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Research Paper

Caregiver wellbeing during Covid-19: does being hopeful play a role?

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ABSTRACT

Background Informal (unpaid) carers represent a core component of health and social care systems. However, their experiences, health impacts and care needs during Covid-19 have been largely overlooked. This study aimed to explore the health and wellbeing impacts of Covid-19 on carers and the contribution of hopefulness.

Methods Data were collected from an online survey hosted on the Qualtrics platform.

Results Three hundred and sixty-nine participants consented to the survey. Data are reported on 186 participants with an 80% or higher completion rate. Most participants (> 80%) reported poor sleep quality, while nearly half the sample met case threshold for anxiety (46.2%) and 29% for depression. Mood disturbance in carers was associated with higher levels of sleep disturbances. Positive wellbeing in carers was best predicted by having a more hopeful outlook and fewer symptoms of depression.

Limitations A cross-sectional survey-based design that is unable to offer no definitive conclusions about the direction of the results. The study was also limited by having carer participants as the only informants.

Conclusions Though informal carers are found in all areas of society, their experiences and health correlates during Covid-19 have not attracted much research attention. The additional and unique challenges of the pandemic for the health and wellbeing needs of carers must not be overlooked as is sadly so often the case. Instead, the experiences of carers and their needs should be prioritised, publicised, and matched by needs-led interventions. Identifying carers and enquiring about their wellbeing would be a laudable first step.

1. Background

The 11th March 2020 witnessed the global declaration from the World Health Organisation of the Covid-19 pandemic. This was followed by a series of unprecedented local, national, and international restrictions (lockdowns), which have included lengthy closures of schools, workplaces, leisure facilities, religious worship venues, and country borders, in parallel with enforced episodes of self-isolation and shielding. The restrictions, to varying degrees of acceptability, adherence, and success, have been designed to reduce the risk of virus transmission and avoid overwhelming health and social care providers. However, they have also meant that an individual's usual source of healthcare and support has been impacted. Since the declaration, much has been published about the experience and psychological impact of Covid-19 on frontline health care staff (i.e. formal carers) (Greenberg, 2020; Pappa et al., 2020; Cipolotti et al 2021; Magnavita et al (2021), however, the

experience of informal carers has, hitherto, been largely neglected.

In the United Kingdom (UK) there are an estimated 13.6 million people (approximately 26% of the population) in informal caregiving roles, with numbers increasing since the start of the pandemic. These are people providing unpaid care and support to a relative, partner, or friend with long-term or terminal health conditions, disability, or care needs related to old age (Carers UK, 2020; Verbakel, 2018 Jun) Global shifts in population size, demography, and related health problems, in the context of limited financial resources, have made informal caregiving an essential feature of health and social care systems (Pickford 2008; Cotagiri & Sykes, 2019; Pickard & King, 2012).

Informal carers provide a valuable role in society, which delivers significant multi-billion-pound cost savings each year (Fox, Sparrow, & Webber, 2010, The Schizophrenia Commission, 2012; Carers UK, Buckner & Yeandle, 2015) There are, however, significant personal costs attached to the role with carers typically reporting higher levels of

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physical and psychiatric morbidity particularly when compared to non-carer peers (George, Kecmanovic, Meade & Kolt, 2020; Cottagiri and Sykes, 2019; Lacey et al., 2019; Koutentaki et al 2020) Poorer health status is marked for those engaged in more caregiving hours (Smith et al 2014; Thomas, Saunders, Roland, Paddison, 2015) For example, the English national adult psychiatric morbidity survey revealed a positive relationship between caregiver status and clinical range psychiatric symptoms, with an observable decline in carer mental health in those providing 10 hours caregiving or more per week and a two-fold increase in clinical range symptoms (Smith et al 2014) The associations were independent of life stressors, such as financial problems that are also elevated in caregiver groups (Stansfeld et al 2014) Poorer functioning occurs alongside caregiving duties which, for many, can feel burdensome and negatively impact their quality-of-life (Thomas et al 2015; Gupta et al 2015; Topcu, Buchanan, Aubeeluck & Ulsever, 2020), and the amount and quality of direct caregiving they are able to provide (Kuijpers, Onwumere & Bebbington, 2010; Giordano et al 2016) Compared to the general population, reports of social isolation and loneliness are elevated in carer populations (Vasileiou et al 2017), and disproportionately affect some carer groups more than others. In a study of family carers across different groups (e.g. brain injury, schizophrenia), carers of those with severe mental illness reported significantly poorer levels of social support (Magliano, Fiorillo, Malangone, De Rosa, & Maj, 2006).

