

Enhancing Dementia Care Through Digital Health

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ABSTRACT

Dementia is a debilitating and progressive medical condition that is increasing in prevalence due to aging populations worldwide. Although there is currently no medical cure for dementia, there is a great need to improve the care and support provided to persons with dementia (PWD) and their caregivers. PWD are among the highest utilizers of healthcare services, but much of this utilization could be avoided through improved preventive care. Digital health technologies are rapidly growing in development, but their utility in dementia care has yet to be explored in depth. In this article, we identify specific areas of dementia care and propose ways in which digital health technologies can provide needed support to PWD and their caregivers, enabling them to live independently and avoid unnecessary hospitalizations. Despite barriers to adoption, we believe the integration of digital health technologies would greatly enhance dementia care and improve the lives of PWD and their caregivers.

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Dementia is a debilitating, costly, and growing global epidemic affecting patients and their families. Although there are many resources dedicated to finding a cure for neurodegenerative diseases, efforts to improve the care given to persons with dementia (PWD) and their caregivers fall short. However, there is ample opportunity for the adoption and integration of digital health technologies to enable healthcare providers and caregivers to address remaining gaps in dementia care. Within this article, we identify opportunities for the adaptation of existing technologies to address the holistic needs of PWD.

Dementia: Pathophysiology, Epidemiology, and Current Care

Dementia is not a specific disease, but a general term to describe a severe decline in brain function that affects one's memory, behavior, language, judgment, and motor skills. This loss of function results from the damage or death of neurons in the brain.¹ There are different types of dementia, but the most common is Alzheimer disease, which accounts for 60% to 70% of all dementia cases.² At best, a few FDA-approved drugs may temporarily improve symptoms, but there are currently no pharmacologic interventions to slow or cure dementia, an ultimately fatal condition.³ As a result, much of dementia care relies on the management of symptoms associated with disease progression.

Dementia is most common in adults older than 65 years, and the prevalence of dementia increases with age.⁴ In 2015, there were 46.8 million people worldwide living with dementia, and this number is predicted to double every 20 years, with the largest growth projected to occur in countries with growing elderly populations, such as China and India.⁵

The current approach to dementia care in the United States fails to provide the support that PWD and their caregivers need. Without any effective medical cure or treatment, these frail individuals are largely neglected in our healthcare system. Consequently, as their condition worsens, poor management causes PWD to become some of the highest utilizers of healthcare services. PWD have, on average, 60% longer stays in the hospital⁶ and are about 10 times more likely to be placed in a nursing home than people without dementia.⁷ These differences in healthcare utilization are most prominent in community-residing individuals. Studies indicate that community-residing individuals with dementia are more likely to have a preventable hospitalization or emergency department visit that could have been avoided through better preventive and primary care.⁸

Not only is the progression of dementia difficult for patients themselves, but it also takes a tremendous toll on their caregivers. Approximately 92% of PWD rely on help from family members or other informal caregivers.³ In 2015, caregivers of PWD provided approximately 18.1 billion hours of unpaid support, with an economic value of about \$221.3 billion.³ Dementia caregivers provide significantly more hours of care⁹ and are more likely to experience financial, emotional, and physical difficulties than non-dementia caregivers.¹⁰ Caregiving needs intensify toward the end of the patient's life, a time of heightened stress when caregivers feel they are on duty all hours of the day. In fact, a significant number of caregivers express relief when their patient with dementia dies.¹¹

There is an acute need, which digital health technologies can potentially fulfill, to provide proactive support for PWD and their caregivers and prevent unnecessary hospitalizations. We examine specific areas of dementia management and emerging and existing technologies that have the potential to enhance dementia care. Many of the technologies we present were not necessarily designed with the patient with dementia in mind. This presents an opportunity for digital health companies to adapt their solutions to serve the needs of this patient population.

Fall Prevention and Early Detection

Falls occur in approximately 70% to 80% of elderly PWD,^{12,13} which is approximately twice the fall prevalence in those without dementia.¹⁴ Moreover, PWD are more likely to incur serious injuries from falls,¹⁴ making falls the leading cause of their hospitalizations.¹⁵ Furthermore, PWD who experience falls are 5 times more likely to be institutionalized than PWD who do not experience a fall.¹⁶ Thus, it is critical to develop interventions to prevent falls from occurring, monitor patients, and provide prompt medical response to address the situation should a fall occur.

