

White Paper Series on mHealth and Aging



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mHEALTH TRANSFERRING THE BURDEN OF CAREGIVERS TO MOBILE TECHNOLOGIES

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Ada Kwan, mHealth Alliance, United Nations Foundation



In 2000, the number of people over the age of 65 was just over 500 million, and this number is expected to triple by the year 2050.

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ABSTRACT



THIS WHITE PAPER, WHICH HAS EVOLVED FROM PRIOR RESEARCH¹, IS ONE PART OF A THREE-PART SERIES DEVOTED TO EXPLORING THE USE OF MOBILE AND WIRELESS TECHNOLOGIES IN HEALTH (MHEALTH) and the opportunities for impacting and advancing healthy aging in low- and middle-income countries (LMICs). This specific paper focuses on the use of mHealth for caregivers of aging individuals.

In 2000, the number of people over the age of 65 was just over 500 million, and this number is expected to triple by the year 2050²⁾. These figures reflect many achievements in public health, such as vaccination, disease control, and access to safe drinking water and basic sanitation. However, the growing size of an older world population foreshadows significant challenges. As individuals age and develop age-related health conditions, these growing numbers will place considerable stress on the families, social networks, and health systems that provide caregiving support. Such stress can have costly consequences. Fortunately, mHealth offers unique solutions that can not only complement existing health care delivery systems but can also be implemented in resource-poor

environments, such as those often seen in LMICs. mHealth solutions can support family members in their roles as informal caregivers to the elderly and can provide support to formal caregivers, such as health care professionals or professional caregivers. This paper defines the variety of caregivers for the rapidly growing older global population and details the role mobile technologies currently play and could potentially play to support the various types of caregivers in LMICs, while being mindful of anecdotal mHealth examples from high-income countries. For caregivers and care recipients, mHealth solutions can be developed to fill social, functional, and instrumental task needs⁽³⁾. Finally, a call to action is made to bring together stakeholders from a variety of sectors to achieve the full potential of mHealth as a tool for caregivers around the world.

The number of mobile phone subscriptions globally is set to equal and even surpass the world population of seven billion in 2014.



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INTRODUCTION



THE BURDEN OF CAREGIVING FOR OLDER PEOPLE IS QUICKLY INCREASING AROUND THE WORLD. The number of people over the age of 60¹ is expected to grow from 810 million in 2012 to over a billion in less than 10 years, with the figure expected to reach 2 billion by 2050⁽⁵⁾. These figures reflect many achievements in public health, such as vaccination, disease control, and access to safe drinking water and basic sanitation. However, the rapidly expanding and aging population will place considerable stress on families, social networks, and health systems and can have costly consequences if action is not taken now^{2,3}.

Globally, the burden placed on caregivers will grow as the world population ages and confronts age-related health conditions, such as chronic diseases (e.g., cardiovascular diseases, cancer, and diabetes) – the major causes of death around the world – as well as declining cognitive acuity and mental health⁽⁷⁾. Current dynamics between informal and formal caregiving and existing health systems demonstrate that there is a lack of preparedness to respond effectively to aging

populations, especially as health conditions of the elderly combine with poverty⁽⁵⁾. In low- and middle-income countries (LMICs), where the majority of the growth of elderly populations is expected to occur,⁴ the situation is more straining^(2,8). Demographic transitions in LMICs are requiring countries to take on the additional burden of responding to chronic conditions while maintaining and improving effective responses to existing health threats such as malnutrition and infectious diseases⁽⁹⁾.

As the number of mobile phone subscriptions globally is set to equal and even surpass the world population of seven billion in 2014^(10,11), there is massive potential for mobile and wireless technology to support healthier aging and to reduce the strain being put on caregivers around the world. *The two objectives of this white paper are to (1) define the needs of caregivers for the rapidly growing older adult populations in LMICs, and (2) to understand the role mobile technologies have in supporting the various types of caregivers in LMICs, while being mindful of anecdotal mHealth examples from high-income countries (HICs).*

¹ The World Health Organization accepts 65 years to define the term 'elderly' or 'older person' in the majority of developed countries; however, the age of 60 is often considered in low- and middle-income countries⁽⁴⁾.

² In the future, there will be a reduction of support base for older adults and an increase in their dependency on social support and health care services⁽⁴⁾.

³ Although estimates of caregiving are difficult to achieve, a study focusing on the United States alone placed the economic value of informal caregiving at 18% of national healthcare spending⁽⁸⁾.

⁴ The United Nations Population Fund (UNFPA) predicts that by 2050, the population aged 60 years or older will reach 10% in Africa, 24% in Asia, 24% in Oceania, 25% in Latin America and the Caribbean, 27% in North America, and 24% in Europe⁽⁵⁾.