Thus, informal carers serve as a hidden workforce (Eikemo, 2018) where many report unmet needs that are typically neglected by services. However, carer wellbeing, presents significant implications for health and social care providers particularly during Covid-19 (Onwumere, 2020; Gallagher & Wetherell, 2020) Caregivers in poorer health are more likely to relinquish their support roles, which can itself lead to poorer outcomes for those they care for. Despite what is already known about poorer carer health, the literature has remained surprisingly scarce on carers' health and wellbeing during the pandemic and reinforces the hidden nature of their contribution and their needs. The potential for further lockdowns and of different pandemics caused by communicable diseases is already acknowledged (World Health Organisation, 2018) The timescale for large scale vaccination for Covid-19 means that seeking to understand the health impacts of Covid-19 on a frontline, but hidden, workforce offers an important opportunity to identify areas of need and inform potential support interventions.

2. Aims

This study sought to provide a cross-sectional investigation of carers' reports of psychological health and wellbeing during Covid-19 and explore the extent to which having a hopeful outlook confers a protective benefit on their overall positive wellbeing.

We hypothesised that carer participants will report clinically elevated rates of psychological morbidity and low rates of positive wellbeing. We also predicted that carer reports of hopefulness will be positively associated with wellbeing and share a negative association with levels of psychological morbidity.

3. Methods

The study received ethical approval from King's College London (LRS-19/20-18206).

This was a cross-sectional and online study where adult informal (i.e., unpaid/family) carers were the targeted sample. For the purposes of the study, carers were recognised as parents, spouses, or partners of the person receiving care (i.e. care recipient) and living with the care recipient; or individuals living with the care recipient and willingly classified by themselves and the care recipient as a carer; or individuals acknowledged as carers not living with the care recipient, but in close contact for at least 3 months prior to completing the survey. The online survey, hosted on the Qualtrics platform, remained open over an

approximate four-month period (05.05.2020-02.09.2020) with participants recruited through social media adverts initially put forward by the university. No specific carer population was targeted. In recognition of the likely challenges that participants might be exposed to, all participants were provided with a resource of helpful online services.

4. Measures

A broad range of socio-demographic details, including carer age, gender, employment, and hours per week spent caregiving were collected, along with demographic data on care recipients (e.g. age, gender, health condition).

4.1. Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)

The 14-item HADS is a well-known self-report screen of anxiety and depression symptoms and severity. Items are rated on a four-point scale (0-3), which reflect the participant's level of agreement with each item. It offers two subscale scores and an overall score. Subscale total scores range from 0-21; higher total scores are indicative of greater mood disturbance. The measure has been widely used with caregiver groups and has good psychometric data (Fortune, Smith & Garvey, 2005).

4.2. Pittsburgh Sleep Quality Index (PSQI, Buysse et al 1989)

The PSQI is a 19-item self-report screening tool for sleep difficulties experienced during the past month. Overall scores are generated from 7 areas exploring sleep duration, sleep latency, habitual sleep efficiency, sleep disturbances, use of sleep medication, daytime dysfunction and subjective sleep quality. Total global scores can range from 0-21. A global score of greater than 5 indicates sleep quality difficulties that can differentiate control groups from those with a sleep disorder or psychiatric condition, and higher scores indicating greater sleep dysfunction. The measure reports good psychometric data (Mollayeva et al 2016), and has been widely used with different populations, including carers (e.g. (Smith et al., 2019 Jun).

