

Care burden, loneliness, and social isolation in informal caregivers in Ireland: Before and during COVID-19

Emilia Grycuk, Arianna Almirall-Sanchez, Irina Kinchin, Miriam Galvin, Nikki Dunne, Eimear McGlinchey, Brian Lawlor, Yaohua Chen, and Iracema Leroi



CLIC Carer

Survey on Coping with Loneliness, Isolation and Covid-19

Funding:

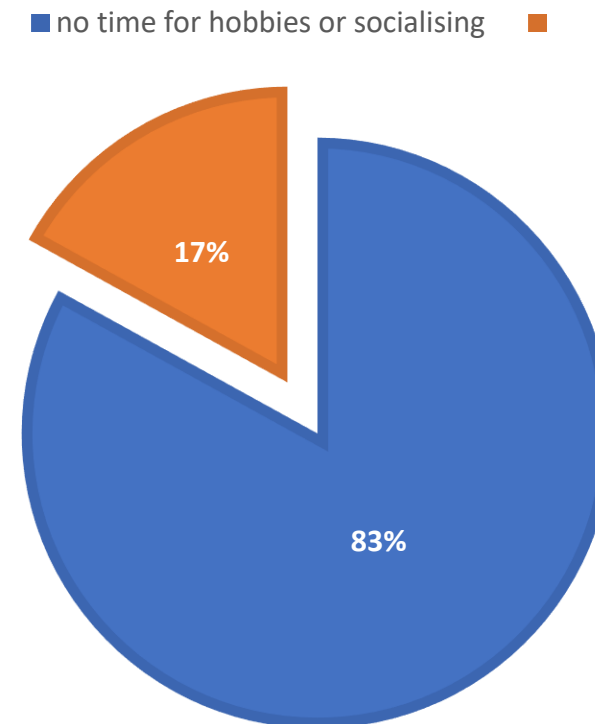
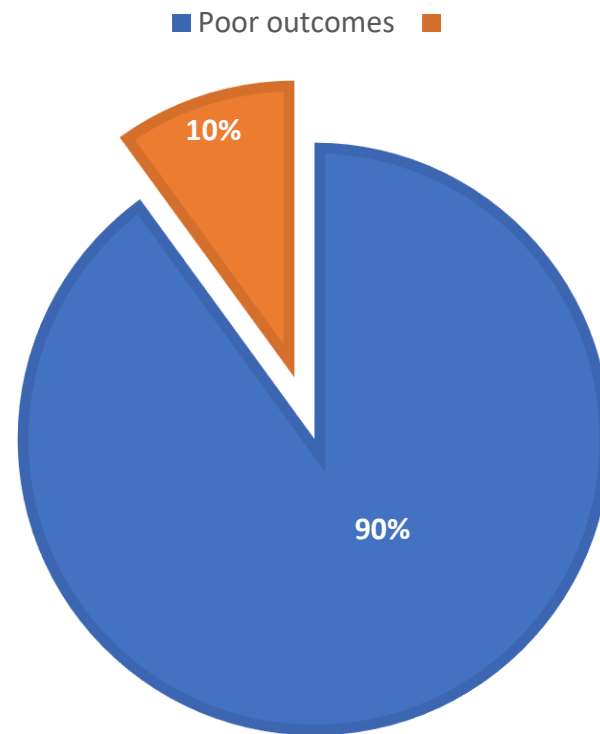
Trinity COVID-19 Response Fund

