

## TILDA Participants in Nursing Homes

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# 8

### TILDA Participants in Nursing Homes

#### 8.1 Background

There are 576 registered nursing homes in Ireland, providing a total of approximately 32,000 beds.

The estimated 30,000 people living in nursing homes faced disproportionate likelihood of adverse outcomes during the COVID-19 pandemic. Nursing home residents had higher risk of infection due to higher prevalence of frailty and serious illness, and this risk was magnified by residential care environments, where people live together in close quarters and staff supportive care involves a lot of physical contact. If infected, nursing home residents had a higher risk of adverse outcomes, including mortality, due to underlying medical conditions.

#### 8.2 TILDA data

#### 8.2.1 Overview

At Wave 1 (2009) the study recruited over 8,500 community-dwelling people aged 50 and over – that is, no participant was living in a nursing home or residential care at baseline. Over the 11 years that the study has been running, some participants have moved permanently to living in a nursing home and conducted their interviews for later waves in this setting. In addition, TILDA has collected information on deceased participants through 718 end-of-life interviews completed by family members and friends. Of these, 97 (14%) participants' reported place of death as a nursing home. In this appendix we describe the characteristics of participants from those two data sources, which are not mutually exclusive.

#### 8.2.2 Participant interviews in a nursing home

Of the 100 participants who were interviewed in a nursing home, the mean (SD) age was 83.7 (7.2) years and 62% were female. Eighty-five had a long-term health problem, illness or disability limiting their day-to-day activities, and 26 had a history of dementia or cognitive problem. When asked to self-rate their physical health, 61 could not self-report

due to a cognitive and/or physical problem; 22 reported that their physical health was 'good, very good or excellent', and 12 reported it as 'fair'. The remaining 5 reported their physical health as 'poor'.

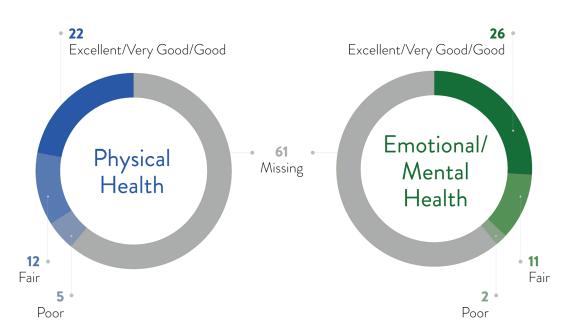


Figure 8.1. Self-rated physical and emotional/mental health of TILDA nursing home participants

#### 8.2.3 Participants who died in a nursing home

To date, TILDA has collected 718 interviews on the end-of-life experience of deceased participants. Among these, 97 deaths occurred in a nursing home; the mean (SD) age at death was 85.0 (8.5) years and 51 (53%) were female.

Fifty-eight percent had a history of hypertension, 46% of Alzheimer's and related dementias, 31% congestive heart failure, 20% diabetes, 17% heart attack, 17% cancer, 13% anxiety and 11% depression.

Eighty percent had had disability for 4 or more basic activities of daily living (ADLs), and a further 13% had had disability in 1-3 basic ADLs. Seventy-nine percent had had disability for 4 or more instrumental ADLs, and a further 10% had had disability in 1-3 independent ADLs.

Fifty-seven percent had been troubled by pain in the last year of life, and 61% had fallen in the last year of life.

The most common causes of death were cardiovascular/circulatory (32%), respiratory (16%), infection (13%) and cancer (10%).

#### 8.3 Conclusion

TILDA nursing home participants were chronologically very old, had very high levels of physical and cognitive morbidities, and very high levels of physical disability.

Nevertheless, when TILDA nursing home participants were able to self-report, a majority reported that their physical and mental health was fair, good, very good or even excellent. Not being able to self-report was mostly associated with the presence of cognitive and communication problems, including dementia.

The personal perspectives of our TILDA nursing home participants provide an important reminder that quality of life is often rated higher by oneself than by proxies, even in the presence of very advanced age and extensive comorbidities and disabilities.

From these two data sources alone, it is not possible to infer the proportion or incidence of institutionalisation in the Irish population. The small number of participants included in this short report comes from a secondary data analysis and is not necessarily representative of the nursing home population in Ireland.

With the above caveats in mind, we have described the characteristics of TILDA's small sample of nursing home participants. TILDA cares very much about our nursing homes residents. Nursing home residents have been disproportionately affected by the COVID-19 pandemic and we will welcome further research that includes this very vulnerable group.