4.3. The Herth Hope Index (HHI, Herth 1992)

The HHI is a 12-item self-report measure designed to assess multi-dimensional aspects of hope in adults in clinical settings. Participants are required to read through brief statements (e.g. I have a positive outlook towards life), and indicate to what extent the statement best applies to themselves on a 4-point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree) Total scores range from 12 to 48 and higher scores are indicative of higher levels of hope. The measure, an adapted version of the longer 30-item Herth Hope Scale (Herth, 1991), has established reliability and validity with several translations across the globe and applications with different groups, including carers (Lobban et al 2020).

4.4. Warwick Edinburgh Wellbeing Scale (WEMWBS NHS Scotland, Tennant et al 2007)

The WEMWBS is a 14-item self-report assessment of positive mental wellbeing in adults. Individuals are required to read through individual statements (e.g. I've been feeling relaxed) and indicate how much they agree with the statement over the last two weeks on a scale ranging from 'none of the time' to 'all of the time'. Items are scored on a 1-5 scale with total scores ranging from 14-70. Higher scores indicate greater levels of positive wellbeing. The measure reports good reliability and validity data (Maheswaran et al 2012) and history of use with caregiver populations (e.g. Sin et al 2021).

5. Statistical analyses

Analyses were undertaken using the Statistical Package for Social Sciences (SPSS) software package (version 26) (SPSS Inc., Chicago, IL) Socio-demographic data were presented through descriptive statistics while Pearson’s bivariate correlations were employed to assess the pattern of associations between carer outcome measures. Multiple linear regression modelling was used to describe effect of carer wellbeing (WEMWBS, Tennant et al 2007), carer mood (HADS, Zigmond & Snaith, 1983) sleep (PSQI, Buysse et al 1989) and hope (HHI, Herth, 1992) on the WEMWBS wellbeing total score. Assumption of correlations were assessed by visual inspection of scatter plots, while assumptions of multiple regression were assessed by visual inspection of residuals and partial regression plots. No violations of assumption were detected. Test alpha levels were set at .05 level.

6. Results

Three hundred and sixty-nine participants originally signed up to the survey. 183 entries were not included in the analyses due to partial completion (<30%) Data are reported on 186 participants who provided 80% or greater data. Partial-completers were more likely to be younger [Mean(yrs): 48.44 vs 56.60; $t_{212} (=3.85, P <.001), 95\%CI, 3.98$ to 12.3] and non-white [$X^2(1)=135.12, P<.001$]. No significant differences were noted across gender [$X^2(1)=0.39, P=0.532$].

The socio-demographic data of the sample are reported in Table 1. Carer participants comprised mostly of married females, aged in their middle 50s, with mainly white British ethnicity. They were mostly either in paid employment or retired and caring for a spouse/partner. The majority of carer participants reported being in a caregiving relationship for a decade or longer and providing more than 50 hours of caregiving each week. Care recipients were approximately evenly split between male and females and had a mean age of 58 years.

6.1. Emotional distress

The mean scores for HADS-anxiety was 9.84 (SD=4.39) and 46.2% (n=86) met case threshold. For HADS-depression, the mean score was 8.32 (SD=4.04) and case threshold was met by 29% (n=54).

6.2. Sleep

For the PSQI, the mean score was 9.09 (SD=3.83) with 83.3% (n=155) exceeding cut off for poor sleep quality.

6.3. Hope and wellbeing

The mean score for hope, on the HHI, was 33.3 (SD=5.13) and for positive wellbeing, as measured on the WEMWBS, was 40.6 (SD=8.89).

6.4. Bivariate correlations

Table II summarises bivariate correlational data. Carer reports of anxiety and depression, as measured by the HADS, were positively associated with sleep difficulties but negatively correlated with reports of hopefulness and overall positive wellbeing. Reports of carers experiencing sleep disturbances were positively associated with depression scores and negatively correlated with levels of hopefulness and positive wellbeing.

