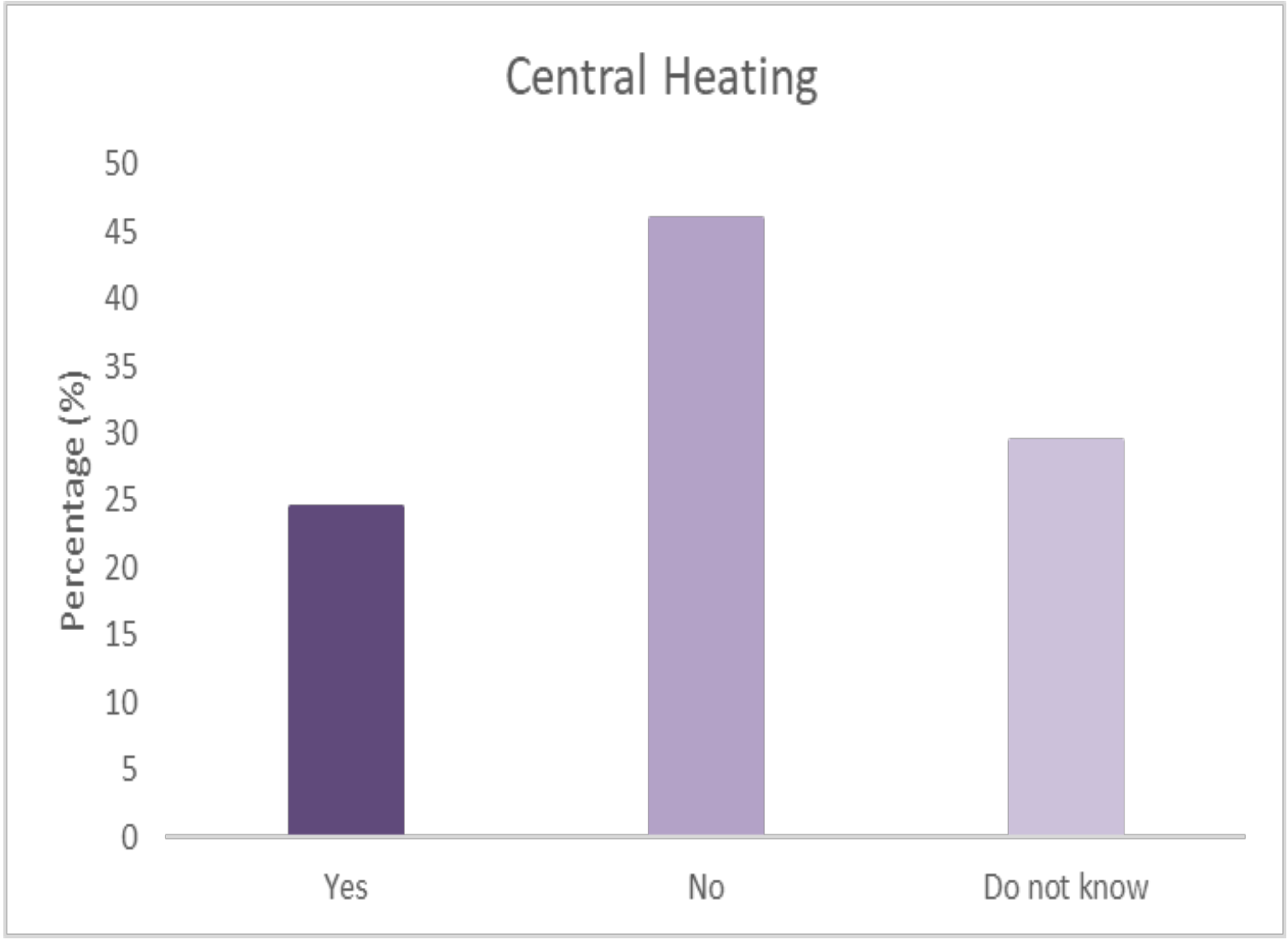
