

# COVID-19-related loneliness and social isolation in caregivers of people with brain health challenges: The CLIC-Caregiver Global Survey

Yaohua Sophie Chen<sup>1,2,3</sup> | Bárbara Costa Beber<sup>4</sup> | Dawn Higgins<sup>5</sup> | Miriam Galvin<sup>6</sup> |  
Stefania Ilinca<sup>7</sup> | Brian Lawlor<sup>8,9,10</sup> | Tomas Leon<sup>11,12</sup> | Iracema Leroi<sup>6</sup> |  
Eimear McGlinchey<sup>7</sup> | Carol Rogan<sup>5</sup> | Sanjib Saha<sup>7,13</sup> | Anna Tjin<sup>5</sup> |  
Roger O'Sullivan<sup>14</sup> | CLIC-Caregivers Study Group

<sup>1</sup> CHRU Lille, Lille, France

<sup>2</sup> Global Brain Health Institute -Trinity College, Dublin, Ireland

<sup>3</sup> Université de Lille, Lille, France

<sup>4</sup> Universidade Federal de Ciências da Saúde de Porto Alegre (UFCSA), Porto Alegre, Brazil

<sup>5</sup> TCD, Dublin, Ireland

<sup>6</sup> Global Brain Health Institute, Trinity College Dublin, Dublin, Ireland

<sup>7</sup> Global Brain Health Institute, Dublin, Ireland

<sup>8</sup> Global Brain Health Institute, Trinity College, Dublin, Ireland

<sup>9</sup> Trinity College Dublin, Dublin, Ireland

<sup>10</sup> St James Hospital, Dublin, Ireland

<sup>11</sup> Global Brain Health Institute, Dublin, Ireland

<sup>12</sup> Memory and Neuropsychiatry Disorders Clinic (CMYN), Santiago, Chile

<sup>13</sup> Lund University, Lund, Sweden

<sup>14</sup> Ulster University, Belfast, Ireland

## Correspondence

Yaohua Sophie Chen, CHRU Lille, Lille, France  
Email: [yaohua.sophie.chen@gmail.com](mailto:yaohua.sophie.chen@gmail.com)

## Abstract

**Background:** Prior to COVID-19, >90% of caregivers of people with brain health challenges (dementia, mental ill health, intellectual disability) experienced high levels of distress, burden, loneliness and social isolation. The COVID-19 pandemic has significantly increased these impacts, particularly since these caregivers are often older and physically vulnerable themselves. The aim of this cross-sectional study is to explore coping and caregiver burden, loneliness and social isolation in caregivers of people with brain health challenges during the COVID-19 pandemic.

**Method:** CLIC-Caregiver was a cross-sectional, online, and global survey (June 2<sup>nd</sup> - November 15<sup>th</sup>, 2020) using self-administered questionnaires directed at informal caregivers of people with long-term brain health challenges. The study was embedded within a larger survey of loneliness and social isolation for general public ('Comparing Loneliness and Isolation in COVID-19' (CLIC)), including validated loneliness and isolation tools. Translated into ten different languages such as Arabic, French, Romanian, etc, the survey was disseminated over 100 countries. Respondents were included in the CLIC-caregiver sub-study if they answered yes to the question '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)'. The CLIC project received the initial global ethical approval from Ulster University. The data were fully anonymized.

**Result:** From the CLIC main study, 5243 (25%) identified themselves as caregivers. This proportion varied in different countries, from 12 % in Romania to 65% in France. 2323 (44%) had care recipients with dementia, 1761 with physical conditions (disability or long-term illness), 832 with enduring mental health problems, and 404 with intellectual disability. Measures of caregiver burden, loneliness and social isolation will be compared across geographic regions, sociodemographic factors, and risk factors for poor outcomes sought. Findings will be distributed to relevant stakeholders in the form of a project report, with region and country-specific outcomes. This will support recommendations and actions supporting caregivers of people with brain health challenges.

**Conclusion:** This represents the largest, most widespread survey on the impact of the COVID-19 pandemic on caregivers of people with long-term conditions to date. It will be an important resource for support agencies and to inform policy.