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Viewpoint

Decrease in Stroke Diagnoses During the COVID-19 Pandemic: Where Did All Our Stroke Patients Go?

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Abstract

Despite the evidence suggesting a high rate of cerebrovascular complications in patients with SARS-CoV-2, reports have indicated decreasing rates of new ischemic stroke diagnoses during the COVID-19 pandemic. The observed decrease in emergency department (ED) visits is unsurprising during this major crisis, as patients are likely to prioritize avoiding exposure to SARS-CoV-2 over addressing what they may perceive as mild symptoms of headache, lethargy, difficulty speaking, and numbness. In the central and south Texas regions where we practice, we suspect that patient admission, treatment, and discharge volumes for acute stroke treatment have decreased significantly since COVID-19–related shelter-at-home orders were issued. Symptoms of stroke are frequently noticed by a family member, friend, or community member before they are recognized by the patients themselves, and these symptoms may be going unnoticed due to limited face-to-face encounters. This possibility emphasizes the importance of patient education regarding stroke warning signs and symptoms during the current period of isolation and social-distancing. The south Texas population, already saddled with above-average rates of cardiovascular and cerebrovascular disease, has a higher stroke mortality rate compared to Texas and U.S. averages; however, the number of patients presenting to EDs with acute ischemic stroke diagnoses is lower than average. In our viewpoint, we aim to present the relative literature to date and outline our ongoing analyses of the highly affected and diverse stroke populations in San Antonio and Austin, Texas, to answer a simple question: where did all our stroke patients go?

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KEYWORDS

stroke; ischemic stroke; COVID-19; SARS-CoV-2; emergency medicine; cerebrovascular

Introduction

In the midst of a pandemic, the advice from medical professionals to “stay home, save lives” may be preventing patients from seeking medical care when symptoms of stroke arise due to fear of contracting COVID-19. Anecdotal reports across the United States are highlighting missed care during the current COVID-19 pandemic [1-3]; the World Health Organization has acknowledged a marked decrease in stroke presentations and a widespread impact of the pandemic on stroke care [4]. Local and state shelter-at-home orders have imposed strict limitations on clinic and hospital access, restrictions on nonessential travel, social distancing policies, and mandated isolation of populations that are especially vulnerable to COVID-19 infection, such as older and immunocompromised people. In our persistent efforts to educate communities about

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COVID-19 infection risk, we may be undermining potentially lifesaving public health education campaigns for emergent medical conditions such as heart attack or stroke. The aim of this viewpoint is to present the relative literature to date and outline ongoing analyses of the highly affected and diverse stroke populations in San Antonio and Austin, Texas.

In the central and south Texas regions where we practice, we suspect that patient admission, treatment, and discharge volumes for acute stroke treatment have decreased significantly since COVID-19–related shelter-at-home orders were issued. This decrease appears to mirror sharp downward trends in emergency department (ED) visits since Texas municipalities began enforcing local guidelines for social distancing. This is especially concerning for the San Antonio metropolitan statistical area. Our population is already saddled with above-average rates of cardiovascular and cerebrovascular disease and has a higher stroke mortality rate compared to the Texas and US averages [5-7]. Hesitation to leave shelter-in-place due to COVID-19 and present to the ED could result in worse outcomes, particularly for ischemic stroke [8,9]. To put it simply: where did all our stroke patients go?

Answering this question presents a unique opportunity to maximize the information-laden infrastructure already in place for tracking acute stroke care: "Get With The Guidelines" (GWTG) stroke registry of the American Heart Association/American Stroke Association (AHA/ASA). Required for Joint Commission and Det Norske Veritas Germanischer Lloyd (DNV-GL) stroke center certification, GWTG registries provide a mechanism for hospitals to track the efficiency and effectiveness of their acute stroke care for continuous program evaluation and quality improvement. It should be noted that in April 2020, a COVID-19 item for tracking testing and outcomes was added to the registry case report form.

Increasing Stress on the Hospital System

Without the typical rigorous process of development, refinement, and peer review of national recommendations, on March 20, 2020, the AHA/ASA released a broad but flexible policy statement that reflects both the commonality of the pandemic across the United States and the individual variability at local sites [10]. The report was issued as a temporary statement and interim stopgap opinion pending a more thorough and contemplative process. Obstacles to acute stroke care were cited, including shortages in personal protective equipment (PPE), hospital personnel, and hospital beds.