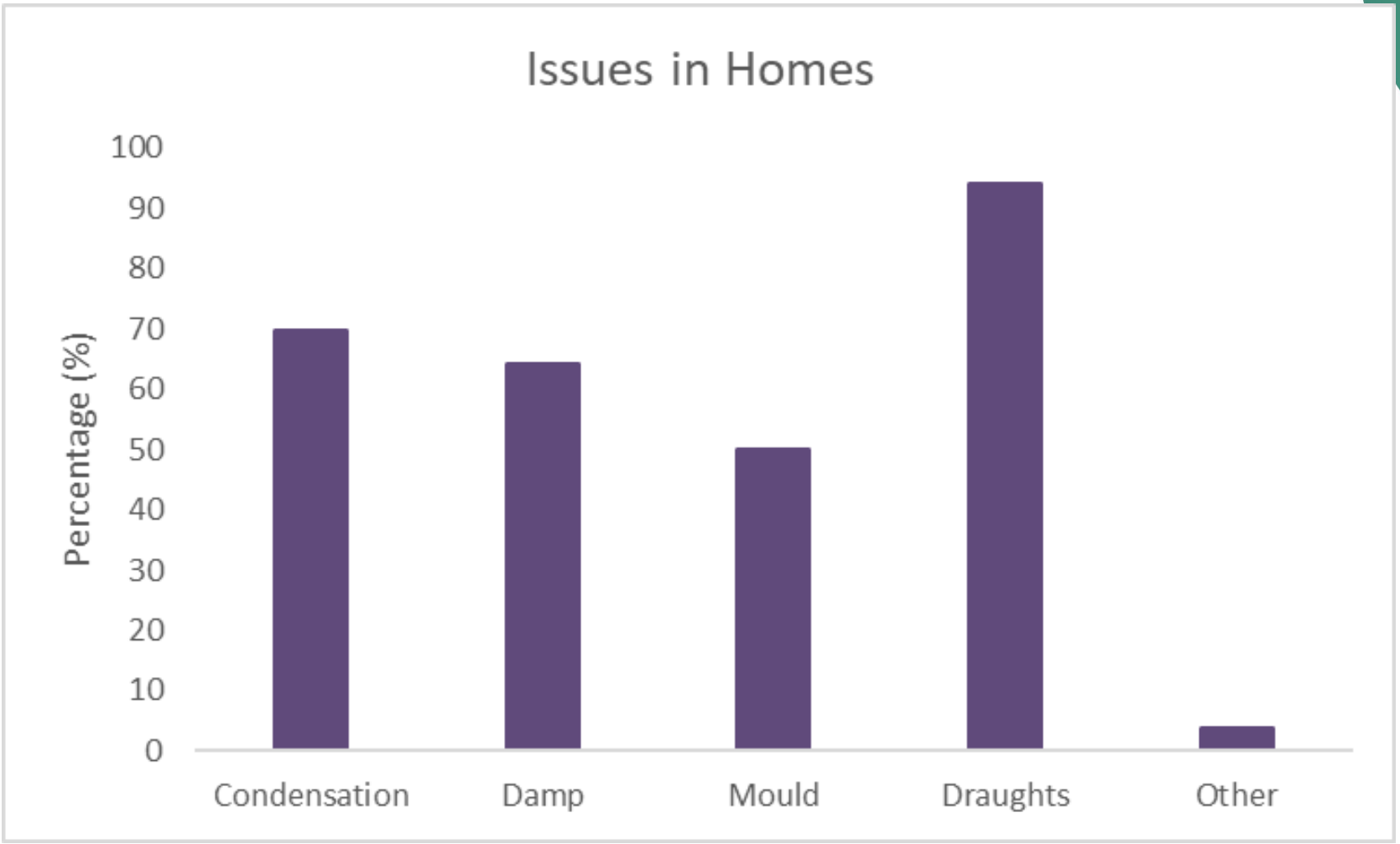