BACKGROUND



AS HEALTHY INDIVIDUALS AGE, THEY CAN DEVELOP EARLY OR STABLE CHRONIC CONDITIONS, WHICH CAN LATER BECOME SERIOUS AND CAN LIMIT DAILY ACTIVITIES⁽¹²⁾.

Further advancement of chronic conditions can have fatal outcomes. Advancing illnesses require older adults to rely less on self-care and more on the attention and services offered by different types of caregivers (see Figure 1). Caregivers can be informal (e.g., family

members, spouses, other elderly individuals) or formal (e.g., health care professionals or caregivers at institutional care centers)⁽¹³⁾. In HICs, formalized care options often exist, such as home care, nursing homes, and residential care for individuals at advanced stages of illnesses⁽¹⁴⁾. These care options are not as easily available, if at all, in LMICs, nor can institutionalization meet the growing needs of a globally aging population.



Figure 1.

A visualization of the evolution of advanced illness among individuals (adapted from Coalition to Transform Advanced Care's Call to Action on Transforming Advanced Illness Care⁽¹²⁾) with the changing roles of different types of caregivers who may be involved in an individual's life during aging.

Informal caregivers are the primary type of caregivers for older adults. These are usually family members who are primarily women, such as a daughter or daughter-in-law, but can also be members of extended families^(14,15). These caregivers are often motivated by virtue of their binding duties and the sense of honor in supporting older kin – reciprocity and self-interest⁵, respectively⁽¹⁵⁾. For example, a saying in Ghana goes, “If your parents look after you when you are growing your teeth, you must also look after them when they are losing their teeth”⁽¹⁵⁾. Limited resources, rising costs of living, and escalating medical needs force caregivers in LMICs

to make trade offs between caregiving and other life priorities, such as work and time with other family members. This scenario is further complicated as family structures are spread geographically, with older adults living in rural areas and young adults migrating to urban areas for employment. This urban migration may improve financial support, but it also removes social support structures for elderly care, especially when the older generations are responsible for caring for younger generations.

⁵ Children feel less obligated to give care if they feel as though their parents “failed” them.⁽¹⁵⁾

Informal caregivers are often the only or main caregivers, but they seldom have the proper health training or skills to properly and completely care for older adults with age-related health conditions, such as chronic diseases. Chronic diseases, in particular, develop slowly with unclear symptoms, so early detection when prevention or cures are still possible is often difficult to achieve⁽¹⁶⁾. Thus, formal caregivers often enter the equation when an older adults' condition or health episode triggers or warrants special care. Formal caregivers are trained and have the skills to respond to the health needs of older adults but lack extremely useful information to make decisions considering the individual or family dynamics⁽¹⁷⁾. The link between informal and formal caregivers is complicated in LMICs where health systems can be fragmented and getting appropriate health services to older adults in a timely manner can be financially and geographically challenging.

The global caregiving burden is exacerbated by insufficient resources and support for caregivers of older adults, as well as by a lack of adequate facilities with medical, psychiatric, and rehabilitative services⁽¹⁸⁾. Around the world, elderly care is rarely considered a priority, which further complicates the challenge of mobilizing resources for appropriate services targeted at aging populations and their caregivers. In hard-to-reach locations and rural areas, for example, outreach services that go to households and communities tend to focus on reducing maternal and child morbidity and mortality and do not have explicit efforts tailored for the older segment of the population. At the policy level, many LMICs lack comprehensive national policies for elderly populations⁽⁹⁾. A study that analyzed over 6,000 projects backed by the United Nations in 2010-2011 found that only 61 (1%) targeted older adults or individuals with disabilities⁽¹⁹⁾. In 20 countries, there were no projects that targeted older adults⁽¹⁹⁾.

Reducing the burden of caregiving around the world involves identifying how caregivers can be supported in their responsibilities. Emotions, financial duties, and instrumental tasks are three specific areas that can create burdens for caregivers, and identifying ways to support caregivers in these areas can help reduce the burden of caregiving on an individual level^(20,21). These

are described further below, but it is important to note that the needs for different kinds of support can change over time depending on the stage of the caregiver's journey⁽²²⁾ (see Appendix A).

Emotional support: Informal caregivers often report feelings of guilt, resentment, and hostility when they make personal sacrifices to provide care to older adults⁽²³⁾. These feelings can be quite overwhelming for the caregiver. Strategies for balancing and alleviating this stress include obtaining information (e.g., information on home-based care or information on any conditions affecting the care recipient), skill building, getting psychosocial support, and accessing additional resources that can help in balancing tasks.

Financial duties: Caregivers often have financial duties for the elderly they care for. In some countries, because of rural-to-urban migration for work, working-class adults, who sometimes also play the role of informal caregivers, send remittances from urban centers to the rural areas where the elderly reside⁽²⁴⁾. However, sending remittances can be challenging for these caregivers as banks and having bank accounts are not common in some places.