Initial reports from other countries have already highlighted the stress of COVID-19 on their intensive care units (ICUs) and resources [11-13]. A recent case series of critically ill patients with COVID-19 in Seattle, Washington, reported a median ICU stay of 14 days and a median duration of mechanical ventilation of 10 days [14]. With EDs and ICU triaging and caring for increasing numbers of patients with COVID-19, the COVID-19 pandemic will have a tremendous impact on available resources for the triage and treatment of acute ischemic stroke.

Many patients with stroke often fail to recognize mild symptoms such as visual field disturbance, facial droop, or neglected extremities. Symptoms of stroke are frequently noticed by a family member, friend, or community member before they are recognized by the patients themselves, which emphasizes the importance of patient education regarding warning signs and symptoms of stroke during the current exigent period of isolation and social distancing.

Suggested Guidelines for Stroke Care

Current practice for the management of acute ischemic stroke will require modification, and although it has been recommended that guidelines should be relaxed while maintaining a high standard quality of care [15], most published guidelines or recommendations (Table S1, Multimedia Appendix 1) state that established guidelines should be followed [10,12,14,16-22]. Others have published suggestions for acute ischemic stroke care with modifications to standard treatment guidelines [23-25]. There is an overall collective aim to avoid contributing to the rapid spread of COVID-19 while conserving what are likely to be very limited resources (including personnel, ICU and hospital beds, and physicians) while providing acute ischemic stroke care [15,23]. The concept of a "protected code stroke" during a pandemic, as in the case of COVID-19, was introduced for Canadian practice by Khosravani et al [20]; this concept provides a framework for key considerations, including screening, PPE, and crisis resource management.

Recommendations covering the areas of education, screening, imaging, treatment, transfer, discharge, and follow-up procedures have been published. A number of publications have highlighted the importance of improving educational outreach for health professionals and the public, particularly those at high risk of stroke, to recognize stroke and call emergency medical services (EMS), thus avoiding significant delays and worse outcomes [12,13,19,26,27]. To minimize risk of infection, many guidelines suggest screening for COVID-19 symptoms and exposure as soon as possible, including remotely or by EMS, and communicating the results to the stroke team [14,16,18,20,22,25].

Recommended strategies regarding imaging include establishing a COVID-specific scanner [16,17] and performing magnetic resonance imaging (MRI) first so that patients do not require multiple scanning sessions [25]. Identification of transient ischemic attacks (TIAs) and mild strokes without deficits and no indication for emergent treatment could be addressed with remote management [14,25,26]. While most published recommendations indicate that established guidelines should be followed regarding treatment, French interventionalists suggest withholding treatment from patients in the ICU who test positive for COVID-19 [22] and others suggest remote review of treatment eligibility, including functional exams [10,25]. In specific reference to endovascular therapy (EVT) procedures, some guidelines recommend early intubation of patients prior to initiation [20,21,28] or require confirmed COVID-19–negative status prior to the procedure [24]. Rapid discharge of patients who can be managed at home [12,14,17,25] and remote follow-up consultations [12,14,17,19,20,22,27] are

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also mentioned as strategies. Finally, early recognition of the need for transport to a designated stroke center can reduce interfacility transfers, effectuating a reduction in potential infectious exposure [26].

Decrease in Ischemic Stroke Patients

As people continue to adjust to social distancing, a shift in the epidemiology of stroke and other medical conditions will most likely be observed, as is being seen in myocardial infarction [29] and in other countries [30-37] in the context of acute ischemic stroke. Although there is evidence to suggest a high rate of cerebrovascular complications in patients with SARS-CoV-2 infection [38-43], anecdotal reports indicate a falling rate of new ischemic stroke admissions [30-32,34,37,44-48], stroke code activations [30,36,49-53], imaging numbers [44,45], and diagnoses [45].

This decrease in patient load is hypothesized by some to be driven by fewer patients presenting to the ED [54,55]. Studies have also noted a decrease in admissions of TIAs [31] and a decrease in patients presenting with mild symptoms, as demonstrated by higher National Institutes of Health Stroke Scale (NIHSS) scores [32,34,50] and decreased proportion of large vessel occlusions (LVOs) [45]. These data may indicate that a smaller proportion of patients are seeking services for mild symptoms [45].