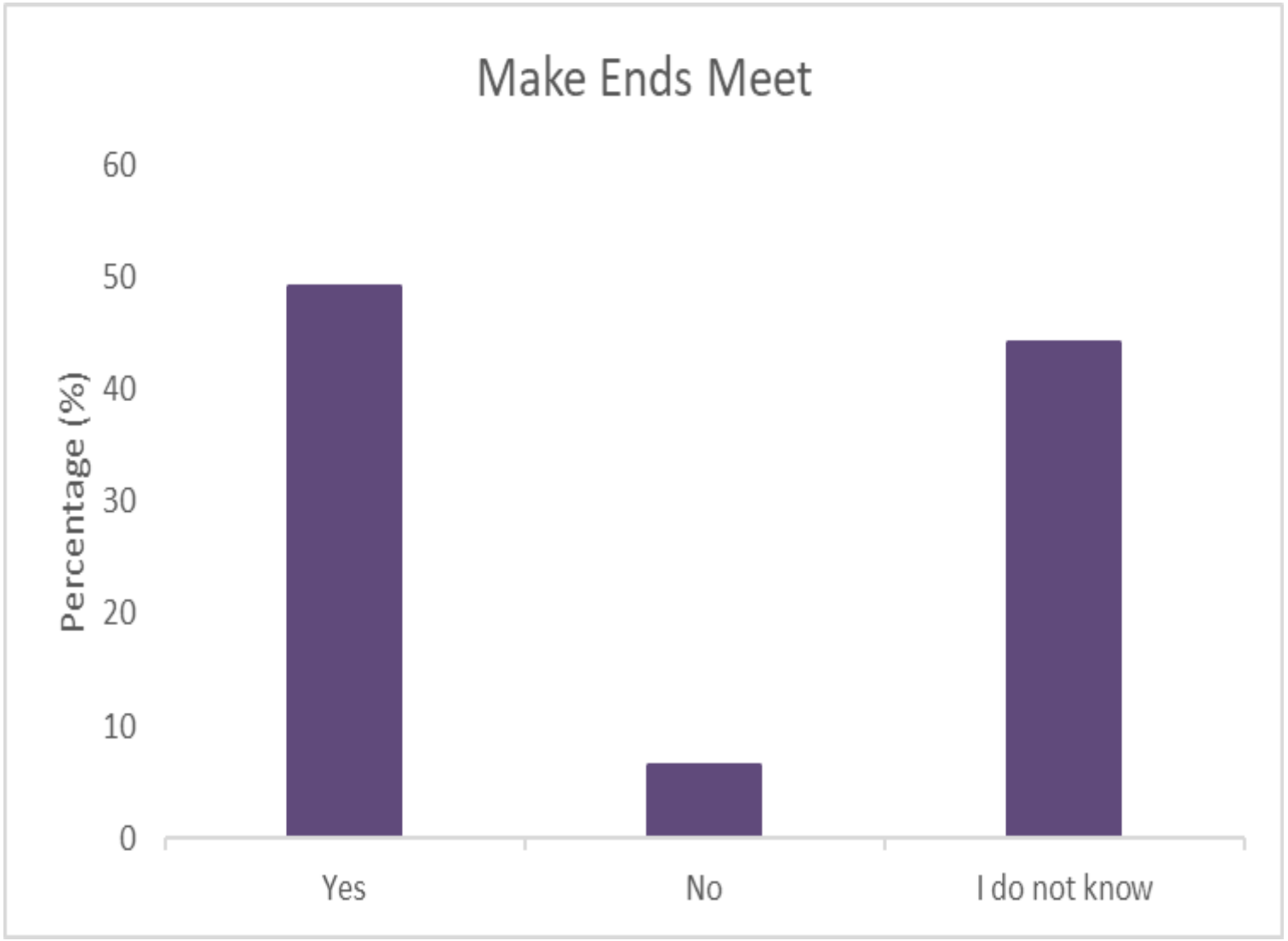