Instrumental task support: Caregivers have to manage a multitude of tasks that play an instrumental part in daily activities, such as running errands, shopping for food, providing personal care, taking care of the house and household, and filling in when assistance is needed^(13,25). Caregivers often require a great deal of support, as they are not only providing care, but also attempting to balance caregiving with other life activities that require time and energy. This is reflected in existing caregiving research in developed countries, which often evaluates caregiver burden, depression, subjective wellbeing, perceived caregiver satisfaction, ability, and knowledge⁽²¹⁾. For formal caregivers, instrumental tasks are those related to providing health or social support services, such as disease management, treatment support for older adults taking medications, or patient monitoring, particularly in the case of chronic diseases. Appendix B lists tasks that often belong to general caregivers⁽²⁰⁾.



For the emotional, financial, and instrumental support needs of informal caregivers, mobile options are plentiful...

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EXISTING SOLUTIONS: mHealth in Caregiver Support



FOR CAREGIVING, MOBILE TECHNOLOGIES OFFER NEW OPPORTUNITIES TO DELIVER EXISTING SOLUTIONS, BUT THE VERY PRESSING CHALLENGE Hinges ON MAKING CAREGIVING OVER A DISTANCE EASIER.

By addressing this challenge, individuals would be able to live where they choose and maintain a supportive ecosystem wherever they happen to be. It is expected that over time the increasingly interconnected world will rely even more heavily on technologies to support healthy aging.

The current field of mHealth for caregiving is being created in and for developed countries, but it has yet to gain full momentum in LMICs. Currently, mHealth caregiving solutions focus on improving the quality of life for informal caregivers and providing monitoring tools for formal caregivers. Most of these efforts are concentrated in high-income countries, which can be linked to the lack of prioritizing both aging and caregiving support in LMICs. In general, certain caregiving burdens can be addressed by meaningfully designed technology, which will be detailed in this section. If leveraged appropriately, mobile strategies can offset massive and increasing costs related to

informal caregiving and aging-linked health system inefficiencies, such as late diagnoses, access to medications, hospital readmissions, and excessively long hospital stays.

For the emotional, financial, and instrumental support needs of informal caregivers, mobile options are plentiful, as the field is in the midst of understanding and applying what can be useful:

For emotional support, mobile solutions that assist caregivers in obtaining psychosocial support include voice calls, text messaging, and other multimedia communication (e.g., video communication). Mobile games aimed at assisting caregivers in improving physical rehabilitation of the elderly, social networking, and mobile access to networks could help fill the needs of caregivers. Mobile and wireless technologies can support caregiver networks so caregivers can exchange with each other psychosocial support and information, such as how to balance tasks and look for additional resources.

For their financial duties, the ability to send money with mobile phones offers caregivers an easy way

to support the elderly they care for. In particular, mobile money options in LMICs, such as G-Cash in the Philippines or mPesa, first launched in Kenya and now available in other countries, allow for money or credit transfers to happen without bank account requirements⁽²⁶⁾. This is helpful since family members in LMICs often do not live near one another and their health systems are not fully equipped to support or respond to age-related conditions⁽⁵⁾.

For instrumental task support, mHealth solutions that ease the demands, eliminate or reduce the risks, and lower the costs of caregiving can reduce the actual toll absorbed by caregivers⁽²⁰⁾. mHealth solutions and services linked to mobiles can allow older adults to maintain their independence not only by delivering ways to better self-manage daily activities but also by offering opportunities for caregivers to help encourage healthier behavior in older adults⁽¹⁴⁾. Education and support programs delivered to mobile technologies have also been identified as ways that can help support the instrumental tasks of caregivers. More specifically for instrumental task support among formal caregivers, mHealth allows health care professionals to monitor blood pressure, blood glucose levels in patients with diabetes, heart rates, and other vitals, such as respiratory rates, from afar to better manage disease conditions, as well as monitor symptoms and how patients perceive their quality of life^(27,28). As specialized care becomes necessary, mobile technologies allow formal caregivers to remotely interact and observe higher level issues, such as drug adherence and treatment compliance and acute or emergency care referrals.

The context for caregiving varies based on individual preferences, severity of health issues, availability of family members, and economic and social resources⁽¹⁴⁾, which makes it particularly valuable to use mobile tools that are tailored to individuals and take into account their contexts. Below are examples of existing mHealth initiatives for informal and formal caregivers. Since very few examples of mobile strategies for caregivers have been applied in the LMIC context, examples are drawn from developed countries.

mHEALTH FOR INFORMAL CAREGIVERS

Unfrazzle, United States – an iPhone application that helps users remember, keep track of, and coordinate care activities while considering a caregiver's larger spectrum of other life responsibilities⁽²⁹⁾.