LEGSys and BalanSens. Two of the most common causes of falls are gait and balance disturbances.¹³ Recent technological developments enable clinicians to conveniently assess gait and balance in elderly

patients and take proactive measures to prevent falls. LEGSys and BalanSens are portable gait and balance evaluation systems, respectively. Studies have shown that these wearable technologies are viable alternatives to camera-based motion analysis in determining center of mass trajectory.¹⁷ Whereas camera-based motion analysis requires a laboratory setup, LEGSys and BalanSens enable clinicians to perform comprehensive gait and balance assessments in virtually any space, including a patient's home, and automatically generate a detailed fall risk and balance assessment. With these technologies, clinicians can make prompt assessments and recommendations to keep patients safe in their home. Other portable motion analysis technologies include Physilog and MotionNode.

QMedic. When falls do occur, it is important to provide emergency services promptly. QMedic is a medical alert service worn as a simple wristband or pendant with an emergency button that alerts a 24/7 call center when pressed. A 2-way communication base station allows a nurse triage and care management team to communicate with the user and determine the appropriate course of action. QMedic also detects subtle deviations from the user's baseline sleep and activity levels, at which point the call center is notified to determine whether an intervention is needed. QMedic is waterproof and has a battery life of 2 years. The simplicity and low maintenance of the device may have contributed to the finding that QMedic users are 3 times more likely to wear the device 24/7 than users of traditional medical alert services.¹⁸ GreatCall Lively Wearable is another medical alert service that can be connected via Bluetooth to the user's smartphone.

Existing wearable technologies, like Apple's market-leading smartwatch, have many of the same and some additional technological capabilities compared with the QMedic and GreatCall Lively devices. Given its open software development platform and robust App Store, the Apple Watch presents new possibilities for software developers to create innovative solutions for PWD and their caregivers using existing, stylish, and stigma-free wearable technologies. For example, hardware such as the Apple Watch or the Samsung Gear S3 can be tailored through the use of apps to address issues such as fall prevention and wandering.

CleverCare. This device is an example of a smartwatch specifically configured to help those with dementia and other memory impairments. CleverCare uses Global Positioning System (GPS) and cellular technology to monitor the user's location. Medication and task reminders can be customized to trigger alerts at appropriate times of the day. CleverCare offers a Carer's Dashboard through which caregivers can set important reminders, track their loved one's location and movement, and define "Safety" and "Danger" zones so that they can be notified if unwanted movement occurs. Additionally, if the user presses and holds any of the buttons on the watch, the user will be connected with a 24/7 emergency response call center where

a responder will speak to the user through the watch and determine the appropriate course of action.

Wandering Prevention

Wandering is a common behavior in PWD which can threaten their health and safety. Although there is not one universal definition for wandering, it generally refers to a frequent, repetitive, and disordered locomotive behavior that manifests in lapping, random, or pacing patterns, which sometimes results in leaving home and getting lost.¹⁹ It has been estimated that about 20% of PWD wander.²⁰ However, studies suggest that this prevalence increases in people with severe dementia and in community-residing patients with dementia.²¹ Studies have shown that wandering behavior often leads to adverse health outcomes, such as injury,²² malnutrition,²³ sleep disturbance,²⁴ social isolation,²⁵ and earlier institutionalization.²⁶ By utilizing digital health technology to closely monitor PWD who are prone to wandering, caregivers may help keep their loved ones safe while also enabling their independence for as long as possible.

GPS SmartSole. This device is a sole insert for shoes that uses GPS and cellular technology to monitor users. It checks the user's location every 10 minutes and updates the location data in an app on a caregiver's smartphone. Caregivers can designate geozones, and when the GPS SmartSole enters or exits these geozones, alerts will be sent to the caregivers via e-mail or text message. GPS SmartSole also offers a "Concierge Monitoring Service," which, in the case of an emergency, can assist caregivers to locate the user and notify emergency services.

SafeWander. This bed exit alarm sensor detects changes in body position and instantly alerts caregivers when a PWD attempts to leave his or her bed. A small sensor securely and discreetly attaches to the patient's clothing, and a Wi-Fi-connected gateway plugged into an outlet near the patient's bed sends an alert to an app on the caregiver's mobile device whenever a change in body position is detected. Caregivers can view a historical log of bed exits and simultaneously monitor several SafeWander devices on 1 platform, which may be valuable for staff of care facilities.