Irish Research Council- New Foundations Fund

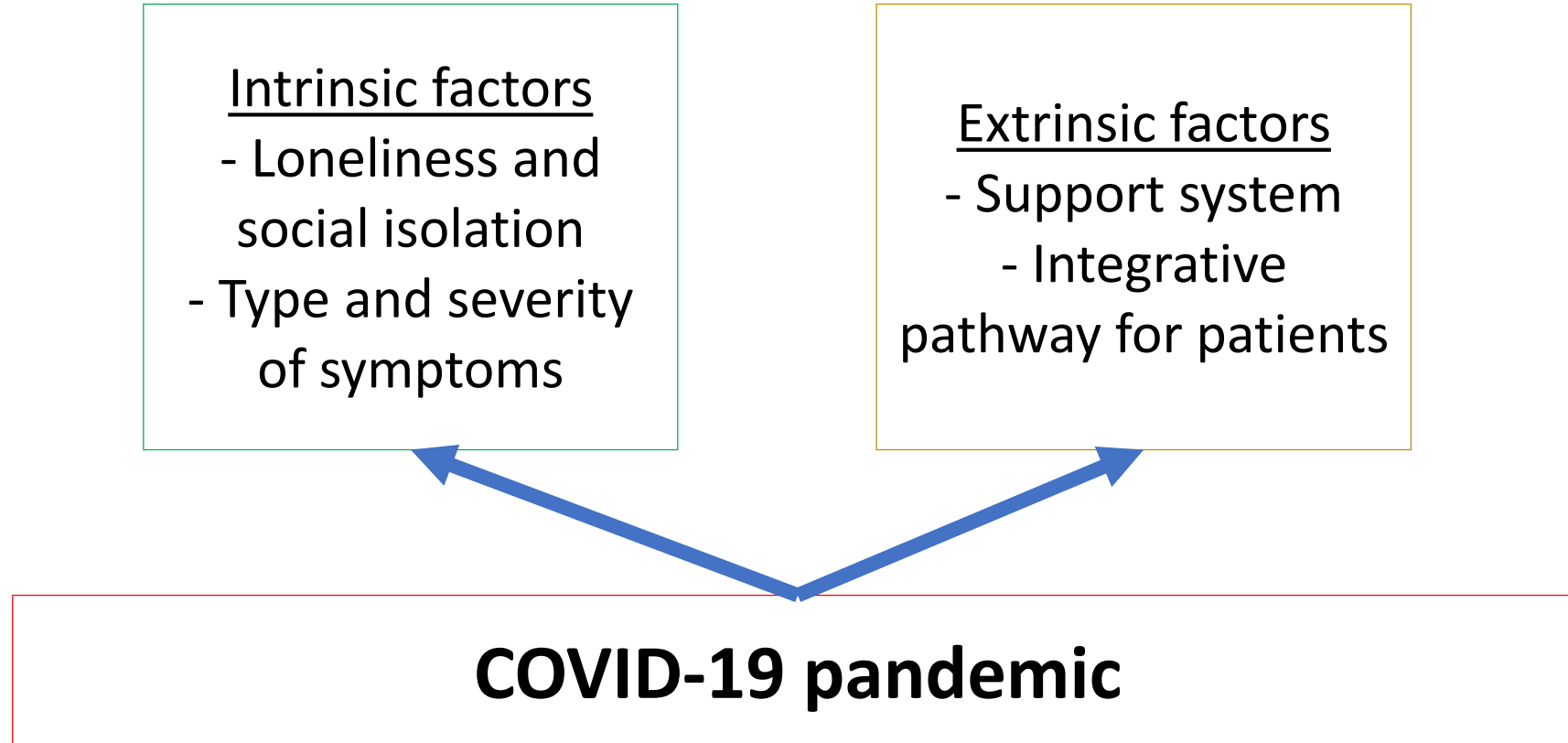
Poor health outcomes for carers: Pre-Covid 2020

Survey by **Family Carers Ireland (FCI)** n=1000

Clinical depression in carers for people with dementia was
3x the Irish national average



Impact of the pandemic on caregivers



Caregiver burden in COVID-19

*“COVID-19 added pressure on myself as the carer as my mother’s behaviour has become **more challenging** and her supports were withdrawn so I get **even less of a break** than before. I get none now.”*

*“When I got sick in early March and had to go to the hospital, my partner had to go into a nursing home as she requires 24/7 care. When I came home a month later of course she wasn't there. In addition to losing her presence in our home, at the same time I **lost** visiting privileges with her. I also **lost** in person visits with friends, attending church, going safely to public places, and participation in my activities.”*



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Survey on Coping with Loneliness, Isolation and Covid-19



