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Informal home care providers: the forgotten health-care workers during the COVID-19 pandemic

Published **Online** June 1, 2020 https://doi.org/10.1016/S0140-6736(20)31254-X

The COVID-19 pandemic has placed pressure on many national health-care systems worldwide. Due to the rapid surge in caseloads and resource constraints in health systems, in many high-income settings, the focus has been on disease screening, with those who have severe disease prioritised for hospitalisation. But the COVID-19 pandemic has also led to an unprecedented reliance on home care as one pillar of the health-care system to support people with confirmed or suspected COVID-19. Meanwhile, informal home care provision and challenges faced by care providers, excluding those who are formal and paid, in the home context have largely been overlooked. In such population-wide public health emergencies, home care can be the only care option for people in low-income and resource-constrained settings who do not have access to health-care facilities due to such factors as distance, lack of transport, financial issues, or cultural–linguistic barriers.[1] Of course, people in need of home care are not limited to those with COVID-19. A large proportion of home care recipients include patients with chronic diseases, mental disorders, or disabilities who require essential life-sustaining care, health maintenance support, and supplementary care during this pandemic. Moreover, home care recipients can include healthy but dependent individuals such as infants, young school-aged children, or older people.[1]

In public health emergencies, informal home care providers are a crucial human resource that improves the community's health-care capacity, especially in regions with an ageing population and areas with suboptimal health-care systems.[2,3] Yet our knowledge of the characteristics of these informal home care providers and the challenges they are facing during the COVID-19 pandemic is limited. The physical, mental, and social wellbeing of home care providers has been largely overlooked in the research literature. Policy planners who advocate for home care often make the assumptions that home care providers possess an appropriate level of health literacy, disease knowledge, psychological readiness, and medical care abilities. Another common assumption is that care recipients live in housing with adequate space where there are facilities for isolated care with ready access to home care materials. However, evidence gaps have shown there is a need for research with appropriate study outcomes to facilitate home care for people who

Panel: **Research priorities relevant to informal home care providers[1]**

Care service provision

- Updating clinical home care guidelines related to health risks, disease, and clinical management of COVID-19 to support formal and informal home care providers
- Special challenges associated with various home care settings, including informal settlements, in adhering to guidelines
- Disease management for home care models
- Strategies for formal home care providers to best support informal care providers during COVID-19 while protecting the safety of staff and organisational integrity

Health monitoring and clinical outcomes of home care models

- Health outcome comparison studies of home care models
- Home care-related clinical and health outcome monitoring and evaluation studies
- Evidence-based disease-specific home care advice for people with chronic conditions with and without COVID-19 in the home context

Impacts on and support for home care

- Sociopsychological research linked with clinical and public health issues to address the vulnerable urban population
- Situation of informal care providers of vulnerable groups: burden, physical and mental wellbeing, support, and burnout
- Coping strategies of vulnerable people living alone and the related impact on their physical and mental health
- Impact and support for people with mental disorders and their care providers during home confinement, and access to telehealth services
- Application and limitation of telemedicine and telehealth in supporting vulnerable groups and their formal and informal care providers
- Prioritise support for individuals at risk of domestic violence during home care
- Contribution and problems of online learning to home care for children during school closure
- Role of private sector in supporting home care during a pandemic

live in informal settlements,[4] such as in some parts of south Asia and Africa, and other special dwelling conditions—eg, bond room or subdivided housing, multiple-dwelling units, and displaced refugee settings.[1,5] The COVID-19 pandemic reminds the global community that the domestic environment is a complex context for the care of sick and vulnerable people. Public health measures, such as home isolation designed to support disease control and prevention, might have unintended consequences and has been associated with increases in domestic violence toward women recorded globally during lockdowns.[6]

Findings from our cross-sectional population-based survey in an urban setting of Hong Kong affected by the early phase of COVID-19 suggest that a sizeable proportion (nearly 25%) of the general population took up informal home care responsibilities during this period.[1,7] Given that over half of these individuals were economically active, many informal home care providers bear a double burden of working and being the primary care provider. During the pandemic, a proportion of these informal home care providers reported having inadequate knowledge about the health-care duties required and increased psychological stress.[7] However, there is insufficient scientific evidence and further research is needed to direct policy, guidelines, resources, clinical support, quality assurance, and monitoring and outcome evaluation for informal caregivers (panel).