Activities of Daily Living

As dementia progresses, PWD need increasingly more assistance with activities of daily living (ADLs), such as grooming, bathing, and feeding. PWD, on average, need caregiving assistance with 2 ADLs and 4 instrumental activities of daily living (IADLs), such as shopping, cooking, and managing medications.²⁷ Healthcare technology has the potential to improve the quality of life of PWD by providing assistance with ADLs and IADLs and closely monitoring health risk factors, thereby enabling them to live independently for as long as possible.

Smart-home devices and platforms. Although not specifically designed for dementia care, smart-home devices are powerful tools that can enable PWD to live independently in their home for as long as possible. Smart-home devices include appliances, lighting, air conditioning, and heating that can be controlled remotely using wireless technologies and programmed to follow a specific schedule. Smart-home devices are typically connected to a central hub that is controlled by a smartphone, Web-based dashboard, or mounted terminal. Some devices that may be useful for PWD are smart-home sensors that can detect whether doors, cabinets, or windows are left open. Additionally, water leak, carbon monoxide, and smoke detectors can send alerts if levels deviate from normal. Smart-home devices can enable PWD and their caregivers to monitor and manage many of the devices and appliances in their home to help maintain a safe environment and prevent accidents.

Tile. This small Bluetooth tracker attaches to and helps users locate important items, such as wallets or house keys, using a smartphone app. If the item is within Bluetooth range (50-150 feet), the Tile emits a loud tune until the item is located. If the Tile is not within range, a map in the Tile app will show where the item was last detected. Users can also use Tile's crowd-sourcing feature to help locate the item. In addition to Tile, there are other Bluetooth trackers available, including Protag Duet, Chipolo, and TrackR bravo. These Bluetooth trackers can enable PWD to locate valuable objects in their home and enhance their ability to live independently.

GoLivePhone and GoLiveAssist. GoLivePhone is a mobile app that transforms a user's smartphone into a powerful remote monitoring tool to enable independent living. It can be used for fall and wandering prevention, activity monitoring, and medication reminders. The GoLivePhone app monitors fall risk through anomaly detection and trend analysis of movement patterns. Wandering prevention is accomplished through a geo-fencing feature that notifies both the user and caregiver when the user leaves a geo-fenced area and then provides the user with directions home. The app also enables an emergency button that is always visible on the smartphone and, when pressed, can alert caregivers in the case of an emergency. GoLiveAssist is a Web-based platform that provides real-time insight into the health metrics and trends of a GoLivePhone user, which can be a valuable tool for caregivers.

Mood and Cognition

It is estimated that between 50% and 80% of PWD experience psychiatric symptoms, such as anxiety, depression, and psychosis.²⁸ Psychiatric symptoms have been shown to lead to functional impairment,²⁹ earlier institutionalization,³⁰ and accelerated progression of the dementia disease process.³¹ Major depression is particularly prevalent in PWD. Studies estimate that between 20% and 30%

of people with Alzheimer disease suffer from major depression,^{28,32} whereas it is estimated that only 5% of community-residing elderly adults without Alzheimer disease have major depression.³³ In addition to decreasing quality of life for the patient, these symptoms also increase caregiver burden and depression.³⁴ Thus, finding innovative ways to address the psychiatric symptoms of dementia can have beneficial effects on the lives of both patients and their caregivers.

PARO. This interactive robot provides the benefits of animal therapy without the maintenance required of a live animal. PARO weighs approximately 6 pounds and is shaped as a baby harp seal with white synthetic fur and large beady eyes. PARO has different sensors that detect touch, light, sound, temperature, and posture. PARO can move its head and flippers, purr when stroked, and alter its activity levels based on the time of day. PARO also has some learning capabilities, such as responding to its name. Surveys and other early studies show promise in PARO's ability to improve users' cognition and mood, particularly in elderly populations.³⁵⁻³⁷ Findings of a recent study indicated that regular interaction with PARO reduced anxiety and depression and alleviated the need for pain and psychoactive medications in elderly patients with mild to moderate dementia.³⁸ Other examples of therapy robots include Joy For All Companion Pets and Ollie the Baby Otter.

IndependaTV. PWD are at significant risk of social isolation and loneliness, which contribute to increased mortality in elderly adults.³⁹ IndependaTV is a smart TV device that allows patients to message, video chat, and virtually attend events with their friends and family through their television. IndependaTV also allows patients to immediately contact their caregiver in emergencies. Leveraging this technology delivers much-needed social connection to PWD in the comfort of their own home. The IndependaTV platform can be integrated with other wireless health devices and home monitoring sensors to create a more robust monitoring tool.

