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RESEARCH ARTICLE

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Care burden, loneliness, and social isolation in caregivers of people with physical and brain health conditions in English-speaking regions: Before and during the COVID-19 pandemic

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Abstract

Background: Public health restrictions due to the COVID-19 (SARS CoV-2) pandemic have disproportionately affected informal caregivers of people living with long term health conditions. We aimed to explore levels of care burden, loneliness, and social isolation among caregivers of people with enduring physical and brain health conditions in English-speaking regions worldwide, by investigating outcomes before and during the COVID-19 pandemic.

Methods: A cross-sectional anonymous online survey data from 2287 English-speaking caregivers of people with long term health conditions from four English-speaking regions (UK, Ireland, USA, New Zealand) included measures of care burden, loneliness, and social isolation, reported before and during the COVID-19 pandemic. Analyses were descriptive, followed by an ordinal regression model for predictors of burden.

Results: Compared to pre-pandemic levels, all caregivers experienced a significant increase in burden, loneliness, and isolation. Caregivers of people with both brain health and physical conditions were the most burdened and had the highest levels of loneliness and isolation compared to caregivers of people with either a brain health or physical condition only. The increase in care burden among caregivers of people with brain health challenges was associated with caregiver's gender, moderate and severe emotional loneliness, magnitude and frequency of isolation during the pandemic, and care circumstances (cohabitation with the care recipient, restrictions on the ability to provide care).

Conclusions: Health and social care interventions should target caregivers' care circumstances and psychological outcomes, particularly in women, accounting for

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On the behalf of the CLIC Caregiver study group(See Appendix A).

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the significant additional burden of care, loneliness, and isolation resulting from pandemic-related restrictions.

KEYWORDS

brain health, brain health conditions, Caregiver burden, caregivers, COVID-19, dementia, loneliness, mental health, mental illness, social isolation

Key points

- This study highlights the significant negative impact that COVID-19-related restrictions have had on informal caregivers of people with enduring health conditions in four English speaking regions, globally.
- Heightened levels of burden, loneliness, and social isolation occurred during the pandemic compared to pre-pandemic in caregivers of people with enduring physical and brain health or physical health conditions.
- The increase in burden in caregivers of people with brain health conditions was associated with caregiver factors (including gender, emotional loneliness, and increase in social isolation) and pandemic-related external factors, such as cohabitation with the care recipient and the impact of COVID-19-related restrictions on the ability to provide care.
- These findings have implications for policy development and healthcare interventions to target care circumstances and psychosocial outcomes of informal caregivers and ensure their equitable access to social support, taking into consideration pandemic-related changes.

1 | INTRODUCTION

Most of the care and support provided for people living with enduring brain health conditions including dementia, other neurodegenerative disorders, and chronic mental illness, is provided by informal caregivers, who are often spouses or life partners, adult children, or other family members.[1–5] Caregivers are critical in supporting disease management and activities of daily living of people with such conditions. However, providing care can negatively impact caregivers' self-efficacy, quality of life, and physical and mental health, and result in caregiver burden.[6–8] Caregiver burden as a construct has multiple dimensions in the context of enduring brain health conditions, including social and psychological constraints, personal strain, interference with personal life, concerns about the future, and guilt,[9] all of which have been significantly impacted by the COVID-19 pandemic and the resulting national and regional public health-related restrictions.

Public Health social measures and restrictions related to the pandemic in most English-speaking countries started around March 2020 and have continued into 2021. Patterns of informal caregiving have been disrupted by the loss of external support and respite provision, closure of clinics, long periods of cohabitating, and/or separation of caregiver and care recipient.[10] Such sudden and unforeseen changes of caregiving patterns have worsened mental health outcomes of informal caregivers[11–18] and potentially accentuated the already significant risks associated with increased care burden, loneliness, and social isolation.

Loneliness is a subjective sense of inadequate quantity or quality of social contact and longing for close and emotional relationships with others. In contrast, social isolation is an objective and quantifiable lack of, or reduction of, social network size and social contact.[19–21] Prior to the COVID-19 restrictions, older adults were already at risk of social isolation and loneliness due to bereavement, relocation, living alone, or the loss of friends and social networks.[22] Loneliness may also arise in the context of marital or cohabiting relationships, particularly due to changes in intimacy, functional decline, or the emergence of illness.[4,6] Pre-pandemic, loneliness in caregivers was associated with many adverse health outcomes, low quality of life, depression, and psychological distress.[23–29] This is particularly the case for those providing care for people with enduring brain conditions, due to social segregation, and cognitive and emotional deterioration of the care recipients, reflecting a dyadic impact.[4,5,30–34] Pandemic-related restrictions have now exaggerated rates of loneliness and social isolation globally,[35] particularly in older people,[7,8,36–38] women,[2,5,39–43] and informal caregivers of people with enduring health conditions.[14,16,36,44,45] Informal caregiver status is an independent risk factor for increased loneliness during COVID-19.[35]