Energy Poverty Indicators



Financial Struggles



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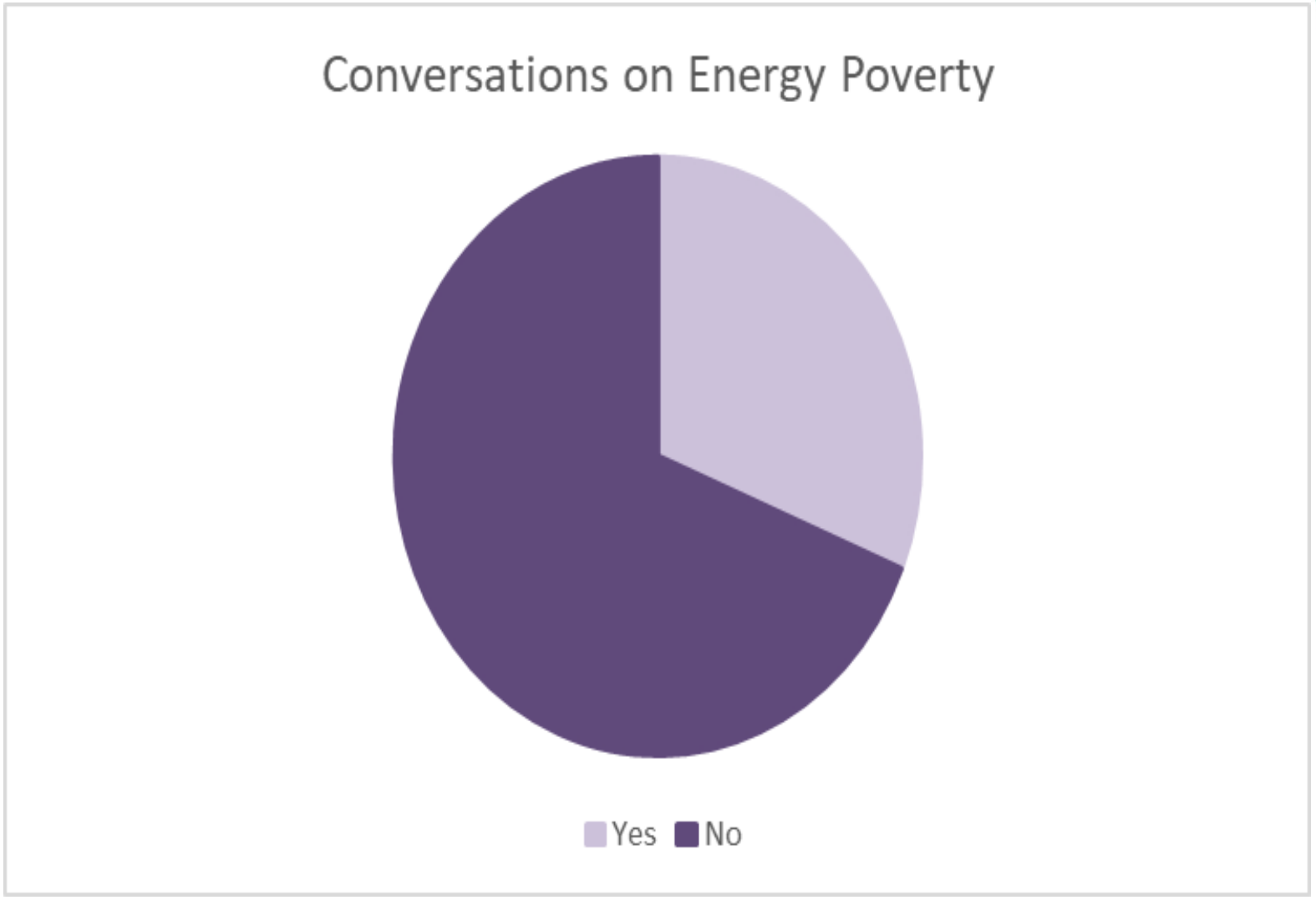