Potential Challenges

There are a number of potential barriers and challenges to the adoption of digital health technology for dementia patients, which include:

Cost of the technology. Dementia places a great financial burden on families and caregivers: 41% of dementia caregivers have a household income of \$50,000 or less, and caregivers, on average, lose over \$15,000 in annual income due to sacrifices made to meet the demands of caregiving.³ Whereas more simple devices, such as Tile, are sold for about \$25, more complex devices, such as the medical alert service QMedic, require an initial set-up fee and a monthly maintenance fee. The most expensive devices, such as PARO, can cost as much as \$6000. Many of these devices are not yet reimbursed by Medicare or commercial health insurance companies. Although it

may be difficult for individual patients and caregivers to afford these devices, there may be a financial case for health systems or payers to provide these devices to proactively care for their patients and reduce unnecessary healthcare utilization.

Device management. The management of multiple devices may be another challenge for PWD and their caregivers. Many digital health devices are point solutions and are not integrated with other complementary devices or services. As such, each device has its own dashboard or app that collects and analyzes the data from the individual device. However, if a user has 3 such devices, they would need to run 3 separate applications in order to review the data from each device. To allow for a more seamless experience and ultimately more effective condition management, developers should integrate multiple existing digital health tools, tailored for the dementia population, into one common platform. In addition to working to pursue integrated platforms for enhanced management of multiple devices, developers should also strive to create interfaces that are simple and intuitive for elderly users and their caregivers.

Acceptance and adaptation. Although there are many assistive technologies that are being developed to support daily living for elderly adults, perhaps the key determinant for success of technological implementation is acceptance of the technology itself.⁴⁰ However, health technology has not been widely adopted by older adults,⁴¹ and various studies have speculated about the factors that contribute to the adoption of technology within this population.⁴²⁻⁴⁴ Some of these factors include living environment, physical and mental health status, and opinions of family and health professionals. PWD may be particularly hesitant to adopt technology, as there is a prevalent fear of failure and making mistakes, especially misusing technology, in this population.⁴⁵ Furthermore, it is difficult for PWD and caregivers to alter their routines, which may impede the integration of technology into their daily lives.⁴⁵

However, studies suggest that the main driving force of technology adoption is its perceived need.^{46,47} That is, the technology must clearly address a specific need, and PWD and their caregivers must perceive the technology as useful to them. As caregivers assume an integral role in the care of PWD, it is necessary to understand the specific needs of the caregiver-patient dyad and develop technological tools that meet those needs most effectively, while clearly communicating the potential impact of the technology.

Healthcare delivery. Implementing these technologies in a widespread and sustainable way ideally requires a holistic redesign of how dementia care is delivered and reimbursed. The dominant model of fee-for-service healthcare, in which providers are only reimbursed for billable services and supplies, often does not allow health systems to provide nonbillable digital health technologies to their patients,

despite proven health benefits. However, value-based care models, in which reimbursement for a given population of patients is provided via lump-sum payments, allow health systems the flexibility and incentives to deploy traditionally nonbillable technologies to optimize patient outcomes. For example, CareMore Health, based in Cerritos, California, has an innovative care model that allows digital health technologies to be readily integrated into healthcare delivery. For its Medicare beneficiaries, CareMore receives a fixed, risk-adjusted payment per member from the federal government, allowing it the freedom to allocate those funds toward the effective management of their member population. This payment model promotes the development of creative solutions to improve members' health and prevent unnecessary hospitalizations. Additionally, as an integrated health plan and care delivery system, CareMore regularly interacts with its most chronically ill patients and is able to implement innovative solutions directly into the care delivery process. There is ample opportunity to integrate digital health technology into healthcare delivery, but payment models and delivery systems must be structured to support these solutions.

Conclusions and Future Directions

Although there is tremendous potential for digital health technology to augment dementia care, the adoption and integration of this technology does not come without challenges, especially for PWD. Ultimately, each individual with dementia needs to be assessed for his or her particular needs, and the appropriate technology must be introduced within that individual's financial and adaptive capabilities.

In this article, we have identified opportunities to integrate digital health technology into current dementia care and adapt existing technologies to serve this population. We challenge the digital health industry to recognize the various needs of PWD and their caregivers and to create solutions that ultimately enable safe, independent living and prevent unnecessary hospitalizations. In the absence of a pharmaceutical cure for dementia, we must strive to develop innovative solutions to improve the quality of life for individuals and families affected by dementia.

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