Additionally, decreases in acute ischemic stroke treatment numbers have been noted for both thrombolysis [46,53,56,57] and EVT [30,33,47,53,56], with an excellent meta-analysis presented by July et al [53], including data from nine studies [30,56,58-64]. Details of each of these studies, as well as other related studies [65,66], can be found in Table S2 (Multimedia Appendix 1). Interestingly, despite noted decreases in EVT numbers overall, some studies have shown that the proportion of patients receiving EVT increased [48,53], possibly due to an increase in the number of late presenters [34,58] or an increase in the number of patients eligible for EVT. Upon examination, the majority of studies reported no change in process times, such as time last known well (TLKW) to arrival [45,47,49,51], TLKW to imaging [45], TLKW to thrombolysis [45,48,49,51], and length of hospital stay [47]. However, other studies reported an increase in the process time from TLKW to EVT procedure [33] or no change in the length of hospital stay [47].

Of particular interest for our planned analyses is the report by Kansagra et al [44] quantifying the stroke imaging load for each state via the RAPID software database (iSchemaView Inc). Texas-specific data show that prepandemic (February 1 through February 29, 2020), Texas had a mean of 63.3 patients per day (95% CI 60.2-66.5), and in the early pandemic (March 26 through April 8, 2020), the mean was 43.1 patients per day (95% CI 40.1-46.2), representing a change of –31.8% (95% CI –25.8% to –37.6%). There were no significant differences with respect to age, sex, race, vascular risk factors, or severity. Upon examining stroke type, the proportion of new LVOs nearly doubled in the COVID-19 period (n=20, 38%, vs n=59, 21%, P=.01) relative to the pre-pandemic timeframe. Despite differences in proportions, the mean number of LVO patients in the COVID-19 period (0.43 per day) did not differ significantly (P=.61) from that pre–COVID-19 (0.39 per day). Finally, evaluation of time revealed that patients treated during the COVID-19 period had no significant delay from TLKW to arrival or from arrival to imaging or treatment [45]. These results further support that the driving factor for the decrease in stroke volume is that patients experiencing mild strokes are not seeking acute care.

Accurately identifying the root cause of the decrease in stroke volume is challenging due to a combination of socioeconomic and pathophysiologic factors. Widely observed decreases in acute ischemic stroke presentation are potentially influenced by the risk profile of the population: during the COVID-19 era, patients with risk factors such as hypertension, hyperlipidemia, coronary artery disease, lack of insurance, or urban location increased their proportion of the stroke cohort [52]. Population health strategies to reduce COVID-19 may also lower infection rates with vasculotropic viruses and allergens that can trigger atherosclerosis and plaque rupture, which may result in neurovascular and cardiovascular morbidity [67,68].

Disparities

There is increasing evidence that some racial and ethnic minority groups are being disproportionately affected by COVID-19 [69-73]. Hypothesized mechanisms include an elevated severity of response to SARS-CoV-2 and increased socioeconomic risk [74]. Persons who are African American, Black, or Latino are contracting SARS-CoV-2 at higher rates and experiencing higher mortality [75-78], and comorbidities may explain these differences [74]. Due to this increased risk, Black and Hispanic or Latino patients, particularly those without health insurance [52], may avoid medical care. Observations from a telestroke registry in North Carolina reported that a lower percentage of Black patients presented during the pandemic (13.9% versus 29% before the pandemic, P<.001).

Racial and ethnic minority groups who are more likely to rely on the ED for primary care may avoid seeking primary care because of concerns about the infection risk in the ED. The avoidance of primary care for chronic disease management can subsequently manifest in an increase in emergent hospitalization for stroke. A statistically significant increase in the proportion of Black and Hispanic patients presenting with strokes was noted in California, Pacific hospitals, Western hospitals, and all hospitals in the United States during various months studied, comparing 2020 to 2019 [79]. It is not clear what proportion of patients with severe strokes are foregoing medical care or are otherwise underdiagnosed.

Further work is needed to explore the complex interplay of socioeconomic factors and pathophysiologic mechanisms and the impact this interplay has on acute stroke presentation in minority populations. Until this work is performed, it may be difficult to effectively target population health resources and address the disparity.

