Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
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IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

Family Carers Ireland
No one should have to care alone

Exploring experiences of carers in the Covid 19 pandemic

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Background

349 million care-dependent individuals globally: 5% are children aged under the age of 15 years, and 101 million (29%) are older people 60 years of age and over (WHO, 2017)

195,263 Irish family carers (CSO, 2016).

Irish Health Survey 2019: 1 in 8 are carers (Over 500,000 when extrapolated to the national population).

Gender Breakdown: 60.5% Female, 39.5% Male.

Age 45-64 years (highest) (FCI, 2019)

Average of 5.5 hours per day, 8.7% provide 24Hr care (CSO, 2016).

Financial cost to replace: **€20bn.**

- 116,838 recipients of the annual Carer's Support Grant. €1,850
- 89,549 carers receive Carer's Allowance (caring for 99,505 care recipients) (€219.- €385.50)
- 3,427 carers receive Carer's Benefit (caring for 4,043 care recipients) (€220- €330).

Experiences of caregiving: What the research indicates.

A sense of giving back to someone who has cared for them, and the satisfaction of knowing that their loved one is getting excellent care (Associated Press-NORC Center for Public Affairs Research, 2014).

Being valued by care recipient, resilience, self-worth, accomplishment (Bauer et al., 2013)

Physical and Mental impact: depression and or anxiety, physical ill health (FCI, 2019; Da Costa et al., 2014; Gupta et al., 2015;Mosquera et al., 2016; Charles et al., 2017; Ambugo et al., 2021).

Poor diet and limited exercise **(**Tatangelo et al., 2018)

Quality of life: (Caputo et al., 2016; Irfan et al., 2017; Maresova et al., 2020)

Financial impact: Burnout for caregivers and society, Impacts of financial demands on caregivers, and Direct costs of caregiving for caregivers (Lambert et al., 2019; Irfan et al., 2017; Gardiner et al., 2014; Gardiner et al., 2019; Coumoundouros et al., 2019; Blue Cross Shield of America, 2021)

Social impact: Social exclusion (self/other), loneliness (Rodger et al., 2014; Charles et al., 2017; Ambugo et al**.,** 2021)

Loss: of a social partner ie spouse living with dementia (Vasileiou et al., 2017; Family Caregiver Alliance, 2021), quality of relationship, shrunken personal space, diminished social interaction (Victor et al., 2021)

Bereavement (Moorehouse & O’Conner, 2021)

Caregiving in Covid-19

84% worry about getting the virus and not being able to look after the person(s) they care for

63% are concerned about a decline in the health and wellbeing of the person they care for

63% experience delays or cancellations of medical appointments, treatments or surgery

61% think there is not enough information and advice targeted at family carers about COVID-19

60% worry about a decline in their own mental health and wellbeing

56% are concerned about their loved one displaying increased challenging behaviours

47% are unable to access appropriate PPE during the outbreak

43% fear that normal services will not be restored after the crisis

39% worry about the financial costs and implications of the pandemic

37% worry about becoming more socially isolated

26% worry about their access to essential supplies such as groceries

14% cancelled home care services for the person they care for

Family Carers Ireland, 2020

"Parental caregivers who increased the frequency of providing personal care reported significantly more mental health strains, that is, feeling sad/depressed and anxious/nervous more often since the outbreak of the pandemic. With respect to receiving care, about one out of five care recipients had difficulty in obtaining adequate care from outside the household during the pandemic." (Bergman & Wagner, 2021: 13)

Intensity of care increased, psychological well-being was impacted (Vislapuu et al., 2021; Courtney Hughes et al., 2021)

"fear and anxiety about visiting hospital, attending appointments and not having access (to accompany/visit), access to care essentials/ respite/resumption of services/needs being met (FCI, 2021)

Methodology

Qualitative methodology: Semi-structured interviews and use of a modified photovoice approach

Ethics from Faculty of Health Sciences Research Ethics (TCD)

Data collection: via FCI as gatekeeper. Information and invite via regional care support managers.

Interviews: n=15 a) interviews took place From 22nd Sept – 18th November, 2021, b) Gender divide: 14 Female, 1 Male, c) age range of caregiver: 39-68 years and care recipients: 8-82 years, d) 15 caregivers providing care to 19 care recipients.

Interviews were inputted to NVIVO

Analysis using Braun & Clarke (2006: 2021; 2022)

Preliminary comments on findings

Caregivers demand services/help

- Caregivers are in crisis

The devastating impact of school closures on family life

- Special schools for young care recipients must be considered an essential service

Several participants highlight the need for a designated person – such as an information officer to be appointed to each caregiver/family

- Caregivers need to know what services are at their disposal – They are left to fend for themselves.

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