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Survey on *Coping with Loneliness, Isolation and Covid-19*

- Cross-sectional, online, pragmatic, global survey
- Adults > 18 y.o., capacity to consent to research
- June 2nd - November 15th 2020
- Self-administered questionnaire
- > 20,000 adult participants from 100 countries worldwide
- 15 min to complete (129 Q)
- Validated loneliness and isolation scales
- The overall aim: to examine the psychological impact of the pandemic through validated self-report measures of loneliness and social isolation



Parent Survey: CLIC

Coping with Loneliness, Isolation and Covid-19 – online survey









International Journal of
*Environmental Research
and Public Health*



Article

Impact of the COVID-19 Pandemic on Loneliness and Social Isolation: A Multi-Country Study

Roger O'Sullivan ^{1,2,*} , Annette Burns ^{1,2}, Gerard Leavey ² , Iracema Leroi ³, Vanessa Burholt ^{4,5} , James Lubben ⁶, Julianne Holt-Lunstad ⁷ , Christina Victor ⁸, Brian Lawlor ³, Mireya Vilar-Compte ⁹, Carla M. Perissinotto ¹⁰, Mark A. Tully ¹¹ , Mary Pat Sullivan ¹², Michael Rosato ², Joanna McHugh Power ¹³, Elisa Tiilikainen ¹⁴  and Thomas R. Prohaska ¹⁵



CLIC -Carers

Survey on *Coping with Loneliness, Isolation and Covid-19*



- 5243 Identified as carers

If they answered « yes » to:

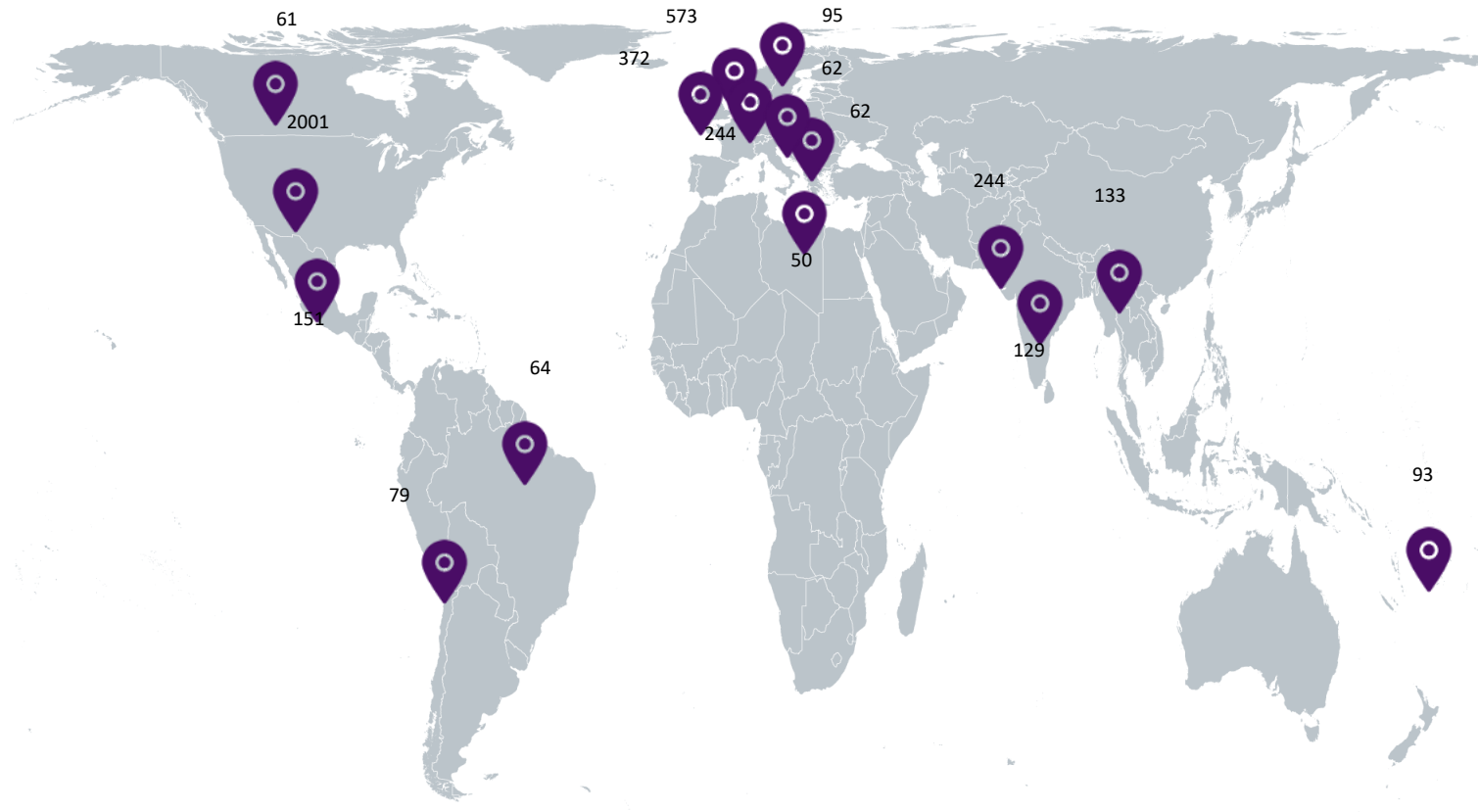
« Do you provide care and support to a family member or friend with a long-term or life-limiting health problem or disability (including mental health) ? »