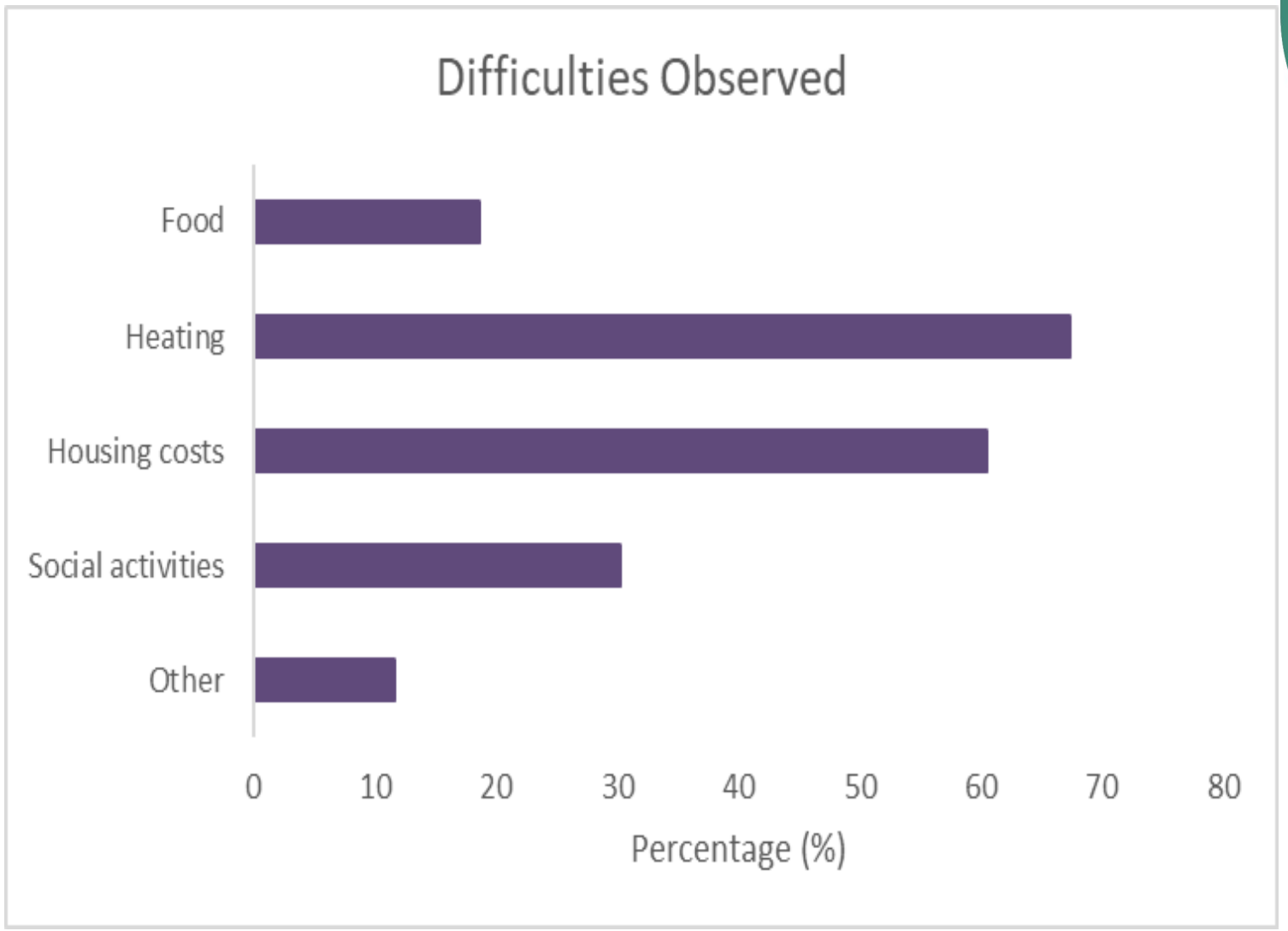
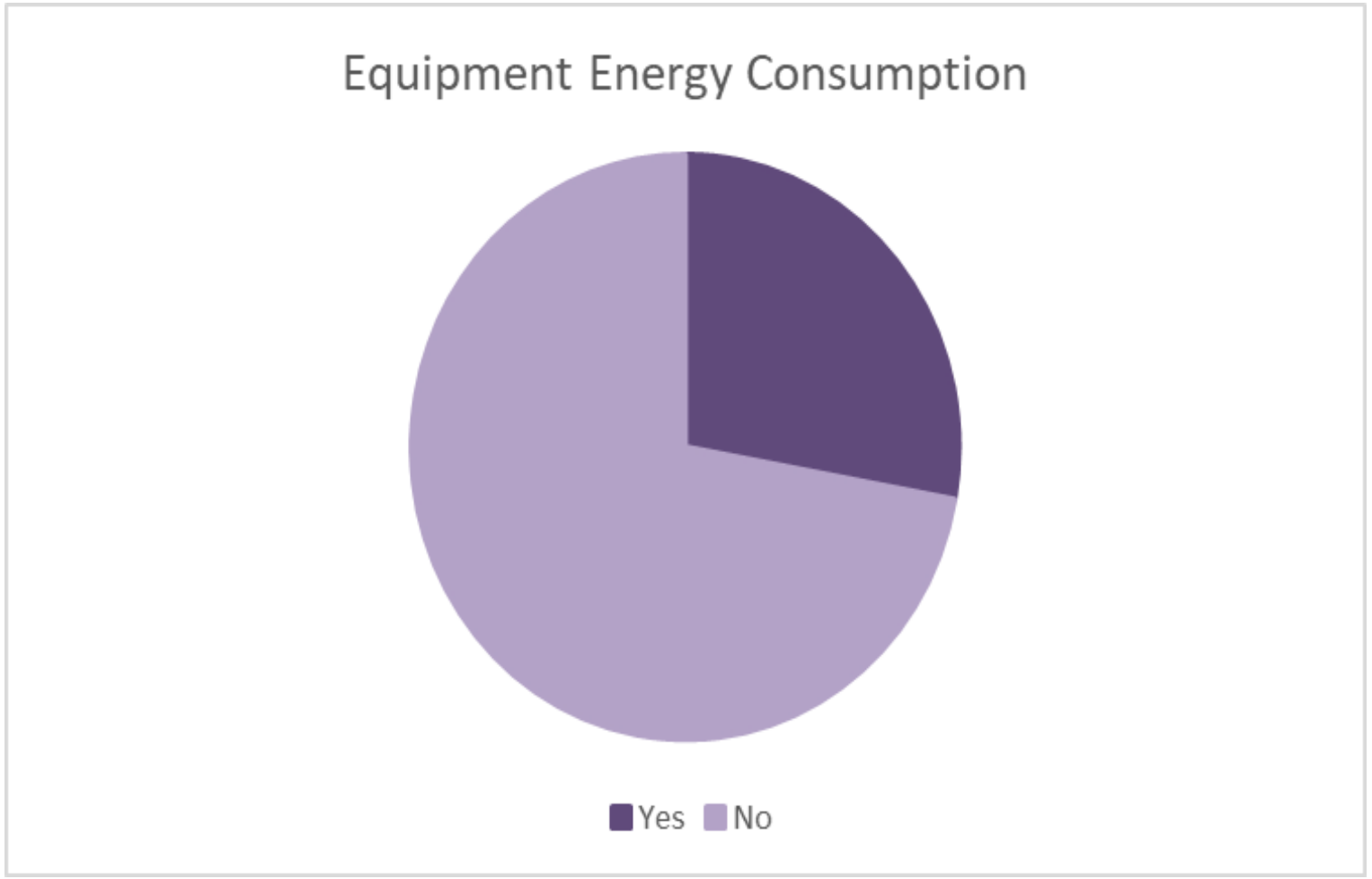