Almost all the recent COVID-19-related surveys of care burden, loneliness, and social isolation during the pandemic have focused on only a single country or a single health condition, accessed through existing networks of disease-related stakeholders, rather than more representative respondent sampling.[14,16,36,44,45] Moreover, most surveys did not utilize validated scales to examine loneliness and social isolation. To address these issues, here, we explored the impact of the COVID-19 pandemic on burden in informal caregivers of people with enduring health conditions across four English-speaking regions worldwide (UK, Ireland, USA, and New Zealand), measuring loneliness and social isolation using well-validated tools. The choice of countries allowed us to capture a global perspective without the limitation of linguistic differences. We focused particularly on caregivers of people with enduring brain health conditions, including dementia, other neurodegenerative disorders, and mental illness. Conditions affecting brain health are increasingly in the spotlight due to worldwide population aging, which is often associated with neurodegenerative conditions.[46] The restrictions placed on caregivers due to the pandemic allowed us to explore caregiver perceptions of burden, loneliness, and social isolation in two sets of circumstances – pre-pandemic and during the pandemic, when the risk of social isolation and loneliness increased.

We hypothesized that:

(1) The increase in caregiver burden is greater in caregivers of people with both brain health (dementia and mental illness) and physical conditions compared to caregivers of people where only one of these categories is present.
(2) In caregivers of people with brain health conditions, the increase in caregiver burden is associated with intrinsic factors, such as increased loneliness (especially emotional as compared to social loneliness) and social isolation, with the additional risk factors of gender and age.
(3) The increase in caregiver burden, among caregivers of people with brain health conditions, is associated with extrinsic factors, such as caregiving circumstances, nature and location of care provision, which changed due to the pandemic-related restrictions.

2 | METHODS

2.1 | Study design

The Coping with Loneliness, Isolation, and COVID-19 (CLIC) was an international study involving a cross-sectional online self-administered survey, directed at adults over the age of 18 with the capacity to consent to research.[35] It had over 20,000 adult participants from 100 countries worldwide. The overall aim of the CLIC study was to examine the psychological impact of the pandemic through validated self-report measures of loneliness and social isolation; details of this survey are reported elsewhere.[35] The CLIC Global Caregiver study, referred to here, was embedded within the CLIC study and focused on the experience of informal caregivers of people with enduring health problems, particularly physical and brain health conditions.

2.2 | Participant sample

Setting: Recruitment for the survey was coordinated by a nominated investigator for each participating country, who accessed potential participants through the email lists and websites of public or voluntary sector organizations supporting family or informal caregivers of people with brain health conditions. Data collection took place between June 2, 2020 and November 16, 2020, with the survey link circulated through social media networks such as Facebook and Twitter. To maximize uptake, each investigator distributed the survey at least twice during the data collection period, with a minimum of 4 weeks between distributions.

Inclusion criteria: For the purposes of this study, only English-speaking regions (USA, UK, Ireland, and New Zealand) were included in the analysis. We specifically chose these geographically disparate but language equivalent regions to reflect the global impact of the pandemic while controlling for the potential effect of cultural and linguistic differences, which may impact perceptions and self-reports of loneliness and social isolation.[40,46] Finally, to ascertain the participants identified as informal caregivers, we included only those who positively answered the survey 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)?*

Participants: Across 101 countries, the parent survey, CLIC, enrolled 23,609 people, among whom 5236 were caregivers of people with long-term health conditions, including 3234 caregivers of people with specific brain health conditions (2379 with dementia and 855 with mental illness), and 1803 with long-term physical conditions. Within the four English-speaking regions selected for this analysis, there were 2287 participants, including 1575 (65.9%) from the USA, 426 (18.9%) from the UK (18.9%), 219 from Ireland (12.2%), and 67 (3.1%) from New Zealand. Of these, 1602 (53%) participants were caregivers of people with enduring brain health conditions (1338 of whom were caregivers of people with dementia and 264 were caregivers of people with mental health issues), 685 (23%) cared for people with physical conditions, and 362 (12%) were caregivers of people who had both aforementioned conditions.

2.3 | Survey instrument

The survey instrument was co-developed through consensus with an international panel of professional experts in loneliness/social isolation, dementia, other brain health conditions, the Alzheimer Society of Ireland (ASI) patient involvement (PPI) team, as well as Family Carers Ireland. It was informed by preliminary findings from a small-scale survey undertaken in Ireland at the beginning of the COVID-19 pandemic (Spring 2020) by ASI, which indicated significant levels of distress, burden, and isolation among caregivers of people with dementia. A draft version of the full survey, CLIC, including the CLIC Global Caregivers survey was field tested in regions globally. Only measures of loneliness and social isolation that had been previously validated and used in large-scale population studies were included.[47–49] The final survey took approximately 15 min to complete and included 129 questions, including sociodemographic factors, measures of caregiver burden, loneliness, social isolation, and general health, relating to their status before and during the COVID-19 pandemic.