QMedic, United States – a wearable, fashionable, and wireless platform that passively monitors physical activity and sleep in older adults and provides clinical support available through a call center accessible 24 hours a day, 7 days a week⁽³⁰⁾. The platform also notifies caregivers when individuals have fallen and can send real-time alerts to family members in the case of any abnormal behaviors or emergencies.

mHEALTH FOR FORMAL CAREGIVERS

Parental Health's MISTY (Medical Information Systems To You) Daily Activities Feature, United States – a remote patient monitoring product, MISTY has nine features, one of which is designed to allow home health agencies and other formal caregivers, in addition to family members, to monitor the daily

⁷ Voice over IP, or Voice over Internet Protocol, are technologies that allow for communication to happen over the Internet



activities of the elderly⁽³¹⁾. In addition to being able to share with caregivers their activities, such as their meals and moods, the elderly can access clinical assistance through a video call center.

Medication reminder and feedback system, Thailand – a platform that leverages Voice over IP⁷, text messaging, and web services. This system sends out reminders and enables feedback interactions among older adults in Thailand and their health care professionals⁽³²⁾.

Procura Clinical Solution at PatientPoint, United States – a remote monitoring platform that helps professional caregivers coordinate workflow and manage adults with complex disease conditions. With the platform, clinicians are able to update patient files and use case management and decision support tools to improve the quality of care received by older adults⁽³³⁾.

Electronic Dispenser by Helsinki City Health Care, Finland – an electronic medication monitoring system that sends a voice call reminder to customers who have not taken their medication⁽³⁴⁾. If the medication is not removed from the pill dispenser, even after the reminder, an alarm is sent to the individual, and a message is sent to a nurse's mobile phone.

Community 2.0, South Africa – an ICT project in South Africa that aims to lower barriers that exist from lack of information and poor education to identified communities that experience stress⁽³⁵⁾. The project reported success in having caregivers develop their own

mobile phone content, which was then transformed into educational and social media delivered on mobile phones.

Due to the diversity of caregivers and the range of relationships that exist between caregivers and recipients, there is no panacea approach on how to apply mHealth to caregiving. However, existing categories for caregiver interventions, described by Sorenson et al. (2002) help identify areas of caregiving that have not yet capitalized on the opportunities offered through mHealth⁽²¹⁾. These interventions can be delivered to individuals, in group settings, and sometimes mixed individual-group^(21,36). In Table 1 below, Sorenson et al.'s categories are used to frame both existing and potential mobile strategies for caregiving.

APPROACH	APPROACH DEFINITION ⁽²¹⁾	mHEALTH POTENTIAL
Psycho-educational interventions	<p>"Structured programs geared towards providing information about the care receiver's disease process and about resources and services and training caregivers to respond effectively to disease-related problems, such as memory and behavior problems in dementia patients or depression and anger in cancer patients. These are usually delivered through lectures, group discussions, and written materials by a trained leader"⁽²¹⁾.</p>	<p>Information and messages delivered to handsets on training, education, and support in self care or caregiving (e.g. on geriatrics or specific chronic diseases)⁽³⁷⁾</p> <p>mHealth strategies that educate caregivers on what actions they can participate in to reduce the consequences of late diagnosis, medication-related issues, hospital readmissions, and institutionalized care</p> <p>mHealth treatment support for caregivers that can inform and support them in making sure older adults take their medications, understand the frequency, and where they can obtain medication</p>
Supportive interventions	<p>"Often led by professionals or peers, unstructured support groups focused on building rapport among participants and creating a space in which to discuss problems, successes, and feelings related to caregiving. Support groups assist participants in recognizing that others have similar problems, while offering space to exchange ideas and generate strategies for coping"⁽²¹⁾.</p>	<p>Platforms and services that bring together caregivers to improve the efficiency of caregiving workflow across caregiver types</p> <p>Creating social awareness through mobile platforms, such as raising awareness within communities about aging, age-related conditions, and how youth can successfully age healthier in terms of physical and mental health</p> <p>Applications or services that provide psychosocial support, improve mental health, or emphasize networks⁽³⁸⁾ or advice or support hotlines that can connect caregivers with other caregivers</p>
Respite / adult day care	<p>"Provides at-home or site supervision, assists with daily living activities, or offers skilled nursing care that can add flexibility into the schedules of caregivers. Often, these interventions offer ways to engage with the care recipient from home or stimulating programs toward the client's needs"⁽²¹⁾.</p>	<p>Mobile applications and wireless options that help manage the daily activities of caregivers and check-in on older adults from a distance</p> <p>Ways to interact with older adults in their homes, as well as health providers and community-based health workers since care is often fragmented, as well as ways to connect to additional caregiving resources⁽³⁷⁾</p> <p>Improving training in medical education for formal caregivers to be able to better identify, respond, and treat clients with age-related conditions</p> <p>Monitoring individuals with chronic conditions, which can include linked systems for detecting and preventing any complications or instances that could have severe repercussions. Outside of general activities, the advent of body sensors allows vital signs, such as respiratory rates, blood pressure, sleep activity, and blood glucose levels, to be monitored.</p>

