

RESEARCH ARTICLE:

Who Cares for the Family Caregivers of the Elderly during COVID-19 in Low-Middle Income Countries? A Commentary

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Abstract

The considerable increase in the intensity and duration of care provided to the elderly by family caregivers warrants a detailed review of the support interventions available to these “invisible” individuals during the COVID-19 pandemic. Family caregivers had limited access to respite care due to the restrictions imposed by the COVID-19 protocols. This increased their stress and the burden of caregiving. This commentary article details the experiences of family caregivers of the elderly and establishes the type of support interventions available to them during the pandemic, especially in low-and-middle-income countries. A random search of literature was conducted, and themes identified include: “fear of contagion”, “limited resources”, “knowledge deficit” and “grieving in solitary”. In addition, this article recommends strategies to mitigate the burden and stress experienced by them.

Keywords: family caregiving; elderly; low-middle income countries; support interventions

Introduction

Caring for the family caregivers who provide care for their elderly relatives during the COVID-19 pandemic is essential as it could engender improved quality of life and enable them to provide caregiving for a prolonged period of time. The disruptions in caregiving brought about by COVID-19 dramatically increased the responsibilities and the extent of care provided to the elderly, thereby increasing caregiver burden and stress for family caregivers (Cohen *et al.*, 2021, Budnick *et al.*, 2021). Elderly care-recipients, many of whom may have disabling conditions, are more likely to rely solely on family caregivers for caregiving and provision of activities of daily living (Hesamzadeh *et al.*, 2017, Price *et al.*, 2020). Furthermore, caregiving tasks and approaches changed during the pandemic, requiring extra vigilance, and provision of intensive care at home similar to the one obtainable in the hospital. Unfortunately, support interventions were scarce in most low-middle-income countries (LMICs) and there were limited resources to provide care at home which inadvertently impacted the lives of their family caregivers.

A random search of articles was conducted, using the PubMed data base and the search engine Google Scholar. Search terms included; *family caregivers, elderly, support interventions, LMICs, COVID-19, and high-income countries (HICs)*. Articles were reviewed if they documented support interventions for family caregivers of the elderly during the pandemic. Of the eight articles documented in the table, only one was from a LMIC and it reported social protection system for family caregivers. Articles were reviewed if they were published in 2020 and 2021 since those were the years during which COVID-19 spread globally. Themes common to most articles reviewed are discussed below.

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Fear of contagion

Family caregivers who benefitted from respite care from friends and relatives before the pandemic could not do so again because of fear that such friends and relatives might transmit infections to the elderly persons. Lack of support exposes the primary family caregivers to risks of severe morbidity and mortality from burden of caregiving (Mueller *et al.*, 2020). Concerns around reduction of the risk of contracting the COVID-19 virus among the elderly increased stress and burden of caregiving. This resulted in decrease in family caregivers' adoption of their own health promoting behaviours, such as physical activity, hobbies and social lives leading to a reduction in their health related quality of life (QoL) (Greaney *et al.*, 2021).

Limited resources

Limited healthcare capacity and resource constraints peculiar to LMICs context imposed financial stress on family caregivers (Josephson *et al.*, 2021). With many of LMICs countries having fewer social protection intervention services available, respite care, often provided by family members and significant others, became impossible, as infection prevention and control (IPC) protocols limited the provision of care to live-in-persons only (Hindmarch *et al.*, 2021). Basic necessities, such as water, sanitation and electricity, which are required to support activities of daily living (ADL), were inaccessible or unavailable for resource-constrained families and paying for these basic amenities compounds the financial, physical and emotional stress of family caregivers (Park, 2021).

Knowledge deficit

Family caregivers needs for knowledge and training increased during the COVID-19 pandemic, as did their physical, psychological, financial and social needs (Budnick *et al.*, 2021). The lack of training around the use of personal protective equipment (PPE), IPC protocols, disease-specific training for family caregivers increased their emotional burden. Uncertainties around what they could and could not do for the elderly resulted in high levels of stress for family caregivers (Josephson *et al.*, 2021). Previous studies highlighted that family caregivers' needs include need for information and training, effective communication, professional support, and legal and financial support (Silva *et al.*, 2013, Denham *et al.*, 2020). As misinformation intensified both on social and electronic media platforms, family caregivers of the elderly experienced considerable emotional strain (Tasnim *et al.*, 2020).