Table 1 provides an overview of the caregiver survey measures, including validated measures of emotional and social loneliness, social

TABLE 1 Outline of measures collected in the survey

Caregiver characteristics	- Nature of the relationship with their care recipients (*spouse/partner*, *other family member*, *other relative*, *non-relative*)- Type of health condition of care-recipients (*physical health condition*, *dementia*, *mental health condition*, *intellectual disability*, *others*)- Place of care provision (*caregiver's home*, *care recipient's home*, *care facility*, *others*)- Change of their role as informal caregivers or interruption of care due to COVID-19
Caregiver burden	- A single question from the Zarit Burden Interview (ZBI) demonstrated to capture a core aspect of caregiving burden[51] from the full ZBI[52] o Assessment of how often participants felt burdened in their role in COVID-19: from *never* to *nearly alwayso* Assessment of the change of burden: *same as usual*, *more than usual*, or *less than usual*- Description of how they felt about their caring role
Loneliness	- Participants' level of loneliness and social isolation before and during COVID-19 (i.e., *Before COVID-19, how often did you feel lonely?*) measured with the modified 5-item UCLA Loneliness Scale[47] o 3-point Likert scale: *hardly ever or never*, *some of the time*, and *ofteno* Total between 0 and 10: from 0 to 4: no/low loneliness; 5–6: moderate loneliness; and 7+: severe loneliness- Frequency, intensity, and duration of loneliness and social isolation measured with Likert scales ranging from 1 to 5° Intensity scale from *not intense at all* (1) to *very intense* (5)o Duration scale: *hours* (1), *days* (2), *weeks* (3), *months* (4), *longer* (5)o Internal consistency of the before COVID-19 scale $\alpha = 0.8$ and $\alpha = 0.84$ for the during COVID-19 scale
Emotional and social loneliness	- Emotional loneliness (i.e., *Before COVID-19, I experienced a general sense of emptiness*) and social loneliness (i.e., *During COVID-19, there are many people I can trust completely*) before and during COVID-19 measured with the 6-item De Jong Gierveld Loneliness Scale[48] o 3-point Likert scale: *no*, *more or less*, and *yeso* The maximum score of each of the subscales was 9: 0–3: no loneliness; 4 and 5: mild loneliness; 6 and 7: moderate loneliness; and 8 and 9: severe loneliness.o Internal consistency: $\alpha = 0.78$ and 0.77 for the before and during COVID-19 scales, respectively
Social isolation	- Participants' size of social support network, frequency, and closeness of contact with their family and friends pre- and during COVID-19 (i.e., *Usually how many relatives do you see or hear from at least once a month?*) was measured with the 6-item Lubben Social Network Scale (LSNS6)[49] o Likert scale ranging from 0 (*none*) to 5 (*nine or more*)o The summary of scores ranged between 0 and 30, with scores below 12 defined as isolated.- Additional 6 questions assessing if the level of social isolation during COVID-19 was *the same* (1), *more than usual* (2), or *less than usual* (3) o Scores between −6 and 6: −3 or lower indicated a large increase in the subjective isolation during COVID-19.o Validity of the pre- and during COVID-19 scales: $\alpha = 0.83$ and $\alpha = 0.72$

isolation, and questions about the type of health condition and the nature of the relationship with the care recipient, caregiving circumstances, and how they had changed. For brevity, a single item to reflect change in caregiver burden quantitatively was selected. Participants were also asked key non-identifiable sociodemographic-related factors as well as perceptions of their physical and mental health with answers ranging from *excellent* to *poor*, whether and what long-term conditions or illnesses they have. They answered questions regarding their technology use, that is, how satisfied they are with using phone, text, emails, WhatsApp, or face to face technology (i.e., Zoom, Skype, etc.) as a form of communication, and how likely they are to continue these forms of communication after COVID-19. These questions were measured on a Likert scale ranging from 1 (*very dissatisfied* or *very unlikely*) to 5 (*very satisfied* or *very likely*). Moreover, participants provided information about their personal experience with COVID-19, that is, whether they or someone they know had been diagnosed or hospitalized with COVID-19, if someone they know died during that time, and if yes, then whether it was related to COVID-19. Finally, the respondents provided information about their habits in the pandemic related to food, alcohol consumption, sleep quality, physical activity, creative activity, etc.