APPROACH	APPROACH DEFINITION⁽²¹⁾	mHEALTH POTENTIAL
Psychotherapy	"Supports a therapeutic relationship between caregivers and trained professionals and are often approached with cognitive-behavioral approaches to self monitoring, challenging negative thoughts, helping caregivers develop problem-solving abilities for time management, overload, and emotional reactions; and helping caregivers reengage in pleasant activities and positive experiences" ⁽²¹⁾ .	Any aggregator that delivers services to older adults at their homes (to support personal care) with a cognitive-behavioral approach mHealth networks that provide caregivers with preventive support or medical assistance as formal linkages to existing health systems or health care professionals who are able to respond to a potential increase in demand for relevant age-related services Electronic medical dispensers that monitor when individuals take or do not take their medications. If an individual hasn't taken his medication (as detected by the pill container not being opened at the correct time), programmed reminders can be sent to the individual or informal and formal caregivers to help support compliance.
Interventions to improve care receiver competence	"Memory clinics for older adults with dementia and activity therapy programs that improve affect and everyday competence" ⁽²¹⁾ .	mHealth that supports caregivers in encouraging older adults to effectively use and interact with components of existing health systems Mobile components that complement existing care services to make visits to memory clinics or activity therapy programs more seamless
Multi-component interventions	A combination of the interventions above	Any aggregator that delivers services to older adults at their homes (to support personal care) Services that support community-based health workers in offering screening or early diagnosis in the community or home Traditional telehealth and telemedicine technologies – Center for Technology and Aging describes this as technologies that were built for certain purposes with expensive and highly specific hardware

TABLE 1. The table contains caregiver interventions categories as described by Sorenson et al. (2002) that help identify areas of caregiving that have not yet capitalized on the opportunities and potential offered through mHealth⁽²¹⁾. The categories are used to frame the spectrum of existing and potential mHealth strategies for caregiving.

Turning the discussion and devoting fiscal space towards aging will require strong political will and continued efforts demonstrating the urgency of this matter to individuals, families, and societies.

CURRENT BARRIERS TO ADOPTION



THE RESEARCH FOR THIS PAPER HELPED IDENTIFY GAPS IN KNOWLEDGE AND PRACTICE, AS WELL AS BARRIERS TO ADOPTION, FOR APPLYING mHEALTH TO FACILITATE CARE-GIVING. These gaps and barriers need to be taken into consideration when developing and evolving mHealth solutions in order to reach mHealth's full potential towards assisting caregivers. The most predominant barriers identified have been listed in the table.



Low literacy and numeracy in LMICs	Need to customize mHealth content
An increasing number of older people are using mobile technologies around the world; however, in certain LMIC contexts, low rates of literacy and numeracy affect how messages should be delivered to end users. Illiteracy is also a crucial issue, as it is a known risk factor for developing dementia and hinders the use of text messaging to prevent or manage age-related conditions ^(4,39) . Video, which provides a more personal experience than text messaging or voice calls, may be a better option for improving behavior change, compliance, and satisfaction ⁽⁹⁾ .	mHealth interventions, in general, need to be customized to suit the user needs, particularly taking into account language and cultural barriers. mHealth solutions must be developed with cultural sensitivity, and in areas where many languages are spoken, mHealth efforts must be available in (or designed to enable translation into) relevant languages to ensure widespread use and adoption ⁽⁴⁰⁾ .



Invasion of privacy	Wearing identifiable technology that labels people as “old”	Need to design the technology for the end user	Lack of donor interest and fiscal space for aging populations and their caregivers
Some mHealth applications allow for wireless monitoring of older adults. Consequently, developers must create mobile solutions that give users control over their own privacy. If privacy concerns are not addressed, this can hinder the rate of technology adoption. Options should be available for caregivers and care recipients to easily control the type and amount of information that is shared with others.	Care recipients do not like carrying items that visibly display that something is wrong ⁽⁴¹⁾ . For example, carrying assistive technologies that draw attention, such as items with blinking lights or devices that make strange sounds, can make care recipients feel uncomfortable ⁽³⁴⁾ . If the technology is visible (e.g., in the case of wearable sensors), care recipients appreciate devices that give a dignified look and feel.	A study on mobile technology factors that influence the adoption and use among older adults concluded that the end user and the device must match, or as the study describes, “a user must be capable to handle the physical device as well as to understand and remember how the device and the services work” ⁽³⁴⁾ . However, the variety of caregivers and their varying needs makes designing a “one size fits all” solution complex ⁽³⁴⁾ . Feedback from QMedic suggests that users do not want to manage devices – they want to put them on and forget about them ⁽⁴¹⁾ .	In LMICs, mobile strategies are not commonly developed for aging, which can be related to the current lack of donor interest and fiscal space for addressing demographic transitions, in general. For example, in Africa, health programs in many countries focus on maternal and child health and HIV/AIDS, with much lower investment in aging populations or chronic diseases. Turning the discussion and devoting fiscal space towards aging will require strong political will and continued efforts demonstrating the urgency of this matter to individuals, families, and societies ⁽⁴²⁾ .