Grieving in solitary

Grieving was intense because family caregivers could not visit the dying person once admitted to the hospital. Family caregivers also grieved alone without bereavement support as attendance at funerals and burials was severely restricted and limited to only the immediate family (Dhavale *et al.*, 2020). The usual grieving processes and religious ceremonies have been disorganised during the pandemic, which has resulted in family caregivers often grieving and mourning their dead in isolation, with a resulting emotional trauma (Holland *et al.*, 2021). The considerable economic downturn as a consequence of the pandemic has impacted the capacity of LMICs to provide any form of support interventions to family caregivers during bereavement (Josephson *et al.*, 2021). The population of interest in the articles was those of family caregivers of dementia and cancer patients. They appear to receive the attention of researchers probably because patients with dementia suffer cognitive and behavioural challenges and for that reason require substantial care and surveillance from memory loss. Caregiving for cancer patients requires vigilance, compliance with treatment regimen and referrals hence family caregivers might experience burden in the process.

Key interventions identified on the table were those of psychological support and counselling, as well as technology-based support. However, one article reported the use of creative art intervention. Psycho-educational support and counselling provided by most HICs were found to be cost-effective and could be provided by LMICs. Family caregivers may benefit from coping strategies that could include social and peer support, which have been found to relieve the caregivers' burden. Support interventions provided by healthcare professionals and social workers through telephone and video calls have been useful in providing individualised sessions for the family caregiver. The social relief of distress grant (SRD) was disbursed by the South African government to its citizens, refugees and asylum seekers to alleviate the financial crisis experienced during the pandemic. Family caregivers who received support are able to provide quality care for a prolonged period of time, however, its absence is detrimental to their state of health and well-being (*Rahimi et al., 2021*).

Way Forward

- Psychological support, psychoeducation, and counseling are vital interventions highlighted in literature, that have been found to be cost-effective, efficient, and affordable approaches that are relevant to the LMICs contexts. Radio jingles, television programs and one-on-one consultation can be utilised to meet individual needs. Social workers can be engaged to provide support in order to cut down cost.
- Caregiver training and support, as well as spiritual support have been found effective in mitigating stress and strengthen the mental health of family caregivers (*Su et al., 2021*). Family caregivers who receive training and support have been found to be knowledgeable about the disease process and outcomes and are more likely to provide requisite care to the elderly in a less stressful space.
- Social workers working with family caregivers can identify culturally sensitive support interventions suited to their needs. Family caregivers should be encouraged to participate in leisure and physical activities and other diversional therapies that could distract them from the demands of caregiving and protect their mental health.

Limitations

This commentary article documents the support interventions available for family caregivers during the COVID-19 pandemic but did not collect data that could reveal their lived experiences. The articles included in the table were not subjected to the rigorous scrutiny required of a systematic or scoping review, hence findings cannot be generalized. We might have missed some articles because search was limited to the year 2020-2021 and only searched published articles on the PubMed and Google Scholar search engines. However, the authors might have missed important sources due to a limited search.

Conclusion

There is a general lack of support for family caregivers who have provided care to the elderly during COVID-19 in LMICs. Family caregivers of the elderly are largely unrecognized and unsupported before and during the pandemic and have experienced an increased burden of caregiving. Their quality of life has been reduced, leaving them with fewer choices and less time for respite. It is essential that family caregivers of the elderly in resource-constrained countries receive support interventions so that they can then provide care for the elderly as long as it is desired.