2.4 | Data analysis

Data analysis was conducted using IBM SPSS Statistics Version 26.0 for Mac. A two-tailed significance level was set at 0.05. First, chi-square tests of independence, one-way analyses of variance (ANOVAs), and Kruskal Wallis *H* tests were conducted to explore descriptive characteristics and compare differences of participants across three caregiver groups, defined by their care recipients as having multidimensional and enduring brain health conditions (dementia and mental illness), physical health conditions, or both. Additionally, an ordinal logistic regression was conducted to explore factors associated with the increase in care burden. We also performed additional sensitivity analyses that compared caregivers of people with dementia to caregivers of people with mental health issues. Results are reported according to STROBE guidelines.[50]

2.5 | Ethics

The overall study abided by the World Medical Association's Declaration of Helsinki's ethical standards, with approval provided by the

TABLE 2 Sociodemographic characteristics of all caregivers, caregivers of people with brain health, physical health, or both conditions from four English-speaking regions in the CLIC Global Caregiver Survey ($n = 2287$). The data are expressed in percentage (numbers), unless specified

	All caregivers	Brain health conditions	Physical conditions	Both conditions	*p*
Gender					
Women	81.7 (2157)	79.9 (1269)	84.9 (578)	87.3 (310)	0.001
Missing data	8	*13*	*4*	*7*	
Age group					
18–44	10.4 (248)	8.7 (127)	12.2 (76)	13.5 (45)	0.17
45–49	7.1 (172)	7.7 (112)	6.5 (41)	5.7 (19)	
50–54	10.2 (247)	11.2 (163)	8.8 (55)	8.7 (29)	
55–59	15.5 (373)	16.2 (235)	13.9 (87)	15.4 (51)	
60–64	16.7 (403)	15.1 (219)	18.2 (114)	21.1 (70)	
65–69	15.7 (379)	14.3 (207)	18.9 (119)	16 (53)	
70–74	13.6 (327)	14.3 (207)	13.1 (82)	11.4 (38)	
75+	10.9 (263)	12.5 (182)	8.6 (54)	8.1 (27)	
Missing data	237	*150*	*57*	*30*	
Marital status					
Married	69.4 (1827)	70.4 (1120)	68.5 (468)	66.2 (239)	0.07
Cohabitating	6.5 (171)	6 (95)	6.7 (46)	8.3 (30)	
Never married	10.5 (277)	9.8 (156)	11.1 (76)	12.5 (45)	
Separated	1.6 (41)	1.6 (25)	1.6 (11)	1.4 (5)	
Divorced	8.3 (218)	8.9 (142)	6.4 (44)	8.9 (32)	
Widowed	3.8 (100)	3.3 (52)	5.6 (38)	2.8 (10)	
Missing data	15	*12*	*2*	*1*	
Education					
Elementary	0.4 (11)	0.4 (6)	0.4 (3)	0.6 (2)	0.67
Secondary	25.3 (658)	24.7 (389)	26.2 (176)	26.2 (93)	
Undergraduate or higher	74.3 (1932)	74.9 (1178)	73.4 (494)	73.2 (260)	
Missing data	48	*29*	*12*	*7*	
Employment					
Employed	36.3 (955)	35.4 (563)	37.9 (258)	37.3 (134)	0.76
Self- employed	20.9 (549)	5.8 (92)	5.9 (40)	6.7 (24)	
Unemployed	6.1 (160)	6.3 (100)	5.4 (37)	6.4 (23)	
Retired	41.6 (1094)	42.3 (673)	41.8 (284)	38.2 (137)	
Others	10 (265)	10.2 (163)	8.9 (61)	11.4 (41)	
Missing data	19	*11*	*5*	*3*	
The degree of finances meeting current needs					
Very well	43 (1129)	43 (683)	46 (312)	37.4 (134)	0.002
Fairly well	47 (1233)	47.5 (755)	45.7 (310)	46.9 (168)	
Poorly	10 (262)	9.4 (150)	8.3 (56)	15.6 (56)	
Missing data	*25*	*14*	*7*	*4*	

(Continues)

TABLE 2 (Continued)

	All caregivers	Brain health conditions	Physical conditions	Both conditions	p
Place of care provision					
Caregiver's home	45.4 (1202)	44.8 (717)	48.5 (332)	42.4 (153)	0.00
Care recipient's home	30.6 (809)	25.4 (406)	40.4 (277)	34.9 (126)	
Care facility	19.2 (507)	24.3 (389)	7 (48)	19.4 (70)	
Others	4.9 (129)	5.6 (89)	4.1 (28)	3.3 (12)	
Missing data	*2*	*1*	-	*1*	
General physical health					
Excellent	13.7 (359)	13.9 (221)	15.3 (104)	9.5 (34)	0.002
Very good	36.5 (959)	36.7 (584)	36.5 (248)	35.4 (127)	
Good	34 (894)	34.2 (544)	34 (231)	33.1 (119)	
Fair	12.8 (336)	12.8 (204)	11.3 (77)	15.3 (55)	
Poor	2.8 (73)	1.9 (30)	2.9 (20)	6.4 (23)	
Missing data	*20*	*12*	*5*	*3*	
General mental health					
Excellent	10.5 (276)	9.9 (158)	13.2 (90)	7.8 (28)	0.00
Very good	31.8 (837)	32.8 (522)	32.4 (220)	26.5 (95)	
Good	35.5 (934)	36.3 (577)	33.5 (228)	35.9 (129)	
Fair	18.2 (479)	17.2 (273)	17.6 (120)	24 (86)	
Poor	3.8 (99)	3.6 (57)	3.2 (22)	5.6 (20)	
Missing data	*20*	*12*	*5*	*3*	
COVID 19's effect on care provision					
Yes	59.3 (1565)	61.9 (987)	49.9 (342)	65.4 (236)	0.001
Missing data	*8*	*7*	-	*1*	
Intensity if yes[a] (1 = low, 5 = very severe	4.12 (1)	4.2 (1.1)	3.9 (1.1)	4.1 (1.0)	0.002
Missing data	*1430*	*833*	*416*	*181*	