Funding:

- *Trinity COVID-19 Response Fund*
- *Irish Research Council- New Foundations Fund*

Global participation

5236 (22%)
caregivers
worldwide



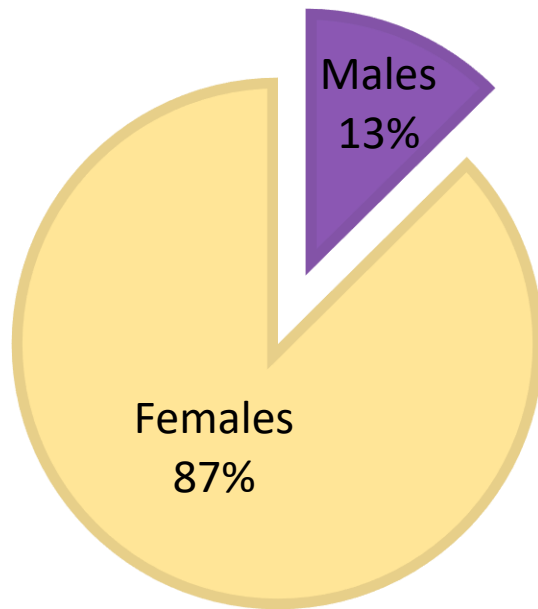
10
languages

59
countries

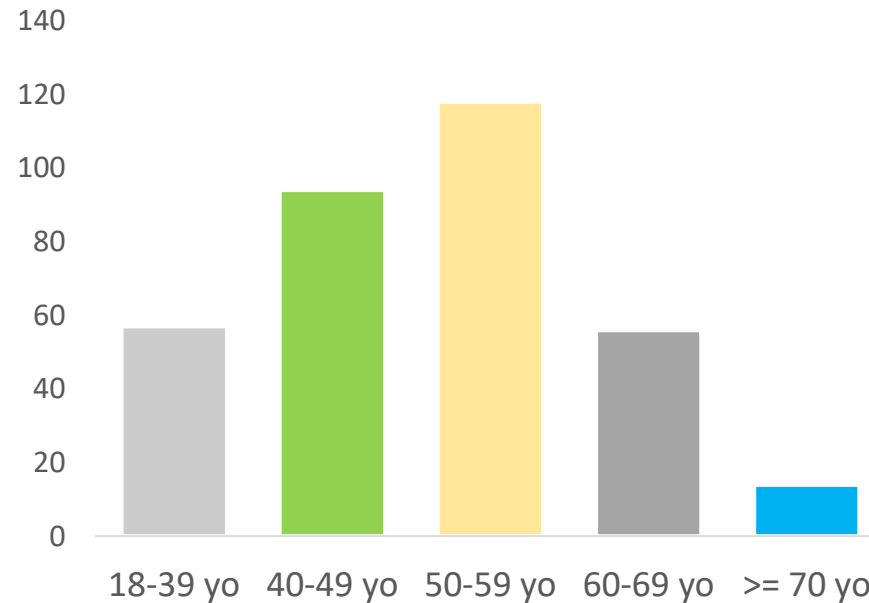
372 informal caregivers in Ireland - Demographic characteristics