6.5. Multivariate analyses

Linear regression modelling, assessing the contribution of emotional distress (anxiety, depression), sleep disturbance, and hope to carers’ overall positive wellbeing, accounted for 68% of the variance ($F_{4,171} = 94.42, P<.001$), with two significant predictors identified. Positive

Table 1

Sample characteristics for carer participants and care recipients.

Characteristic	N	%	Mean(SD) / Range
Age (years)	160		56.60 (13.1) / 25-84
Gender (M)	186	21.5	
Ethnicity			-
White British	151	81.2	
White other	16	8.6	
Black African/Caribbean/other	6	3.2	
Asian: Indian/Pakistan/other	6	3.2	
Any other group	7	3.7	
Relationship status			-
Married	117	62.9	
Single	35	18.8	
Separated	4	2.2	
Divorced	19	10.2	
Widowed	10	5.4	
Civil partnership	1	.5	
Employment*			-
Full-time	33	17.7	
Part-time	24	12.9	
Self employed	11	5.9	
Retired	57	30.6	
Student	3	1.6	
Voluntary	9	4.8	
Other	49	26.3	
Does caregiver live with care recipient (Yes)	123	66.1	-
Care recipient is**			
Spouse/partner	71	38.2	
Child	49	26.3	
Parent	49	26.3	
Grandparent	5	2.7	
Other relative	7	3.8	
Length of caregiving (years)***	18	9.7	-
2yrs or less	46	24.7	
>2 to <5	42	22.6	
>5 to <10	77	41.4	
10+			
Caregiving hours (weekly)****			-
10 or less	29	15.6	
11-20	22	11.8	
21-30	21	11.3	
31-40	22	11.8	
41-50	16	8.7	
50+	73	39.2	
Carer has a confidant (Yes)	119	64	-
Care recipient gender (M)	97	52.2	-
Care recipient age	186		58.79 (24.6) / 5-96
Health condition			
Autism & learning disabilities	10	5.37	
Arthritis	7	3.76	
Blindness & sight loss conditions	4	2.15	
Cancer	6	3.22	
Cancer	3	1.61	
Chronic fatigue/ME	38	20.4	
Dementia related disorders	5	2.68	
Depression & anxiety	4	2.15	
Diabetes	4	2.15	
Epilepsy	4	2.15	
Frailty linked to advanced years	9	4.83	
Heart defects	3	1.61	
Inherited degenerative disorders	5	2.68	
Lung conditions	8	4.30	
Multiple Sclerosis	4	2.15	
	17	9.13	
	5	2.68	
	50	26.9	
Pain Schizophrenia spectrum Stroke Other			
Caregiving for more than one person (Yes)	61	32.8	

* Missing data (n-26)

** Missing data (n-3)

*** Missing data (n-3)

**** Missing data (n-3)

Table II

Pearson’s correlations between carer mood, wellbeing, hope and support outcomes.

	i HADS-A	ii HADS-D	iii PSQI-Sleep	iv WEMWBS	v HOPE	vi SUPPORT*
I	-	.605** P<.001	.342** P<.001	-.588** P<.001	-.543** P<.001	-.096 P.199
II		-	.471** P<.001	-.736** P<.001	-.623** P<.001	-.339** P<.001
III			-	-.431** P<.001	-.354** P<.001	-.128 P.096
IV				-	.751** P<.001	.338** P<.001
V					-	.278** P<.001
VI						-

wellbeing was best predicted by reporting higher levels of hope (B=.797, (95%CI, .603 to .991), $t(= 8.09, P < 0.001; st. b = .456)$ and lower depressed mood (B= -.803, (95%CI, -1.072 to -.534), $t(= -5.89, P < 0.001; st.b = -.367)$, while sleep (B = -.158), (95%CI, -.379 to .064), $t(= -1.40, P = .161; st.b = -.068)$ and anxiety (B= -.167), (95%CI, -.391 to .056), $t(= -1.47, P = .142)$ were not themselves significant predictors.

7. Discussion

This study sought to examine the health and wellbeing correlates of Covid-19 in informal carers and determine the contribution of hopefulness to carer reports of positive wellbeing.