[a]data expressed as mean (*SD*).

University of Ulster, and where required, with additional approvals from ethics' committees in participating countries. The sub-study CLIC Global Caregiver survey was approved by Trinity College Dublin. The survey was fully anonymized and no identifying information was collected nor retained.

3 | RESULTS

3.1 | Participant sample

We analyzed 2287 completed surveys. Tables 2 and 3 provide demographic and other characteristics of the participants. Briefly, 82.2% were women and most participants were over age 45 (90.3%) and married (69.9%). Nearly three quarters (74.3%) of caregivers had at least an undergraduate degree and most were employed (42%) or retired (42.1%). The majority rated their physical (84.2%) and mental health (77.8%), as *good* or better. Caregivers were categorized according to the health condition of the care recipient into 3 groups: those caring for people with brain health challenges, physical health conditions, and both combined. Across the three caregiver groups, as defined by their care recipients, caregivers for people with both brain and physical health conditions were more often women (87.3%, $p < 0.001$), and self-rated as having poorer physical and mental health (21.7% for *fair to poor* general physical health, $p = 0.002$; 29.6% for *fair* to *poor* mental health $p < 0.001$).

3.2 | Caregiver burden

As shown in Table 3, during the pandemic, caregivers (56.9%) reported an increase in care burden compared to pre-pandemic. Over a third (37.1%) felt burdened *quite frequently* or *nearly always* during the pandemic. Caregivers of people with *both* brain and physical health

TABLE 3 Burden, loneliness, and social isolation characteristics of all caregivers, caregivers of people with brain health, physical health, or both conditions from four English-speaking regions in the CLIC Global Caregiver Survey (*n* = 2287). The data are expressed in percentage (numbers), unless specified

	All caregivers	Brain health conditions	Physical conditions	Both conditions	*p*
Frequency of burden in COVID-19					
Never	7.4 (195)	6.7 (107)	9.8 (67)	5.8 (21)	0.00
Rarely	14 (370)	12.3 (196)	20.8 (142)	8.9 (32)	
Sometimes	41.5 (1096)	42.1 (672)	42.5 (291)	36.8 (133)	
Quite frequently	28.6 (754)	29.7 (474)	21.5 (147)	36.8 (133)	
Nearly always	8.5 (225)	9.2 (146)	5.4 (37)	11.6 (42)	
Missing data	*9*	*7*	*1*	*1*	
Change in burden during COVID-19					
Less than usual	4.3 (114)	4.8 (77)	3.4 (23)	3.9 (14)	0.00
Same as usual	38.8 (1022)	37.7 (600)	46.9 (320)	28.3 (102)	
More than usual	56.9 (1497)	57.4 (913)	49.7 (339)	67.9 (245)	
Missing data	*16*	*12*	*3*	*1*	
Pre-COVID-19 frequency of loneliness					
Hardly ever/never	54.6 (1345)	54.2 (804)	56.7 (366)	52.1 (175)	0.24
Sometimes	39.5 (974)	40 (593)	38.1 (246)	40.2 (135)	
Often	5.9 (146)	5.9 (87)	5.1 (33)	7.7 (26)	
Missing data	*184*	*118*	*40*	*26*	
During COVID-19 frequency of loneliness					
Hardly ever/never	33 (810)	30.8 (454)	38.6 (248)	32.2 (108)	0.002
Sometimes	44.9 (1101)	47.1 (694)	42.4 (272)	40.3 (135)	
Often	22 (540)	22.1 (326)	19 (122)	27.5 (92)	
Missing data	*198*	*128*	*43*	*27*	
Pre-COVID-19 frequency of social isolation					
Hardly ever/never	62.4 (1533)	62.5 (924)	63.7 (409)	59.5 (200)	0.32
Sometimes	30.8 (756)	31.1 (460)	29.8 (191)	31.3 (105)	
Often	6.8 (168)	6.4 (95)	6.5 (42)	9.2 (31)	
Missing data	*192*	*123*	*43*	*26*	
During COVID-19 frequency of social isolation					
Hardly ever/never	22.5 (549)	21.5 (316)	26.2 (168)	19.5 (65)	0.001
Sometimes	43.5 (1063)	42.7 (628)	45.1 (289)	43.7 (146)	
Often	34.1 (833)	35.8 (526)	28.7 (184)	36.8 (123)	
Missing data	*204*	*132*	44	*28*	
Pre-COVID-19 UCLA loneliness scale					
None/low	78 (1909)	77.9 (1147)	80 (512)	74.9 (250)	0.25
Moderate	15 (366)	15 (221)	13.3 (85)	18 (60)	
Severe	7 (171)	7.1(104)	6.7 (43)	7.2 (24)	
Missing data	*203*	*130*	*45*	*28*	

