Relevance of Digitalization for Informal Caregivers to Address Support Needs and Reducing Social Isolation during the COVID-19 Pandemic

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DESCRIPTION

In November 2019, a paper I was lead author on, "The role of internet-based digital tools in reducing social isolation and addressing support needs among informal caregivers: a scoping review," was published in BMC Public Health [1]. Little did we know that the issue of social isolation would soon become crucially important for vastly more people worldwide due to the COVID-19 pandemic. Before the pandemic we could see that without proper support informal caregivers were vulnerable to social isolation. Loneliness and caregiving pressures have substantially increased during the COVID-19 era for unpaid informal caregivers who care for a sibling, child, spouse, friend, or neighbor. Many informal caregivers do not have a choice in taking on this role – it often just falls to them because no one else is willing or able to do it. Often, acquaintances of these informal caregivers do not know that the individual has taken on this role. For example, there is little acknowledgment that young people (under 18 years of age) sometimes take on the responsibility of caring for a loved one such as a grandparent, parent, or sibling. Many professionals do not even address youth when discussing the care of a loved one – it is often assumed that an adult provides the care [2]. These underappreciated caregivers need to be acknowledged and supported.

When an informal caregiver's time is consumed by attending to a loved one's needs, this can lead to decreased opportunities to engage with others, a lack of social belonging, and few satisfying relationships outside the home. Long-term caregiving often leads to caregiver burnout, which can negatively affect one's quality of life, both mentally and physically. It is important that people have a sense of social inclusion, which is associated with feelings of wellbeing and fulfillment. It is also important that these caregivers feel that they have a social network where they can obtain emotional support, practical assistance, and resources when needed [1].

Unfortunately, the challenges facing informal caregivers were neglected prior to the emergence of the COVID-19 pandemic and this trend continues. In public health emergencies like COVID-19, home care may be the only care option for low-income people and those who otherwise have limited resources due to, for example, distance from urban centers, a lack of transportation options, or cultural–linguistic barriers [3]. Many informal caregivers also lack knowledge on how to care for others and do not possess appropriate coping strategies for the stress of this unfamiliar role. For instance, many people in Hong Kong were thrown into an informal caregiver role when COVID-19 hit and felt that they had inadequate knowledge to provide the care required. They also felt unprepared to deal with the increased psychological stress in relation to this new caregiving role [4].

With the number of informal caregivers only growing during the pandemic, the high social-relational relevance of digitalization in informal caregiving has become even more evident. Internet-based tools can support informal caregivers' access to information and provide a way of connecting to others [1]. The are many advantages to using Internet-based supports such as anonymity, instant access, and the flexibility of receiving support within one's own home. Moreover, unlike in-person support groups, such social support is not dependent on the caregiver's location [1]. However, there are limitations to Internet-based tools such as a lack of technical knowledge. Thus, technical support would greatly aid informal caregivers [1]. Moreover, there are common but unwarranted assumptions made by many proponents of these technologies. For example, it is often assumed that everyone can afford the necessary equipment and has equal access to the Internet (i.e., lives in a geographic area with high-speed Internet and has unlimited data). Another assumption is that everyone has the digital literacy to use Internet-based technologies. Informal caregivers may need to learn how to use the technology to participate in Internet-based support and this may be difficult when caregiving responsibilities limit their ability to access training.

In the age COVID-19, governments, health policy experts, and decision makers need to recognize that health care systems are reliant on the care informal caregivers provide to the citizens and communities these systems serve. Informal caregivers are actually taking some of the burden off of health care systems and thus are responsible for significant cost savings. Thus, informal

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Citation: Newman K (2020) Relevance of Digitalization for Informal Caregivers to Address Support Needs and Reducing Social Isolation during the COVID-19 Pandemic. J Aging Sci. 8: 243.

caregivers should be recognized as important partners with the healthcare system.

Since informal caregivers are performing a large proportion of long-term care in the home setting, governments, health policy experts, and decision makers should support online communities for informal caregivers. This should include providing education to improve digital literacy, subsidizing digital communication technologies to improve mental health, and improving Internet access in remote geographical areas. Digital technologies can also be a means to access education on caregiving by training informal caregivers on proper caregiving techniques, procedures—similar to the services provided by telehealth nurses. Vulnerable informal caregivers need empowerment and support to use digital technologies to access online communities and increase their social inclusion. We need to recognize that informal caregivers need to be cared for too – digital technologies could assist to improve their social inclusion and their physical and mental health.

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