Planned Analyses

Unfortunately, when patients misinterpret stroke symptoms or assume that the symptoms will resolve without intervention,

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they are delaying clinical care. Without emergency medical attention, strokes can cause devastating and irreversible damage, with the extent being largely dependent on the timing of the intervention. Furthermore, infection prevention protocols may complicate discussions between the patient and emergency responders as well as subsequent management and treatment. Hospital and EMS procedures are consistently adapting to the situation as reports from around the world detail experiences and provide data on which to base acute stroke care decisions during this pandemic.

It is necessary to comprehensively evaluate the impact of current stay-at-home orders and patient fears on incidence and severity of ischemic stroke. Metrics can be extracted from the GWTG stroke registry data along with related neuroimaging exams from hospitals in Texas metropolitan areas (San Antonio and Austin). Unlike San Antonio, Austin and its surrounding counties have lower cardiovascular and cerebrovascular disease rates and stroke mortality rates compared to Texas and US averages due to a combination of socioeconomic status, public health, infrastructure, and demographic differences. Thus, Austin will serve as a de facto control group. For this study, which has been approved by the University of Texas Health Science Center and The University of Texas at Austin Institutional Review Boards, data from San Antonio and Austin will be divided into three cohorts:

1. Prior to the COVID-19 pandemic: Records of stroke patients with admission dates 15 months prior and up to March 31, 2020, when the governor of Texas issued Executive Order No. GA-14, which effectively limited out-of-household social gatherings and in-person contact to only those necessary for providing or obtaining essential services.
2. Stay-at-home order in effect: Records of stroke patients with admission dates from April 1 to April 30, 2020, while the above executive order was in effect.
3. Stay-at-home order rescinded: Records of stroke patients with admission dates up to 15 months after May 1, 2020, when the above executive order was discontinued.

A fourth cohort of stroke patients will be created if stay-at-home orders are reinstated during the 15-month period after May 1, 2020. We will test the hypothesis that the overall stroke presentation rate (including positive and negative cases), absolute numbers of stroke diagnoses, and stroke interventions decline during COVID-19 stay-at-home orders are in effect compared to control time epochs. We plan to analyze admission, treatment, and discharge variables within and between time cohorts and metropolitan areas, and when available, we will analyze data on COVID-19 testing and outcomes that occurred during stroke treatment. San Antonio and Austin-area GWTG data to be extracted for the study data set will include patient demographics (age, gender, race/ethnicity)

- Arrival and admission data (locations where stroke symptoms were discovered, mode of arrival to ED, vital signs, laboratory test results, height/weight/BMI, inpatient unit assigned for stroke care)
- Medical history (pertinent medical history and medications)
- Diagnosis and evaluation (initial NIHSS score and exam findings)
- Symptom timeline (date/time of last known well, date/time of symptom discovery)
- Brain imaging (imaging modality, initiation date/time, interpretation of findings)
- Acute therapeutic interventions (intravenous thrombolytic therapy, EVT, related complications)
- Other in-hospital treatment and screening (interventions for venous thromboembolism, anticoagulation, bacterial/viral infection)
- Discharge status (modified Rankin Scale score at discharge, ambulatory status)
- Discharge treatment (antithrombotic therapy, antihypertensive therapy, statin therapy, antihyperglycemic therapy, patient education, follow-up diagnostic tests and procedures)

We anticipate a sample of n=1000 GWTG records from 11 hospitals (of which 4 are comprehensive stroke centers) in the San Antonio and Austin metropolitan statistical areas for the study data set. Kruskal-Wallis and Levene tests will be used to assess differences in categorical and continuous GWTG variables between and within time periods and metropolitan area cohorts, and segmented regression will be used to assess whether stroke presentation, interventions, and outcomes are more or less severe over the pre-, during, and post–COVID-19 stay-at-home order time periods.

Conclusions

Fear and heightened caution are not the only factors that contribute to reduced ED visits during burdensome times. Looking retrospectively at ED trends during natural disasters offers another perspective on decreasing ED visits. A study that analyzed the effects of Hurricane Sandy, a hurricane that struck the east coast of the United States in 2012, on cardiovascular events found that in the days following the disaster, there were increases in incidence and mortality of myocardial infarction and in stroke incidence [80]. The authors referenced a multitude of studies documenting increased incidence of cerebrovascular events during natural disasters or severe weather events. Although the underlying etiologies of that increase have not been proven, possibilities include emotional stress related to increased platelet activation [81] and delayed treatment due to disrupted transportation networks, health care capacity, and supply chains. In terms of cerebrovascular events, the COVID-19 crisis may represent the worst-case scenario: fear of nosocomial infection causing health care avoidance when, for physiological and/or psychological reasons, the population is most vulnerable.