(Continues)

TABLE 3 (Continued)

	All caregivers	Brain health conditions	Physical conditions	Both conditions	*p*
During COVID-19 UCLA loneliness scale					
None/low	47.6 (1156)	46.2 (675)	51.5 (328)	45.9 (153)	0.03
Moderate	25.8 (628)	26.9 (393)	25.1 (160)	22.5 (75)	
Severe	26.6 (647)	26.9 (393)	23.4 (149)	31.5 (105)	
Missing data	*218*	*141*	*48*	*29*	
Large increase in social isolation during COVID-19					
Not isolated	86.5 (1991)	87.4 (1205)	85.8 (520)	83.9 (266)	0.26
Isolated	13.5 (311)	12.6 (174)	14.2 (86)	16.1 (51)	
Missing data	*347*	*223*	*79*	*45*	
Pre-COVID-19 emotional loneliness[a] (1 = not lonely, 3 = severely lonely)					
	0.72 (1.03)	0.7 (0.98)	0.69 (1.01)	0.85 (1.05)	0.04
Missing data	*293*	*195*	*64*	*34*	
During COVID-19 emotional loneliness[a] (1 = not lonely, 3 = severely lonely)					
	1.55 (1)	1.55 (0.99)	1.49 (1.02)	*1.65* (1)	0.06
Missing data	*294*	*194*	*66*	*34*	
Pre-COVID-19 social loneliness[a] (1 = not lonely, 3 = severely lonely)					
	1.72 (1.35)	1.65 (1.36)	1.76 (1.35)	1.95 (1.25)	0.001
Missing data	*295*	*196*	*64*	*35*	
During COVID-19 social loneliness[a] (1 = not lonely, 3 = severely lonely)					
	1.99 (1.29)	1.95 (1.3)	1.98 (1.32)	2.2 (1.17)	0.007
Missing data	*295*	*195*	*66*	*34*	

[a] data expressed as mean (*SD*).

conditions were more burdened (67.9%), compared to caregivers of people with only one type of condition (57.4% for brain health conditions; 49.7% for physical health conditions; $p < 0.001$). Furthermore, caregivers of both condition types reported a greater impact on their caregiving due to COVID-19 restrictions (65.4%, $p < 0.001$), including the degree to which their ability to deliver care was interrupted ($p = 0.002$).

3.3 | Loneliness

Findings regarding loneliness are presented in Table 3. The proportion of caregivers who rated their loneliness (*as per* the UCLA scale) as *severe* increased from 7% pre-pandemic to 26.6% during the pandemic (Table 3). This increase was most evident in caregivers of people with dual conditions whose loneliness increased from about 7% pre-pandemic to over 30% during the pandemic (31.5%; $p = 0.03$). A similar change was seen on loneliness ratings using the De Jong scale. There was a 12% increase in the proportion of caregivers rating themselves as "emotionally lonely" prior to and during the pandemic (9.1% and 21% respectively). Differences in both points in time ($p = 0.04$; $p = 0.06$) indicated that caregivers of people with both conditions had the highest level of emotional loneliness before and during the pandemic ($M = 0.85$, $SD = 1.05$; $M = 1.65$, $SD = 1$, respectively). Moreover, almost half of the caregivers (47.2%) self-identified as "socially lonely" pre-pandemic, which increased to 58.5% during the pandemic. Differences across the caregiver groups mirrored our findings related to emotional loneliness, with caregivers of people with both brain health and physical conditions having the highest social loneliness pre- ($F(2, 2351) = 6.68$, $p = 0.001$; $M = 1.95$, $SD = 1.25$) and during the pandemic ($F(2, 2351) = 5.04$, $p = 0.007$; $M = 2.2$, $SD = 1.17$).

3.4 | Social isolation

Over 40% of caregivers reported an increase in social isolation, while 13.5% reported a substantial change in social isolation during the pandemic. There were no significant differences in any of these factors across caregiver groups (Table 3). In addition, 6.8% of caregivers often felt socially isolated pre-pandemic, and this proportion increased to 34.1% during the pandemic. We found no significant pre-pandemic differences across the caregiver groups, but the post-pandemic differences, ($p = 0.001$) pointed to caregivers of people with dual conditions experiencing social loneliness most frequently (36.8%).