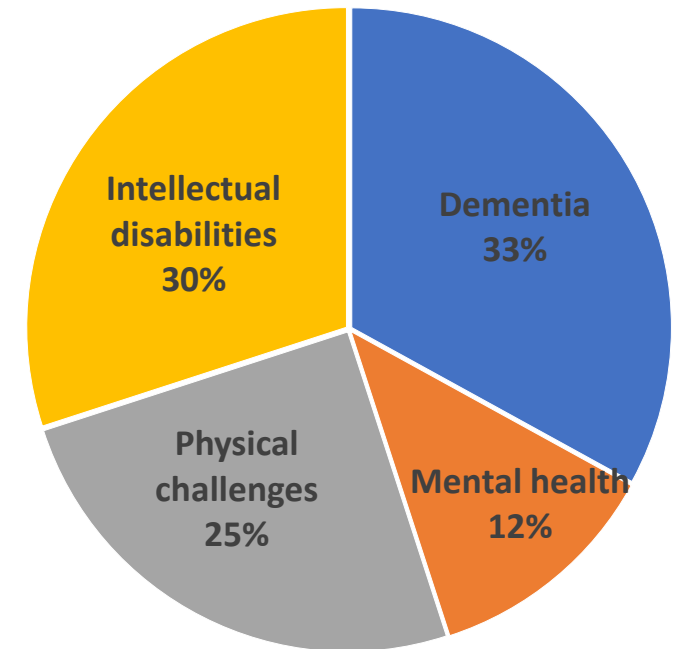
Gender distribution



Age categories



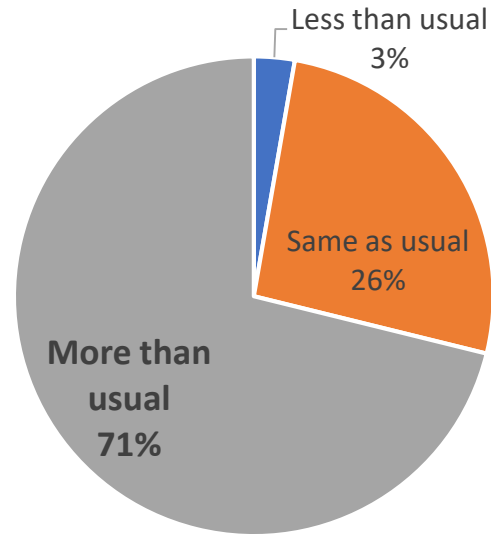
Care for people with



Care burden, loneliness and social isolation - During the pandemic

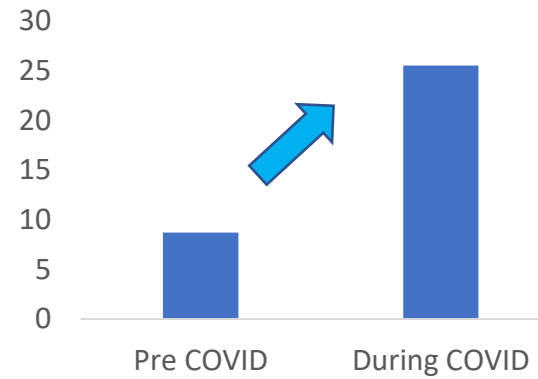


Caregiver Burden

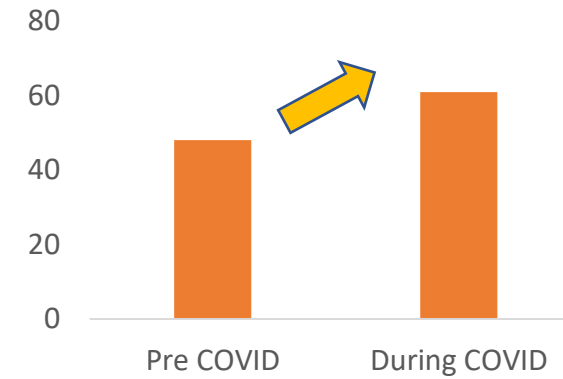


Loneliness

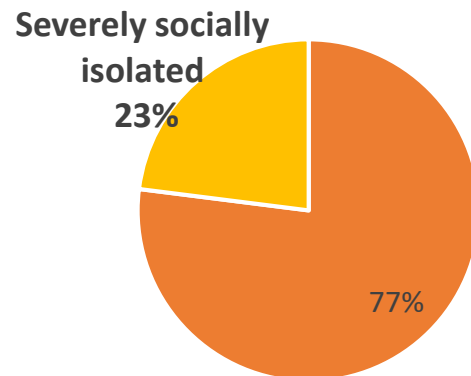
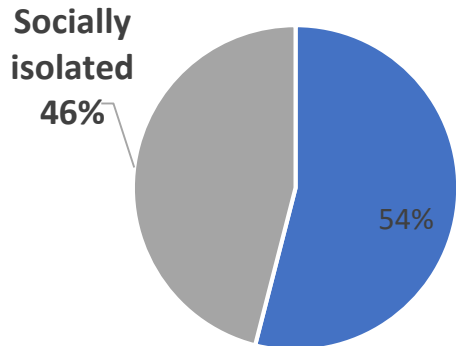
Emotional loneliness



Social loneliness

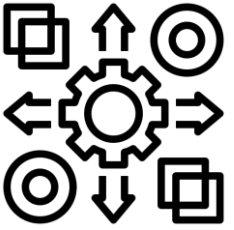


Social isolation in caregivers



→ Among the English-speaking regions of the CLIC study, **Irish caregivers had the most severe outcomes**

Factors associated with burden, loneliness, and social isolation



Burden

	OR	CI
Covid's impact on care provision	5.1	2.4-10.8

Loneliness

	OR	CI
Covid's impact on carers' finances	1.8	1.2-2.8
Moderate and frequent social isolation	2.4	1.5-3.7

Social isolation

	OR	CI
More severe social loneliness	3.2	1.4-7.7

→ COVID-19's **impact on care provision** was the most important factor

“Please describe how the pandemic has changed your ability to offer care”

*“I feel I have **less access to supports**, spending too much time in **confined space** with her. I find myself **getting irritated** with the **lack of supports** from health services.”*

