Digital technology, health and wellbeing and the COVID-19 pandemic: it's time to call forward informal carers from the back of the queue.

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Abstract

Objective- To describe the current challenges of family caregivers during and beyond the COVID-19 pandemic, the need for future digital innovations including involvement from professional nursing roles.

Data Sources- Review of recent literature from PubMed and relevant health and care reports.

Conclusions- The COVID-19 pandemic has caused monumental disruption to healthcare delivery and care. Caregivers face unprecedented levels of uncertainty: both for the people they care for and for their own health and wellbeing. Given that many carers face poor health and wellbeing- there is a significant risk that health inequalities will be increased by this pandemic, particularly for high risk groups. Innovations including those supported and delivered by digital health could make a significant difference but careful planning and implementation is a necessity for widespread implementation.

Implications for Nursing practice- Carers need to be championed in the years ahead to ensure they do not become left at the "back of the queue" for health and wellbeing equity. This situation has been exacerbated by the COVID-19 pandemic. Disruptive change to health and social care is now required where digital health solutions hold considerable promise, yet to be fully realised.

Keywords

Informal carer, digital technologies, COVID-19

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Introduction

On 11 March 2020 the World Health Organization formally declared that Severe Acute Respiratory Syndrome Coronavirus- 2 (SARS-CoV-2) or COVID-19 as a global pandemic (1, 2). The disruption caused by COVID-19 has been unparalleled. While the immediate impact on health and wellbeing demands urgent attention (reviewed elsewhere (3-5)) there remains growing concerns about the long term impact of COVID-19, particularly within societal groups with pre-existing conditions and those susceptible to poor health and wellbeing.

Informal carers (family members and friends looking after another person) are one such group. True champions of the COVID-19 pandemic, yet paradoxically "forgotten" (6). Recent review work suggests that policies developed to support informal carers throughout COVID-19 make false assumptions regarding health literacy levels, disease knowledge, psychological readiness, and medical care abilities (6). Further, collective knowledge of this group appears particularly inadequate- this is despite an obvious "pinch point" on the caring community due to COVID-19. Many individuals are facing additional pressures- not least conforming to local and national "lockdowns" and associated restrictions which to some will translate to more time indoors, caring.

From U.K. national statistics, it appears that almost half of the population (48%) provided help or support to someone outside of their household in April 2020- a significant increase from pre-pandemic levels of 11% (7). The pressure on this population is evident- even taking into account those relatively new to caregiving- U.K. national statistics have demonstrated significantly increased rates of feeling under strain compared to non-carers (7). For those who deliver caregiving with more permanency (e.g. those caring for someone with a long term condition such as cancer or dementia) there is an uncertain future. It is perhaps unsurprising that some are postulating that there is not just single crisis, but in fact three: (i) an acute healthcare crisis, (ii) a healthcare recovery crisis and a (iii) social and economic crisis (8). Further, there is growing awareness that this pandemic is not an isolated event but a "syndemic" where impacts of COVID-19 are being felt in the most vulnerable throughout society- including the growing number of individuals with non-communicable disease(9).

COVID-19 exerts nuanced short and long term challenges to our caregiver population which are as yet poorly understood. We cannot afford to allow carers to end up as "passengers" in this roadmap. The support carers continue to provide needs to be urgently met with proactive approaches to health and wellbeing and constructive conversation. This opinion piece illustrates some of the short and long term challenges ahead, alongside potential avenues for digital health solutions. While the consequences of the COVID-19 pandemic may seem all but inevitable, this is not necessarily the case. To mitigate the risks we must:

1. Understand the carer demographic and the impact of COVID-19- e.g. how have carers responded mentally and physically to the pandemic?
2. Innovate with caregivers and practitioners with rigorous evaluation of technology solutions capable of reaching the front line.

Short term implications of the COVID-19 pandemic on informal caregivers

Caregivers are a diverse group. Previous work in the area suggests that carers are common groups for caregiving include those who are middle aged (e.g. 35 to 65) and female (10). Some studies have suggested that carers report much higher degrees of social isolation and poorer quality of life when compared to the general population (11). During the COVID-19 pandemic many caregivers have assumed extra roles- becoming the face of public health to those cared for: delivering and implementing messages around hygiene, social distancing, shielding and providing reassurance (12). This is beyond the normal workload where 46% of caregivers report caring for 90 or more hours every week (10).