The use of mHealth for caregivers of older adults is at an early stage; however, the potential impact of mHealth is being considered.

REALIZING THE mHEALTH POTENTIAL FOR CAREGIVING



THE USE OF mHEALTH FOR CAREGIVERS OF OLDER ADULTS IS AT AN EARLY STAGE; HOWEVER, THE POTENTIAL IMPACT OF mHEALTH IS BEING CONSIDERED.

The following items related to knowledge and practice have been identified to strategically move the field towards realizing the full mHealth potential for caregivers:

Work to identify effective solutions for caregivers of elderly in LMICs

Issues related to caregiving for older adults in some LMICs are discussed in research, often in parallel with dialogue about how urbanization of populations reduces the number of available caregivers to care for the older adults living in rural areas. However, these findings rarely can be generalized. When developing a solution, there must be an assessment of local needs so efforts can have concrete aims and objectives. Examples of what should be assessed include specific dynamics of informal caregivers in LMICs, such as the nature and causes of declining family support for older adults⁽¹⁴⁾. Another component to consider is how to design mHealth tools so that they capture and communicate aspects of care needs so formal caregivers can more readily understand the history of aging individuals and create tailored care plans.

⁸ An electronic version of IMCI called e-IMCI was developed for health workers in Tanzania and was found to improved adherence to protocols and reduced training time⁽⁴³⁾.

⁹ Assistive technology is the “use of portable devices, such as canes or wheelchairs, and of home modifications, such as grab bars or ramps”⁽¹⁴⁾.



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Adapt already-existing caregiving tools for mobile	Draw insights from relevant caregiving strategies	Design mHealth caregiving solutions for those who need them the most, such as caregivers of the elderly with cognitive impairment	Emphasize the importance of women in their roles as caregivers
<p>Relevant caregiving issues include: preventing health problems (e.g., hygienic practices, preventing malaria, preventing infections); managing symptoms (e.g., managing weight loss, diarrhea, controlling pain); treatment and other support related to HIV/AIDS (e.g., adhering to antiretroviral treatment, grieving after the loss of a loved one, preparing for death). For these issues, materials have already been developed to support caregivers in their responsibilities; however, access can be increased if these materials can be adapted and simplified for mobile phones in a fashion similar to what has been done for the Integrated Management of Childhood Illnesses (IMCI) approach for child health.⁸</p>	<p>Though the evidence for mHealth solutions in caregiving is small^[44], it is possible that some findings from assistive technology⁹ (AT) and aging could be transferred^[14,45]. AT has been shown to accommodate some of the needs of older adults either by itself or in combination with formal and informal care.</p>	<p>mHealth solutions can be better tailored to alleviate the responsibilities of caregivers for individuals with cognitive impairment. For example, many applications have been developed for family and formal caregivers of individuals with dementia, but these applications frequently do not correspond with needs^[46]. One strategy to better design solutions for those suffering from dementia, for example, is to involve individuals with dementia in the decision making process. This strategy can also help empower and increase the autonomy of care recipients and has been shown to improve quality of life^[46].</p>	<p>Changing social dynamics such as declining fertility rates, later marriage, women entering and remaining in the work force, as well as changing family structures around the world will have consequences on caregiving options^[13,47]. In resource-limited settings around the world, women who are informal caregivers generally make tradeoffs in favor of raising their own children, which can affect how much care older adults receive^[15]. Emphasizing the importance of women in their roles as caregivers can help reduce the individual burden that is taken on by these women.</p>



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CALL TO ACTION: REALIZING THE mHEALTH POTENTIAL



THE SOONER APPROPRIATE ACTION IS TAKEN, THE SOONER THE BURDEN OF CAREGIVERS CAN BE REDUCED, WHICH CAN ENHANCE THE QUALITY OF LIVES AROUND THE WORLD. Thus, a call to action is warranted. All stakeholders involved in this call to action must share responsibility in placing more practical emphasis on prevention, early diagnosis, and treatment of age-related diseases so that the effects of these diseases can be less debilitating on older adults and their caregivers.

Partnerships between stakeholders should focus on enabling factors, such as value, usability, affordability, accessibility, and technical support⁽⁴⁸⁾. Identifying partners and collaborating with them to contextualize data that can feedback into the design of mobile solutions will be paramount in creating better solutions.