TABLE 4 Factors associated with the increase in burden among caregivers of people with brain health conditions in COVID-19 in an ordinal regression model (n = 1231)

Predictor	Odd ratio	*p*	95% CI LL	95% CI UL
Gender (men as reference)				
Women	1.57	0.005	1.15	2.15
General physical health (poor as reference)				
Fair	1.44	0.47	0.53	3.88
Good	1.45	0.45	0.55	3.81
Very good	1.42	0.48	0.54	3.76
Excellent	1.53	0.42	0.55	4.26
General mental health (poor as reference)				
Fair	0.51	0.16	0.20	1.30
Good	0.62	0.29	0.24	1.55
Very good	0.46	0.11	0.17	1.20
Excellent	0.45	0.14	0.16	1.29
Frequency of loneliness during COVID-19 (hardly ever/never as reference)				
Sometimes	0.91	0.57	0.64	1.28
Often	0.66	0.16	0.37	1.18
Frequency of social isolation during COVID-19 (hardly ever/never as reference)				
Sometimes	1.47	0.04	1.02	2.12
Often	1.30	0.3	0.81	2.09
During COVID-19 UCLA loneliness scale (none/low loneliness as reference)				
Moderate	1.04	0.85	0.71	1.51
Severe	1.40	0.29	0.75	2.62
During Covid-19 emotional loneliness (no loneliness as reference)				
Mild	1.09	0.65	0.75	1.58
Moderate	1.63	0.03	1.04	2.55
Severe	1.82	0.03	1.08	3.07
During Covid-19 social loneliness (no loneliness as reference)				
Mild	1.03	0.89	0.68	1.57
Moderate	1.40	0.22	0.82	2.39
Severe	1.12	0.49	0.82	1.51
Significant increase in social isolation during Covid-19 (no as reference)				
Yes	1.65	0.03	1.04	2.64
COVID-19′S effect on care provision (no as reference)				
Yes	2.73	0.00	1.84	4.05
Magnitude of COVID-19′S effect on care provision (low effect as reference)				
Mild	0.99	0.97	0.47	2.09
Moderate	0.90	0.73	0.50	1.63
Severe	1.82	0.02	1.10	3.02
Very severe	1.17	0.49	0.75	1.81
Place of care provision (care facility as reference)				
Caregiver's home	2.18	0.00	1.28	3.72
Care recipient's home	1.30	0.37	0.74	2.28
Other	0.69	0.22	0.38	1.25

Abbreviations: CI, confidence interval; LL, lower limit; UL, upper limit.

3.5 | Factors associated with the increase in care burden among caregivers for brain health conditions

Several intrinsic and extrinsic factors were found to be significant in the regression model, which included 1231 respondents (Table 4). Intrinsic factors for higher burden included being a woman caregiver (OR 1.57, 95% CI [1.15, 2.15]), being moderately (OR 1.63, 95% CI [1.04, 2.55]) or severely emotionally lonely (OR 1.82, 95% CI [1.08, 3.07]), and experiencing a large increase (OR 1.65, 95% CI [1.04, 2.64]), or moderate frequency (OR 1.47, 95% CI [1.02, 2.12]) of social isolation. Extrinsic factors for higher burden included caregivers whose ability to deliver care changed due to COVID-19 restrictions (OR 2.73, 95% CI [1.84, 4.05]), experiencing a severe effect of the pandemic on care provision (OR 1.82, 95% CI [1.10, 3.02]), and cohabiting with care recipients (OR 2.18, 95% [1.28, 3.72]).

Finally, a sensitivity analysis showed that caregivers of people with dementia, specifically, were older, reported higher burden, and their care provision was more disrupted due to COVID-19 restrictions, compared to caregivers of people with mental health issues. Loneliness and social isolation outcomes were similar in both caregiver groups (Supplemental Table 1).

4 | DISCUSSION

This study explored the combination of burden, loneliness, and social isolation in informal caregivers of people with enduring physical and brain health challenges during the COVID-19 pandemic. The role of informal caregiving, often referred to as the essential "shadow workforce",[53] has taken on even greater prominence because of the COVID-19 pandemic, which has prioritized acute and urgent care among the professional healthcare workforce and resulted in a dearth of support for people with enduring health conditions.[18,41,54,55] Consistent with the global nature of the pandemic, here, we captured the experience of caregiving across multiple regions worldwide, while accounting for linguistic differences.