The sample demography, comprising mostly white females, aged in their middle years and in married/cohabitating partnerships, was largely consistent with the caregiver literature (Hazell et al 2020; Lobban et al 2020; Smith et al 2014; Gallagher & Wetherell, 2020) There was heterogeneity in the nature of the care recipient needs, which included physical and mental health disabilities such as autism spectrum disorder, psychosis, and brain injuries. The largest proportion, however, experienced age-related degenerative disorders (e.g. dementia) Participants were involved in high intensity caregiving loads; the largest proportion had been in their caregiving role for a decade or longer and providing an excess of 50 hours of caregiving each week. Interestingly, at the time of survey completion, more than two thirds were also living within the same household as the care recipient.

Throughout the pandemic, much has been communicated about the importance of protecting ‘vulnerable’ groups and reducing infection rates primarily via social distancing measures. It is conceivable that for some participants, the pandemic led to significant increases in their usual caregiving loads, particularly during the initial phases when services (e.g. health and social care providers) were making their own adjustments to new ways of operating.

The current findings are in line with data reported from a small number of studies documenting poor psychological functioning in informal carers, at levels that exceed pre Covid-19 rates, rates observed in the general population, and those found in matched non carer peers (e.g. Gallaher & Wetherell, 2020; Willner et al 2020) Our preliminary findings suggested that, in our survey, most carers (>80%) were reporting clinically significant sleeping difficulties. In addition, there were high levels of emotional disturbance, with just under 50% meeting clinical threshold for anxiety problems and almost 30% being depressed.

The rates of sleep problems in carers exceeded levels recorded in a homogenous group of carers of people with early phase psychosis disorders (Smith et al 2019), but remain consistent with overall findings confirming the presence, importance and magnitude of sleep dysfunction in caregivers (McCurry et al., 2015). The case levels for anxiety and depression in participants accord with the literature on carer psychological distress (e.g. Gupta et al 2015, Hayes, et al 2015) Similarly, the elevated anxiety rates complement recent investigations of mental wellbeing following the Covid-19 response in professional carers (e.g.

Sahin, Aker, Sahin, Karabekiroglu, 2020; Ali et al 2020) In line with Sin and colleagues (2021), our carer positive wellbeing scores were low comparative to general population health survey data (i.e. 49.0) (NHS Digital HSE, 2016).

Few have escaped the extensive 24-hour Covid-19 media coverage, the daily national updates on numbers testing positive and Covid-19 related deaths. The responsibility levied towards many in the general population to reduce the virus transmission risk (e.g. home confinement, social distance) have been ongoing. General concerns, therefore, about the virus and specific anxieties about others (e.g. formal carers) inadvertently bringing the virus into the family home during the course of their professional duties, plus implications for their own and their care recipient’s wellbeing, might explain the greater numbers of participants reaching case threshold for anxiety (Onwumere 2020) While there will be commonalities with the general population, in terms of the potential factors driving anxiety, there will also be carer specific factors (e.g. care arrangements for care recipient if carers were to become infirm, incapacitated or die due to COVID-19) that are likely to compound their reports of anxiety and worry (Onwumere 2020).

In line with earlier predictions, carer reports of hopefulness proved to be an important and positive predictor of wellbeing. This result was consistent with themes observed within the wider literature that illustrates positive links between reports of hopefulness and quality-of-life in carers (Duggleby, Swindle, Peacock & Ghosh, 2011) It also concurs with previous work confirming how, during times of uncertainty, carer hope can play a key role in supporting their adjustment to challenging situations (Truitt, Biesecker, Capone, Bailey, & Erby 2012) Over the course of the pandemic there have been few areas that have offered certainty and definitive timelines. A belief in the potential for future positive changes (e.g effective vaccines) has a key role to play in promoting carer wellbeing.

