## "Wouldn't it be easier for everyone if they took them out the back and shot them" Family experiences of visitation restrictions in Irish Nursing Homes during Covid-19



Sarah Robinson (sarah.robinson@ucc.ie)
Graham Gillespie, University of Leicester, Emily Egan, University of Manchester

## WHAT DID WE DO?

**Purpose:** To explore the family experience of visitation restrictions including at End of Life in Irish Nursing Homes during the first 3 waves of the pandemic

**Method:** 17 family members were recruited through family advocacy groups and interviewed using a semi-structured interview protocol. We analysed interviews using Reflexive Thematic Analysis (Braun and Clarke, 2021). We adopted a pragmatist pluralist approach and shared data with researchers in *NUIG Centre for Human Rights* for Human Rights Analysis. Human Rights was submitted to *Irish Human Rights & Equality Commission* as part of evidence of rights violations in NHs during the pandemic.

Through our analysis, we suggest that:

- A medicalised neoliberal ageist discourse disregarded human rights of NH residents, resulting in experiences of a total institution for some
- "Compassionate visits" were officially permitted, but were often denied as they were "only guidelines"
- The essential role of family in care (both social, emotional and physical) was not considered or recognised. This not only impacted residents wellbeing & health, but also burdened staff already working beyond capacity due to Covid-19.
- FMs reported residents undignified deaths, feelings of being disregarded and 'locked-out' and residents feeling 'locked-in', a lack of communication and refusal to refer residents to hospital when needed.
- FMs and residents were primarily women, making this a feminist issue.

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- \* The practical care stopped. You know, I'd find out later from a whistleblower staff member that Mum had a really bad bedsore, you know, going from her back down to her thigh, that it was bleeding, it looked as if the skin was eating itself. The staff member asked for it to be tested for MRSA, it looked that bad and the director of nursing literally said, you know, that's just the skin breaking down. There's nothing we can do, put moisturizer on it. She wasn't given any extra pain relief that we know of, so you know she had, a painful ending. It could have been avoided you know, if staff listened to her, if they listened to me, um you know, some of that pain could have been avoided, right?
  - Participant One whose mother died alone, without pain medication or family support, during the third wave of the pandemic in an Irish nursing home

## WHY IS IT IMPORTANT?

- Ireland has a rapidly aging population & climate crisis may bring more pandemics.
- This work highlights:
  - A legacy of *institutional ageism* in policy decisions for older adults during the pandemic
  - Communication between NHs and family was often poor, contributing to poorer health outcomes as family was unable to advocate
  - NHs did not always provide End of Life or essential medical care and were unable to fulfil social care needs.
- Policy, practice, design and legislation should ensure:
  - quality of life of NH residents as well as life & infection control
  - resident's human rights including liberty are upheld
  - A care partner scheme is legislated for and implemented which enables every NH resident to have regular access to a family member (in the broadest sense) at all times, including during pandemics
  - NH design should enable easy entry and access to the building for every resident, to enable liberty in future pandemics as well as family and nature connectedness.