Caregivers	Developers	Health Care Professionals
Voice your needs and the community's needs in terms of caregiving.	Create mobile solutions for caregivers that can be seamlessly integrated into their daily lives with options to connect to further clinical or social support as needed. For solutions that send messages or monitoring information from care recipients to caregivers, developers must design with the needs of the caregiver in mind and make sure that solutions allow end users to receive useful signals, instead of a constant stream of information where distinguishing what is important and what is less important can become difficult or not useful.	Help support the link of mHealth strategies for caregivers to professional health advice, formal care support, and health systems.

¹⁰ Continua Health Alliance connects over 200 companies around the world to establish interoperable health solutions.

Partnerships between stakeholders should focus on enabling factors, such as value, usability, affordability, accessibility, and technical support.

Organizations	Researchers	Governments	Mobile Phone and Network Operators	Donors
<p>Think of meaningful and contextual ways caregivers can be assisted in their responsibilities.</p> <p>Assure that uniform standards for devices to help treat chronic diseases are adopted (see Continua Health Alliance⁽¹⁾).</p> <p>Implement cost-effective home- and community-based mHealth strategies of care.</p>	<p>Continue developing the evidence base around mHealth for healthy aging, starting with existing mHealth solutions. Find ways to communicate successes, shortcomings, and other lessons learned from implementation so future efforts can learn from experience and the field can evolve.</p> <p>Eventually, research will need to address the costs of implementation and whether mHealth solutions improve efficiencies and health outcomes, which will help investment and policy decisions.</p>	<p>Support aging legislation and policy as long-range planning will be critical in order to avoid or reduce what can be a heavy economic toll. Enhance financial and insurance systems to provide support for caregivers in the larger context of aging. Invest in improving quality of life and universal access to care services that address chronic diseases affecting the older segments of the population. Develop or amend existing policies to remove barriers that prevent integration of mHealth solutions into the mainstream healthcare delivery system.</p>	<p>Participate in this growing need by joining in partnerships that support the aging population. Develop handsets, products, and networks with older adults in mind.</p>	<p>Be active in developing appropriate fiscal space for policies and programs.</p> <p>Earmark funding for projects that aim to improve quality of life and access to care for older adults, the ecosystem of caregivers that participate in their lives, and individuals with chronic conditions.</p>

CONCLUSION

This paper has defined the variety of caregivers for the rapidly growing older global population and has detailed the role mobile technologies currently play and could potentially play to support the various types of these caregivers in LMICs, while also being mindful of anecdotal mHealth examples from HICs. For the informal and formal caregivers taking care of the aging population around the world, mHealth solutions can be developed to fill social, functional, and instrumental task needs⁽³⁾. However, for mobile and wireless technologies to truly make a positive impact, the solutions must meet the needs of the people who use it. Both formal and informal caregivers for older adults have many needs, and there is a place for mHealth to alleviate some of the burden of their responsibilities. A strategic effort for leveraging mHealth to reach its full potential requires action from a range of actors across many sectors. Caregivers, developers, health care professionals, organizations, researchers, governments, mobile phone and network operators, and donors are called to action, and through this action mHealth can have a large and positive impact on caregiving for the world's aging population.