For home care to better support health needs during extreme events, urgent research related to social and economic impacts of home care is needed to update policies and improve health support programmes. The latest WHO home care guidelines were updated in March, 2020,[8] and mostly emphasise methods of infection risk control and clinical management of COVID-19, particularly for those placed under home quarantine. Disease-specific and contextualised—eg, constraints of high-density living arrangements—home care advice for people with chronic conditions with and without COVID-19 in the home context will need to be updated and tailored to support informal home care providers in related clinical guidance and technical reports.

Culturally and gender[9] sensitive guidance related to home care for severely ill patients who are unable to access health facilities, including for the provision of home-based palliative care, is also required. In addition to the widespread support for better working conditions and protection for formal home care workers, there should also be information and material resources, mental health support, salary package with special annual leave for care providers, and flexible workplace policies to enable informal home care duties.[10,11] Overall, policy and programmes that aim to use home care to support vulnerable groups during crisis should have the twin overarching goals to improve self-help ability for home care recipients, including maintenance of basic health, and to provide resources and support for informal home care providers.

Other priorities for ensuring the effectiveness of informal home health care for vulnerable populations are to identify a suitable support model for people living alone—eg, a buddy system—and to identify care

providers with a disproportionate care burden, such as those with multiple care recipients. Additionally, research is required to examine how the closure of elderly residential care facilities and schools has placed additional burdens on informal care providers.[1,3,6,9] Finally, health outcome monitoring, feasibility evaluation of telemedicine, provision of disease-specific advice, home-schooling support, and capacity-building for care providers could all help to enhance the quality of informal home care. Research in these domains will also be instrumental to inform future Health Emergency and Disaster Risk Management (Health-EDRM) practices. Prioritising research in informal home care could help to inform and improve the planning, training, and management of future large-scale public health emergencies in the 21st century.[12]

EYYC and NG are the Co-Chairs of the WHO COVID-19 Roadmap Research Group for Social Science and are involved in the WHO roadmap home care review report. The views expressed by the authors do not necessarily reflect the views of WHO. NG reports grants from European Union's Horizon 2020 research and innovation programme. We declare no other competing interests.

Emily Ying Yang Chan, Nina Gobat, Jean H Kim, Elizabeth A Newnham, Zhe Huang, Heidi Hung, Caroline Dubois, Kevin Kei Ching Hung, Eliza Lai Yi Wong, Samuel Yeung Shan Wong
emily.chan@cuhk.edu.hk

Collaborating Centre for Oxford University and CUHK for Disaster and Medical Humanitarian Response (CCOUC), The Chinese University of Hong Kong, Hong Kong, Special Administrative Region, China (EYYC, ZH, HH, KKCH); Nuffield Department of Medicine, University of Oxford, Oxford OX3 7BN, UK (EYYC, NG); JC School of Public Health and Primary Care, The Chinese University of Hong Kong, Hong Kong, Special Administrative Region, China (EYYC, JHK, ZH, HH, ELYW, SYSW); GX Foundation, Phnom Penh, Cambodia, and Vientiane, Laos (EYYC, CD); Accident and Emergency Medicine Academic Unit, The Chinese University of Hong Kong, Hong Kong, Special Administrative Region, China (EYYC, KKCH); School of Psychology, Curtin University, Perth, WA, Australia (EAN); and FXB Center for Health and Human Rights, Harvard T H Chan School of Public Health, Boston, MA, USA (EYYC, EAN)

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