As with all populations, caregivers are at risk of contracting COVID-19 through community transmission yet have added pressure to protect those that they care for. While the population descriptors above do not necessarily place caregivers directly in the highest risk groups for COVID-19 (e.g. people undergoing cancer treatments such as radiotherapy or chemotherapy, people with chronic and severe lung conditions or those with serious heart conditions (13)) they are reasonably likely to be caring for

someone who within these higher or medium risk groups. Caregivers are also likely themselves to have conditions of their own - including long term conditions such as hypertension (14, 15). National data from the U.K. suggests that twenty four percent of caregivers consider themselves to have a disability (10). Even before the era of COVID-19, there is compelling evidence that caregivers face higher rates of psychological distress compared to non-carer comparison groups (16).

The mental and physical health implications of the COVID-19 pandemic on caregiver communities are yet to be fully explored. What remains likely is that the severe disruption around health and wellbeing (e.g. delays to diagnosis, treatments, increasing social isolation, inability to leave the house) is likely to have impacted on overall carer health and wellbeing. There are many high risk within the carer community such as those: "shielding", from Black and Minority ethnic groups and those facing social inequalities. Due to COVID-19 many caregivers will have changed habits around circadian rhythms, sleep, diet, exercise, alcohol consumption, and social activities. While the development of a successful vaccination programme is much needed, short term: social, health, economic hardship will take time to recover from and could have lasting impact on individual families, communities and carers.

Longer term implications of the COVID-19 pandemic on informal caregivers

The longer term implications of COVID-19 on the caregiver community are particularly unclear- although for those who have already contracted the virus there remain significant questions regarding secondary complications (such as fatigue) over months if not years (17). Aside from COVID-19, there is already evidence that caregivers face an increased risk of depression, stroke and coronary heart disease (18) and have a high percentage of overweight and obesity (19). National U.K. studies in caregiver populations found that 1 in 5 carers reported a preventable emergency hospital admission in the last year (10) and observational studies have found that caregivers find it difficult to adhere to medical appointments and to prescribed treatments(20).

Changes to daily behaviours (e.g. shifts in our daily patterns, sleep and stress) can have significant long term impacts on mental and physical health. Groups who are more susceptible to adverse effects of COVID-19 (e.g. BAME groups) are already at a greater risk of sleep disparities and cardiovascular events in the first place (21).

Collectively, this means that COVID-19 is presenting a sustained risk to our caregiver community and holds potential to further widen health inequalities. This being said, there may be some changes in behaviour that are positive for health and wellbeing and some negative changes may not continue long term. Such intricacies are why observational studies targeting the carer demographic are required: built with health and social care delivery partners in mind from the outset.

The need for innovation and digital solutions to support informal caregivers

Technology solutions form a fast moving, spectrum of possibilities- online interventions, wearables, machine learning, big data- it is perhaps little surprise that concerns have been raised in the field in that technology developments are now outpacing rigorous research and evaluation (22). While this can translate to the use of technologies with poor/no evidence for use in carers or over-engineering of solutions, solid science is still emerging. Such evidence includes psychosocial supports delivered online that have demonstrated clinically meaningful benefits for mental health outcomes including depression and anxiety (16). There is now considerable expansion internationally with appropriate cultural adaptation and personalisation and delivery/evaluation in lower and middle income country settings (23).

Given the plethora of technology options available there is much unrealised potential. U.K. national statistics report that that 4 in 5 carers use digital technologies (10), and there remains a wealth of options across disease monitoring, data analytics, diagnosis, treatments, accessing healthcare information and education and support (see Figure 1). Digital technologies however, are no "silver bullet" and too few great concepts in technology reach the front line where there are significant questions on evaluation methodology (24). Understandably, there are many current efforts critiquing past failures, where researchers are looking to develop robust approaches for successful implementation, cost effectiveness and accessibility (16, 25, 26).