*“I cannot see my mother indoors so visits are weather dependent. I cannot **provide any comfort** when she is **distressed** which is a lot as she has alzheimers. We are not allowed near her or touch her.”*

*“There is now a **constant fear of bringing in infection** to the person and a need for masks which is **unnatural** and interferes with the relationship.”*



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Survey on Coping with Loneliness, Isolation and Covid-19

Findings summarised in the Irish report on carers in COVID-19

**Care burden, loneliness, and social isolation in informal caregivers in Ireland:
before and during COVID-19**

**Report based on findings from the Coping with Loneliness, Isolation, and COVID-
19 (CLIC) study**

Emilia Grycuk, Arianna Almirall-Sanchez, Irina Kinchin, Miriam Galvin, Nikki Dunne, Eimear
Mc Glinchey, Brian Lawlor, Yaohua Chen & Iracema Leroi

November 2021

Policy recommendations

- 👉 Implementation of interventions addressing loneliness and social isolation, accounting for the circumstances caused by COVID-19
- 👉 The introduction of a Statutory Home Support Scheme
- 👉 Legislation of caregivers right to respite
- 👉 Addressing caregivers' access to financial support

Thank you!



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Survey on Coping with Loneliness, Isolation and Covid-19



**GLOBAL
BRAIN HEALTH
INSTITUTE**



**THE ALZHEIMER
SOCIETY of IRELAND**