Table 1: Types of support interventions and their associated countries

Author	Countries	Target population	Type of study	Key Interventions	Support provision by	Benefits
Wiegelmann et al. (2021)	Germany	Informal caregivers of persons living with Dementia	Systematic review	<ul style="list-style-type: none"> • Psychoeducation • Leisure & physical activity • Counselling • Cognitive behavioural • Befriending & peer support 	Healthcare professional	Promotes the mental health of informal family caregivers
Su et al. (2021)	USA	Cancer caregivers	Systematic review protocol	<ul style="list-style-type: none"> • Technology based intervention 	Not reported	Offers access to remote personalised care By-pass spatial distancing constraints Cost-effective
Sriram et al. (2021)	United Kingdom	Carers of persons with Dementia	Cross-sectional survey	<ul style="list-style-type: none"> • Assistive Technology (AT) 	Self	Helps to reduce caregiver stress, anxiety and makes the caregiving easier. AT can be used for more than one purpose
Reblin et al. (2021)	USA	Caregivers of patient with Primary Malignant Brain Tumor	Randomised wait-list Controlled Trial	<ul style="list-style-type: none"> • Web-based social network visualisation tool and resource list (eSNAP) 	Not reported	Improve caregiver and patient well-being and healthcare utilization
Klein et al. (2021)	Germany	Family caregivers of persons with Dementia	Study protocol	<ul style="list-style-type: none"> • Digitally supported care management 	Study trials	Improvements in caregivers' health, health-related quality of life, social support and the use of medical and non-medical services It reduced caregiver burden,
Bratches et al. (2021)	USA	Family caregivers	Systematic review	<ul style="list-style-type: none"> • Technological interventions 	Not reported	Improved health outcomes for caregivers and care-recipients.
Boucher et al. (2021)	USA	Family caregivers	Implementation design	<ul style="list-style-type: none"> • Caregiver training & support 	National Caregiver Support Program of the Veterans Affairs (VA)	Supporting caregivers could facilitate cultural transformation to a more caregiver friendly Veterans Administration Virtual trainings due to COVID-19 were easy to attend.
Dhavale et al. (2020)	India	Caregivers	Exploratory study	<ul style="list-style-type: none"> • Telephonic & video calls • Individualised sessions • Transport • Bereavement support • Home care visits 	Social worker / institutional staff	Provides direct home-based support to patients and families and opportunity for family caregivers to build resilience.
Irons et al. (2020)	United Kingdom	Family caregivers	Integrative systematic review	<ul style="list-style-type: none"> • Creative art interventions 	Healthcare professionals	Helpful in creating social connections and acceptance of caregiver's identity.

References

- Boucher, N. A., Zullig, L. L., Shepherd-Banigan, M., Decosimo, K. P., Dadolf, J., Choate, A., Mahanna, E. P., Sperber, N. R., Wang, V., Allen, K. A., Hastings, S. N. and Van Houtven, C. H. 2021. Replicating an effective VA program to train and support family caregivers: a hybrid type III effectiveness-implementation design. *BMC Health Services Research*, 21(1): 1-10.
- Bratches, R. W. R., Scudder, P. N. and Barr, P. J. 2021. Supporting communication of visit information to informal caregivers: A systematic review. *PLoS ONE*, 16: 1-13.
- Budnick, A., Hering, C., Eggert, S., Teubner, C., Suhr, R., Kuhlmeier, A. and Gellert, P. 2021. Informal caregivers during the COVID-19 pandemic perceive additional burden: Findings from an ad-hoc survey in Germany. *BMC Health Services Research*, 21: 1-11.
- Cohen, S. A., Kunicki, Z. J., Drohan, M. M. and Greaney, M. L. 2021. Exploring changes in caregiver burden and caregiving intensity due to COVID-19. *Gerontology and Geriatric Medicine*, 7: 1-9.
- Denham, A. M. J., Wynne, O., Baker, A. L., Spratt, N. J., Turner, A., Magin, P., Palazzi, K. and Bonevski, B. 2020. An online survey of informal caregivers' unmet needs and associated factors. *PLoS One*, 15: e0243502.
- Dhavale, P., Koparkar, A. and Fernandes, P. 2020. Palliative care interventions from a social work perspective and the challenges faced by patients and caregivers during COVID-19. *Indian Journal of Palliative Care*, 26: S58-s62.
- Greaney, M. L., Kunicki, Z. J., Drohan, M. M., Ward-Ritacco, C. L., Riebe, D. and Cohen, S. A. 2021. Self-reported changes in physical activity, sedentary behavior, and screen time among informal caregivers during the COVID-19 pandemic. *BMC Public Health*, 21: 1-9.
- Hesamzadeh, A., Dalvandi, A., Bagher Maddah, S., Fallahi Khoshknab, M., Ahmadi, F. and Mosavi Arfa, N. 2017. Family caregivers' experience of activities of daily living handling in older adult with stroke: a qualitative research in the Iranian context. *Scandinavian Journal of Caring Sciences*, 31(3): 515-526.
- Hindmarch, W., McGhan, G., Flemons, K. and McCaughey, D. 2021. COVID-19 and long-term care: the essential role of family caregivers. *Canadian Geriatrics Journal*, 24(3): 195-199.
- Holland, D. E., Vanderboom, C. E., Dose, A. M., Moore, D., Robinson, K. V., Wild, E., Stiles, C., Ingram, C., Mandrekar, J., Borah, B., Taylor, E. and Griffin, J. M. 2021. Death and grieving for family caregivers of loved ones with life-limiting illnesses in the era of COVID-19: Considerations for case managers. *Professional Case Management*, 26(2): 53-61.
- Irons, J. Y., Garip, G., Cross, A. J., Sheffield, D. and Bird, J. 2020. An integrative systematic review of creative arts interventions for older informal caregivers of people with neurological conditions. *PLoS ONE*, 15: 1-25.
- Josephson, A., Kilic, T. and Michler, J. D. 2021. Socioeconomic impacts of COVID-19 in low-income countries. *Nature Human Behaviour*, 5: 557-565.
- Klein, O. A., Boekholt, M., Afrin, D., Dornquast, C., Dreier-Wolfgramm, A., Keller, A., Michalowsky, B., Zwingmann, I., Teipel, S., Thyrian, J. R., Kilimann, I. & Hoffmann, W. 2021. Effectiveness of a digitally supported care management programme to reduce unmet needs of family caregivers of people with dementia: study protocol for a cluster randomised controlled trial (GAIN). *Trials*, 22(1): 1-11.
- Mueller, A. L., McNamara, M. S. and Sinclair, D. A. 2020. Why does COVID-19 disproportionately affect older people? *Aging*, 12(10): 9959-9981.

