



**QUEEN'S
UNIVERSITY
BELFAST**

How can we meet the needs of people impacted by terminal illness in future loneliness policy development in Northern Ireland using research evidence?

McConnell, T., Hanna, J., Harrison, C., Patynowska, K., Finucane, A., Hudson, B., McCullagh, A., Paradine, S., & Reid, J. (2022). *How can we meet the needs of people impacted by terminal illness in future loneliness policy development in Northern Ireland using research evidence?*. Poster session presented at Marie Curie Research Conference 2022.

Document Version:
Other version

Queen's University Belfast - Research Portal:

[Link to publication record in Queen's University Belfast Research Portal](#)

Publisher rights

© 2022 The Authors.

General rights

Copyright for the publications made accessible via the Queen's University Belfast Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The Research Portal is Queen's institutional repository that provides access to Queen's research output. Every effort has been made to ensure that content in the Research Portal does not infringe any person's rights, or applicable UK laws. If you discover content in the Research Portal that you believe breaches copyright or violates any law, please contact openaccess@qub.ac.uk.

How can we meet the needs of people impacted by terminal illness in future loneliness policy development in Northern Ireland using research evidence?

T. McConnell^{1,2}, A. Finucane², J. Hanna^{1*}, C. Harrison^{2*}, B. Hudson², A. McCullagh³, S. Paradine³, K. Patynowska², & J. Reid¹

Tracey.McConnell@mariecurie.org.uk (1) School of Nursing and Midwifery, Queen's University Belfast, (2) Marie Curie, (3) Marie Curie Research Voices
Jeffrey.Hanna@qub.ac.uk

INTRODUCTION

-Loneliness is a subjective, unwelcome feeling of lack or loss of companionship which happens when there is a mismatch between the quantity and quality of social relationships that we have, and those that we want. [1]

-In 2020, 20% of people living in Northern Ireland (NI) reported feeling lonely at least some of the time. Yet, NI is the only nation in the UK without a loneliness strategy. [2]

-Feelings of loneliness can impact on someone's health and wellbeing, and is associated with declining physical and mental health with increased reliance on health and social care services. [3]

-A previous study in NI reported people with a terminal illness are twice as likely to report deep feelings of loneliness than those without such conditions. [4]

AIM

To explore health and social care professionals' perceived prevalence, impact and possible solutions to loneliness among people who are terminally ill and their carers in NI.

METHODS

Design: Explanatory sequential multi-methods study.

Sample: Marie Curie Health and Social Care Professionals in NI.

Data Collection: An online survey with 68 professionals (response rate 30%) in April 2021. Three focus groups were then conducted online with fourteen professionals between September and October 2021 to better understand the survey findings.

Data Analysis: Survey data was analysed using descriptive statistics. Qualitative data were analysed thematically.

RESULTS

Understanding and explaining the PREVALENCE of loneliness

Of the survey respondents:

- **92.3%** reported perceived loneliness among their patients pre-pandemic.
- **86.8%** felt they had supported carers experiencing loneliness pre-pandemic. [See Figure 1].

Professionals viewed loneliness as a taboo subject and perceived it is avoided by patient's and carers in conversation for a fear of causing the other person upset, or being seen as a burden.

Loneliness was believed to be heightened during the pandemic for patients and carers due to:

- Patients in the hospital setting had fewer opportunities to maximise social networks.
- Services that provided peer-support such as the Day Hospice and community groups were reduced.

Survey question: 'In your typical pre-pandemic caseload, have you provided care/support for palliative care patients/informal carers who you believe may have been experiencing loneliness?'

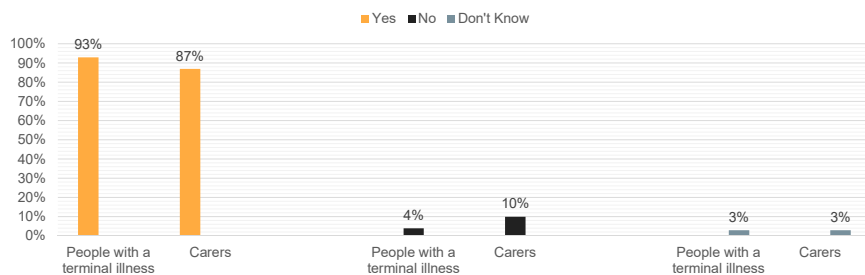


Figure 1: Perceived prevalence of loneliness among patients and carers pre-pandemic

Understanding and explaining the IMPACT of loneliness

Of the survey respondents:

- **63.2%** rated loneliness as having a high impact on a patient's and **66.2%** on a carers psychological wellbeing.
- **55.9%** rated loneliness as having a high impact on a patient's and **60.3%** on a carers social wellbeing.

Loneliness was discussed as having a ripple effect on a person's mental and physical health, with a negative impact on wellbeing, quality of life, and the wider health service.

Experiences of loneliness were considered by professionals to:

- lead to the patient feeling like 'giving up' as they had nothing left to live for.
- a deterioration in the person's condition with an increase in symptom experiences.
- feelings of isolation, frustration, burnout and psychological decline for carers.

Possible SOLUTIONS to loneliness

- Professionals considered it helpful for people with a terminal illness and their carers to meet others who are experiencing similar situations to themselves to provide peer-support and opportunities for respite. This included befriending and companionship services. The Day Hospice model was described as a **vital** service for balancing these factors.
- There is a need to have more open conversations about loneliness and normalise such experiences.

I think that's what's so brilliant about the day hospice... because people are referred here. And it's not that they feel obliged to come, but... it starts off as being part of their medical care. And then it transforms into this wonderful social opportunity, and well holistic is a good word for it. It caters for all needs, once you get the people through the door. And they are glad to come because it's part of their... it starts off as part of their treatment. And then blossoms.



I have been out to him the last two weeks, nearly every night that I've been working. And the issue is not his cancer. The issue is that he is lonely... he has no family here. His nearest family is in England. His mood is quite low as well. He says he has nobody to talk to. And he's ringing out of hours to get me out, or get one of us out, to come and talk to him. And that's really what it was. He is isolated and lonely in his home. And people have not picked up on that.