Across all the research and practice questions above- the role and influence of the healthcare professional remains critical. This includes helping to identify caregivers, establishing unmet needs in caregivers, helping appraise the suitability of technologies from a healthcare viewpoint and feeding back iteratively on how best to implement

solutions. What is becoming increasingly feasible is that preventative, self-management and triage approaches can become a reality for health and wellbeing in carers through the avenue of technology. The technology capability is already there- it is the infrastructure, human supports and the ecosystem that needs to be developed and proven effective. Success could mean a suite of evidence based digital tools built to empower caregivers, protecting the health and wellbeing of this invaluable workforce, and leaving our societies much better prepared for future pandemics.

Conclusions and implications for nursing practice

It is likely that the COVID-19 pandemic will have prolonged effects of the caregiver population where health and wellbeing equity could become further from reach. Undoubtedly, clinical professionals will play a key day to day role in supporting patients and wherever possible their associated caregivers. However, increased demand on health and social care services, restricted budgets alongside the potential for further lockdowns/restrictions means that innovations are sorely needed to champion and support "forgotten" caregivers in a timely manner. At a time where technologies are advancing quicker than rigorous evidence is being accumulated, the ideas, experience and critique of healthcare professional has never been more critical.

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Figures
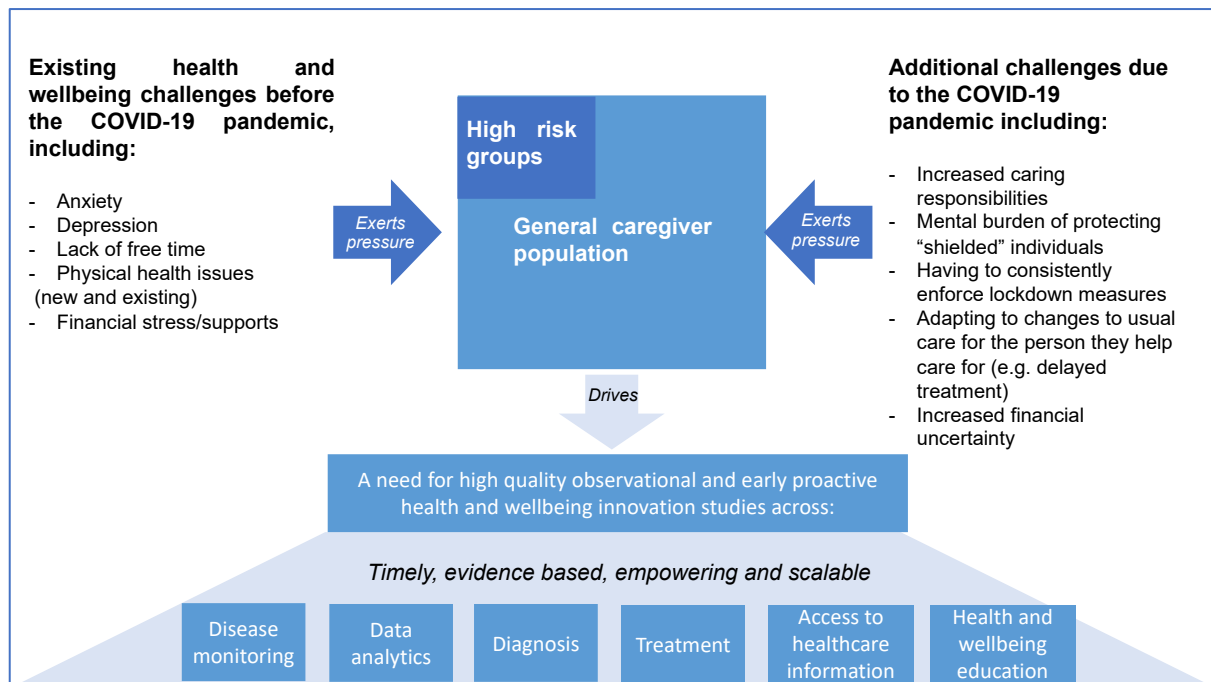
Figure 1 Overview of the caregiver population and pressures face both in general and due to the COVID-19 pandemic alongside some examples of targets for technology based solutions.

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