Financial Struggles

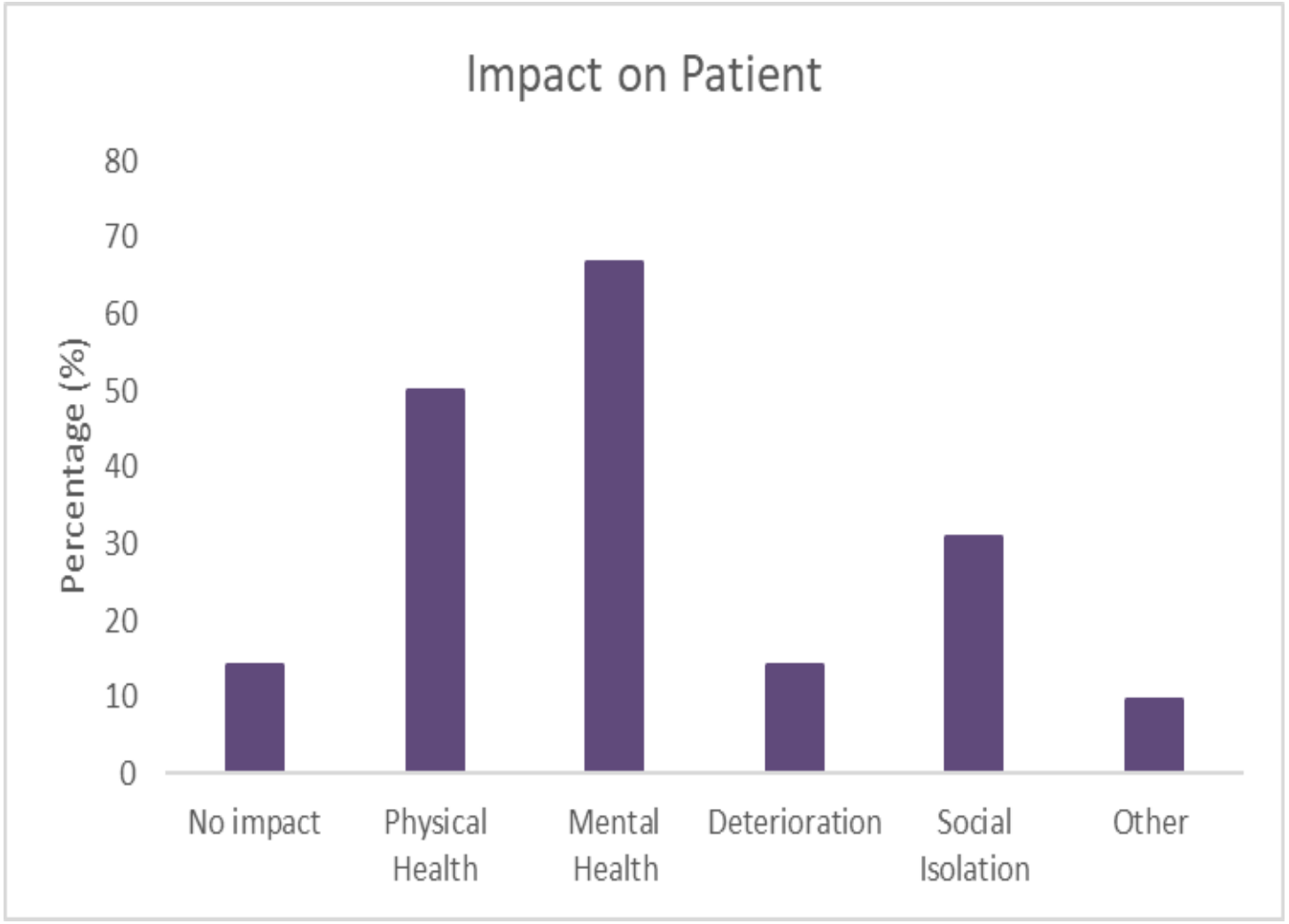


*(n=43)

Financial Struggles



Impact on Patient



*(n=42)

Energy Hardship.

Open ended questions?

‘ patients who have electric plug in heaters on 24/7 to heat the one room….; fuel bills cause huge finiancial worry ….or sometimes family members paying their bills. ’

‘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.’

‘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’

‘last two years ……I feel physically cold ….. patients are usually wrapped up in more blankets or using hot water bottles’.

Summary

Concerns about electricity and energy costs

Implications for Policy

Recommendations

Thank you

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INSPIRING FUTURES

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All Ireland Institute of Hospice and Palliative Care

DCU

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Dublin City University

Irish Cancer Society

SETU

Ollscoil Teicneolaíochta an Oirdheiscirt

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