Our results revealed that caregivers of people with combined brain health and physical health conditions were the most burdened and had the highest levels of loneliness and social isolation. This finding supports our first hypothesis and extends previous findings that caregivers of people with more severe conditions and those with multimorbidity experience higher levels of stress, anxiety, and depression,[56–58] as well as previous findings of high burden in caregivers of people with neurodegenerative conditions, pre-pandemic.[4,5,16,34,40,42,59,60] Outcomes of caregivers of people with dementia and other enduring brain health conditions are often worse compared to caregivers who care for people with physical disabilities alone or who are older and frail.[2–6,16,61–63]

Second, our results revealed that the increase in burden of caregivers of people with brain health conditions was associated with moderate and severe emotional loneliness, as well as a significant increase and moderate frequency of social isolation during COVID-19 restrictions. These results support the second hypothesis and are consistent with pre-pandemic findings, which reported that caregiver loneliness and social isolation are related to burden stronger than the extent, nature, and length of caregiving or support service use.[32] Caregiver emotional loneliness is associated with a sense of being responsible for the wellbeing of the care recipient, which was likely magnified when conventional support services ceased due to COVID-19 restrictions. This emotional loneliness is also associated with negative feelings linked to care burden (i.e., lack of appreciation, feelings of exclusion[64]). Moreover, taking into consideration pandemic-related measures that generated exacerbated levels of social isolation,[16,36,37,44,56] our findings are in line with Zarit's[51] theory of burden and with research indicating a reflection of elevated social isolation in caregivers' increased levels of stress and burden.[32,56] The link between substantially heightened social isolation and the increase in care burden is especially alarming, because it constitutes one of the greatest risk factors for mental health exacerbation of family caregivers, both in the context of the pandemic[16,45,56] and before. For example, our previous work has revealed that loneliness in caregivers of people attending memory clinics is a risk factor for caregiver depression within the following 12 months[34]

We found that compared to pre-pandemic levels, women, compared to men, caregivers experienced a significant increase in burden, loneliness, and social isolation. Women were recognized pre-pandemic to more often take on caregiver roles and take responsibility for physically and emotionally intensive care delivery, including personal care.[2–6,40,41,43,65–67] It is possible that this may be influenced by the need for women to conform to societal gender norms, hence, prioritizing caregiving over their own needs, as well as factors related to culture, more personal approach to care delivery, and being more frequently affected by widowhood.[2,4,5,39–43,68] The last explanation is correlated with age as it has also been proposed that older caregivers have higher burden levels.[7,8,38] However, contrary to most reports, we did not find an association of burden with age, possibly due to skewing of our respondent sample by age, with the majority being over age 45. Alternatively, the profound impact of the pandemic restrictions may have affected all caregivers, regardless of age category.

The increase in care burden of caregivers of people with brain health conditions was also found to be associated with changes in care circumstances, such as the impact of COVID-19 restrictions on the ability to deliver care. Measures such as quarantine and stay-at-home orders can be justified, especially in relation to the vulnerable older population; however, due to the pandemic, informal caregivers experienced higher care complexity, more care load, and higher levels of stress and anxiety that consequently led to greater burden.[14,16,18,56,69] These findings emphasize the detrimental psychosocial effect of the pandemic and other factors associated with burden (especially emotional loneliness and social isolation) on informal caregivers.

Finally, regarding external factors, we found that the increase in burden of caregivers of people with brain health conditions was associated with the place of care provision, with caregivers providing care in their homes being the most burdened. These findings are in line with our third hypothesis and with the existing literature[2,66,70] confirming that cohabitation with the care recipient might add to the heavier patient load, hinder access to respite, and as a result, exacerbate caregiver burden. Living with the patient has also been shown to be a predictor of emotional loneliness,[71] which is especially important to consider, in the light of higher psychological symptomatology of informal caregivers, in the recent crisis.

4.1 | Limitations, strengths, and future directions

We acknowledge some limitations in our study. We adopted a cross-sectional design, which was unavoidable due to the short duration of the period of interest. Since the pandemic now appears to be prolonged, there may be an opportunity to explore burden, loneliness, and social isolation longitudinally, to examine how caregivers have adapted over the longer term. Furthermore, "pre-COVID-19" responses may be prone to recall bias. Our findings should also be interpreted with caution because most of our respondent sample was highly educated, which previously had been found to play a protective role in caregiver burden.[16,44] Ensuring that more diverse populations are included in future research is a priority, including an examination of non-English-speaking participants. Lastly, our sensitivity analysis showed significant differences in the characteristics of caregivers of people with dementia and caregivers of people with mental health issues. Hence, our future studies in the CLIC caregiver group will focus on exploration of risk factors of caregiver burden during COVID-19 for care recipients with neurodegenerative disorders.

The large sample size and global reach of our survey are strengths of our study, as well as the use of properly validated self-report measures which optimize standardization and limit subjectivity of the investigated concepts. Moreover, this study was the first to explore COVID-19 related care burden, loneliness, and social isolation in informal caregivers of people with enduring health conditions.

5 | CONCLUSION

Considering the far-ranging negative impact of the COVID-19 pandemic, particularly on older people, it is critical to continue investigating its effect on informal caregivers of people with enduring conditions such as dementia. Policy development and healthcare interventions should target caregivers' care circumstances (i.e., place of care provision) and psychological outcomes (i.e., loneliness and social isolation), and ensure their equitable access to social and mental health support while accounting for caregivers' differential needs and pandemic-related changes.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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APPENDIX A

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