8. Limitations

The study has strengths in terms of its single focus on informal carers, a group traditionally overlooked in research investigations, and the collection of data that taps markers of poor health status and positive wellbeing. However, the findings must be considered in light of known limitations. First, the cross-sectional study design provides only a single point assessment of carer functioning and precludes any definitive conclusions about the direction of results. The findings highlighting the contribution of hopefulness to overall positive wellbeing could equally be interpreted to suggest that it is carers’ positive wellbeing that contributes to their reported levels of hopefulness. Studies incorporating longitudinal designs that focus on the specific context of Covid-19 and implications and consequences for carer functioning are encouraged. A further noted limitation was carer participants being the sole informant of all data collected. While there was heterogeneity in the reported conditions of care recipients, data were uncorroborated and without nuance. Similarly, participant reports of mood and sleep functioning were extracted from self-report. Though measures were psychometrically sound and have been widely used with carer populations, the absence of clinician administered, and rated, measures was also a limitation. In mitigation, we felt that the costs of implementing clinician interviews for carer participants, who are already known to be stretched for time (Jowsey, McRae, Gillespie, Bonfield & Yen 2013) exceeded the benefits and prioritised brevity and ease of online survey completion.

The socio-demographic homogeneity of the sample, as reflected by the proportionally smaller numbers of black and ethnic minority participants, the absence of child (young) carers, and predominance of white British females, and those in partnerships, limits the generalisability of findings to a broader range of carer groups. The underrepresentation of some groups seems particularly relevant given the disproportionate impacts of Covid-19 infection rates and poorer outcomes on some groups, particularly those from black ethnic minority groups and those experiencing social and economic inequalities (Pareek

et al 2020; ONS, 2020) However, our results, particularly when considered alongside additional studies (e.g. Gallagher & Wetherall 2020), provide a helpful starting platform to consider carer impacts and generate testable hypotheses and investigations of under-represented groups.

9. Implications

The current findings speak to potentially elevated levels of anxiety and poor sleep quality in carers during the first 6 months of the pandemic. These difficulties exist in the context of their high intensity caregiving roles across a range of health conditions and disabilities, and for some carers they were also in paid jobs. In the UK, there was a delay in formally recognising the key worker status and related needs of informal carers during the early phase of the pandemic, which is likely to have contributed to a neglect in considering and addressing their wellbeing.

Our results suggest the importance of active enquiry into carer wellbeing over the course of the pandemic with recognition that some of these carers might also be holding down part or fulltime employment. These enquiries could be undertaken by those involved in the direct health or social care provision of the care recipient or general health practitioners for carers. We purposely advocate the use of either approach given the all-too-common situation where carers, and their wellbeing needs, will often be missed or not prioritised in terms of the delivery of support interventions. Given their level and pattern of needs, carers are likely to benefit from targeted information and signposting on how to cope with low mood, anxiety, and evidence-based strategies to optimise sleep (e.g. <https://www.nhs.uk/oneyou/every-mind-matters/>) A proactive approach to interventions might serve to mitigate against the potential for further deterioration in health status which, in turn, might subsequently require more intensive mental health-based interventions and/or increase the likelihood of carers relinquishing their role and impacting overall outcomes and needs for the care recipient. Given the importance to carer wellbeing of allowing oneself to be hopeful and maintaining a positive mood, it would appear that supporting carers to focus on the realistic prospect for positive changes in the not-too-distant future might prove beneficial.

10. Conclusion

The International Alliance of Carer Organisations describes caregiving as one of the most important social and economic policy issues worldwide and calls for improved identification of carers and targeted interventions (International Alliance of Carer Organisations, 2018) Though the act of caregiving and being a caregiver can be associated with positive emotions, we have also known for many years that carers themselves represent a vulnerable group for psychiatric, physical, and social morbidities. The current pandemic only serves to further emphasise this and the urgency of all stakeholders to respond in a robust and timely fashion.

11. Declarations

11.1. Authors' contributions

JO led the project protocol development and implementation with co-author contributions. The paper was drafted by JO with revisions made by authors. All authors read and approved the final manuscript.

11.2. Ethics approval and consent to participate

The study received ethical approval from King's College London (LRS-19/20-18206) All participants provided informed consent.

11.3. Availability of data and material

Original data will not be made available in line with ethical approval conditions.

Declaration of Competing Interests

The authors confirm they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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