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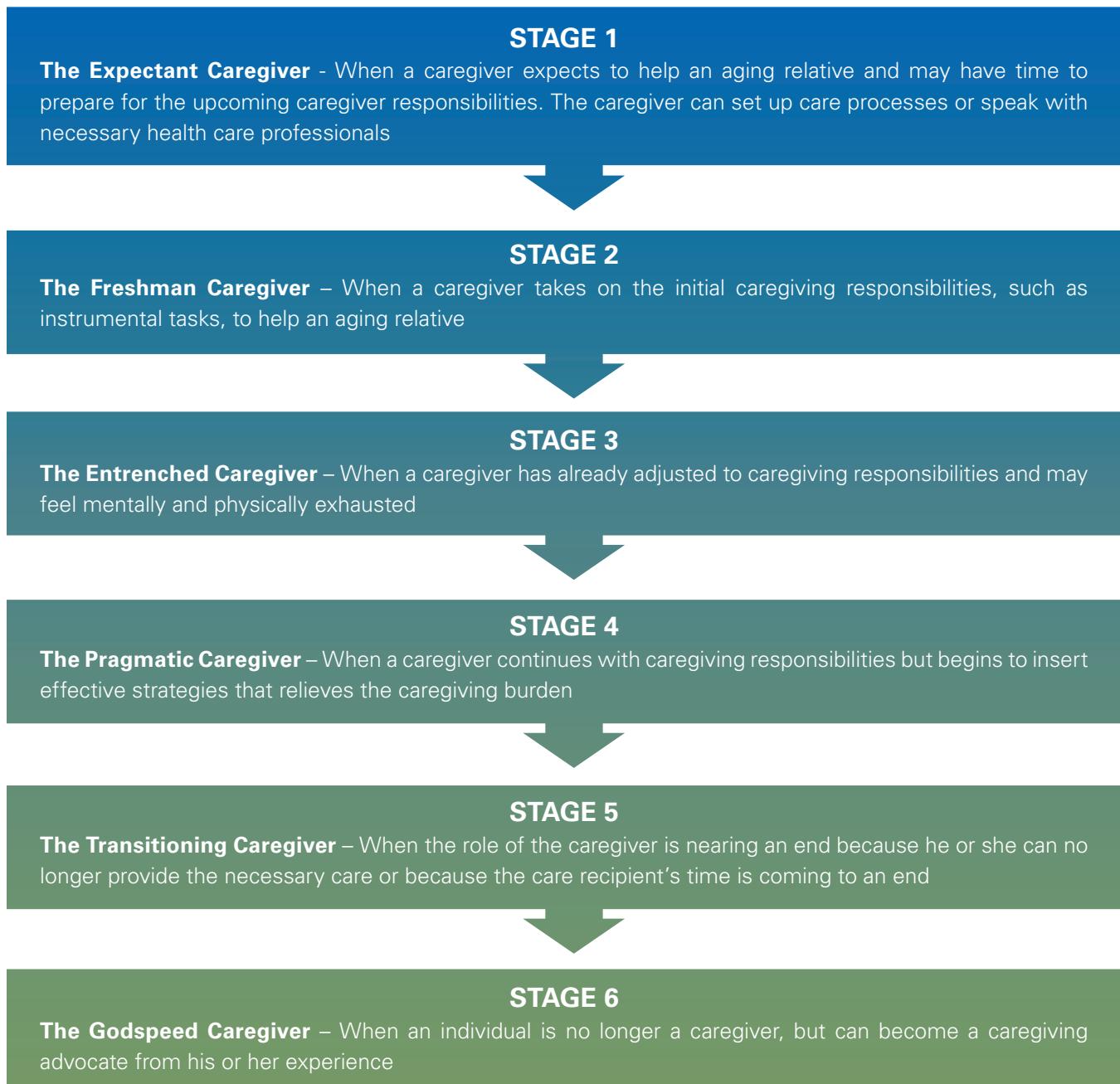
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APPENDIX A: Stages of an informal caregiver's journey^(22,49).



APPENDIX B: Caregiver tasks as detailed by Clark and Rakowski (1983)⁽²⁰⁾.

CAREGIVER TASKS

Tasks associated with the caregiver role as a provider of direct assistance

1. Be available when (or if) needed.
2. Supervise prescribed treatment and general recommendations.
3. Evaluate options for treatment and/or services.
4. Monitor course of the condition and evaluate significance of changes.
5. Evaluate strengths/resources of the care-receiver.
6. Anticipate needs for future assistance and services.
7. Provide structure for care-receiver's daily activities.
8. "Run interference" for care-receiver in social and community settings.
9. "Normalize" care-receiver's routine, within bounds of the impairment(s).
10. Supervise/directly manage care-receiver's resources.
11. Cope with upsetting behavior of the care-receiver.
12. Maintain adequate communication with the care-receiver.
13. Perform basic ADL for the care-receiver.
14. Satisfy need for creativity/originality to offset tedious routines.

Personal tasks faced by family caregivers

1. Compensate for emotional drain from constant responsibility.
2. Compensate for or recover personal time.
3. Gain knowledge about the disease/condition.
4. Avoid severe drain on physical strength/health.
5. Resolve guilt over "negative feelings" toward care-receiver.
6. Resolve disappointment or feelings of guilt over one's performance.
7. Make up for or avoid loss/restrictions on future plans and perspective.
8. Readjust personal routines.
9. Compensate for disruption of sleep.
10. Emotionally accept the likelihood of a progressive downward course.
11. Work through changes in the lifelong relationship between caregiver and care-receiver.
12. Find a locus of blame for the condition/disease.
13. Assume financial costs (actual and potential).
14. Confront the possibility of institutionalization.
15. Compensate for or avoid loss/reduction of physical and emotional intimacy.
16. Separate feelings regarding condition from feelings toward the care-receiver.
17. Resolve uncertainty about one's skills as a caregiver.
18. Release tensions/feelings toward the care-receiver.
19. Adjust to/cope with an uncertain future.

Familial and societal tasks of the caregiver role

FAMILIAL

1. Designate other "responsible caregiver(s)".
2. Maintain family communication and exchange of information.
3. Balance the giving of assistance with responsibilities to other family members.
4. Cope with the loss/restriction of family future planning.
5. Manage feelings toward other family members who do not regularly help.
6. Maintain the family as effective decision-making group over a long period of time.

7. Give appropriate consideration to care-receiver's opinions and preferences.
8. Consider as a family the need for institutionalization.

SOCIETAL

1. Interact with medical, health, and social service professionals.
2. Maintain knowledge of the service system and options.
3. Act as advocate or third-party negotiator for the care-receiver.
4. Maintain knowledge of reimbursement mechanisms.