- Park, S. S. 2021. Caregivers' mental health and somatic symptoms during COVID-19. *Journals of Gerontology: Social Sciences*, 76: e235-e240.
- Price, M. L., Surr, C. A., Gough, B. and Ashley, L. 2020. Experiences and support needs of informal caregivers of people with multimorbidity: a scoping literature review. *Psychology and Health*, 35(1): 36-69.
- Rahimi, T., Dastyar, N. and Rafati, F. 2021. Experiences of family caregivers of patients with COVID-19. *BMC Family Practice*, 22: 1-10.
- Reblin, M., Ketcher, D., McCormick, R., Barrios-Monroy, V., Sutton, S. K., Zebrack, B., Wells, K. J., Sahebjam, S., Forsyth, P. and Byrne, M. M. 2021. A randomized wait-list controlled trial of a social support intervention for caregivers of patients with primary malignant brain tumor. *BMC Health Services Research*, 21(1): 1-8.
- Silva, A. L., Teixeira, H. J., Teixeira, M. J. and Freitas, S. 2013. The needs of informal caregivers of elderly people living at home: an integrative review. *Scandinavian Journal of Caring Sciences*, 27(4): 792-803.
- Sriram, V., Jenkinson, C. and Peters, M. 2021. Carers' experiences of assistive technology use in dementia care: a cross sectional survey. *BMC Geriatrics*, 21: 471.
- Su, Z., McDonnell, D., Liang, B., Kue, J., Li, X., Šegalo, S., Advani, S., Flores, B. E. and Wang, J. 2021. Technology-based health solutions for cancer caregivers to better shoulder the impact of COVID-19: a systematic review protocol. *Systematic Reviews*, 10: 43.
- Tasnim, S., Hossain, M. M. and Mazumder, H. 2020. Impact of rumors and misinformation on COVID-19 in social media. *Journal of Preventive Medicine and Public Health*, 53(3): 171-174.
- Wiegelmann, H., Speller, S., Verhaert, L. M., Schirra-Weirich, L. and Wolf-Ostermann, K. 2021. Psychosocial interventions to support the mental health of informal caregivers of persons living with dementia – a systematic literature review. *BMC Geriatrics*, 21: 94.