An observed decrease in ED visits should come as no shock during times of major crises, as patients prioritize safety from the “current danger” over what they may perceive as mild symptoms of chest pain, abdominal pain, weakness, etc., that they hope will “resolve on their own.” This trend of decreased ED use was previously observed during the 2003 severe acute respiratory disorder (SARS) outbreak, in which ED visits at the height of the epidemic in Taipei showed a 51.6% decline, with a mean of 115.4 visits (SD 16.7) compared to the previous year (mean 238.3 visits, SD 33.4, 95% CI of the mean difference

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109.4-136.3; $P<.01$) [82]. Further analysis showed persistence of this pattern for the 2015 Middle East respiratory syndrome (MERS) outbreak in South Korea as well. The age-standardized prevalence ratio for ED visits per 100,000 people in June 2015 decreased to 0.72, with June 2014 and 2016 as references. The mean age-standardized prevalence for June 2015 was 708.48 (95% CI 706.15-710.82), and the mean number of ED visits for ischemic stroke in 2015 (5406) decreased by 33.1% in comparison to that of the year before the outbreak (6185 in June 2014) and the year after the outbreak (6776 in June 2016) [83]. Subgroup analyses in that study identified a concerning phenomenon: the volumes of high-acuity diseases such as myocardial infarction and ischemic stroke demonstrated a significant decrease in ED visits (14.0% and 16.6% decreases, respectively). These historical trends, including those observed for the current COVID-19 pandemic, raise the hypothesis that fear of nosocomial infection transmission can have deleterious population health consequences.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Suggested guidelines and protocols for management of acute stroke and key studies evaluating acute stroke trends during the COVID-19 pandemic.
[DOCX File , 47 KB - aging_v3i2e21608_app1.docx]

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Abbreviations

AHA/ASA: American Heart Association/American Stroke Association
DNV-GL: Det Norske Veritas Germanischer Lloyd
ED: emergency department
EMS: emergency medical services
EVT: endovascular therapy
GWTG: Get With The Guidelines
ICU: intensive care unit
LVO: large vessel occlusion
MERS: Middle East respiratory syndrome
NIHSS: National Institutes of Health Stroke Scale
SARS: severe acute respiratory syndrome
TIA: transient ischemic attack
TLKW: time last known well

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Original Paper

Disparities in Video and Telephone Visits Among Older Adults During the COVID-19 Pandemic: Cross-Sectional Analysis

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Abstract

Background: Telephone and video telemedicine appointments have been a crucial service delivery method during the COVID-19 pandemic for maintaining access to health care without increasing the risk of exposure. Although studies conducted prior to the pandemic have suggested that telemedicine is an acceptable format for older adults, there is a paucity of data on the practical implementation of telemedicine visits. Due to prior lack of reimbursement for telemedicine visits involving nonrural patients, no studies have compared telephone visits to video visits in geriatric primary care.

Objective: This study aimed to determine (1) whether video visits had longer durations, more visit diagnoses, and more advance care planning discussions than telephone visits during the rapid implementation of telemedicine in the COVID-19 pandemic, and (2) whether disparities in visit type existed based on patient characteristics.

Methods: We conducted a retrospective, cross-sectional analysis of patients seen at two geriatric clinics from April 23 to May 22, 2020. Approximately 25% of patients who had telephone and video appointments during this time underwent chart review. We analyzed patient characteristics, visit characteristics, duration of visits, number of visit diagnoses, and the presence of advance care planning discussion in clinical documentation.

Results: Of the 190 appointments reviewed, 47.4% (n=90) were video visits. Compared to telephone appointments, videoconferencing was, on average, 7 minutes longer (mean 37.3 minutes, SD 10 minutes; $P<.001$) and had, on average, 1.2 more visit diagnoses (mean 5.7, SD 3; $P=.001$). Video and telephone visits had similar rates of advance care planning. Furthermore, hearing, vision, and cognitive impairment did not result in different rates of video or telephone appointments. Non-White patients, patients who needed interpreter services, and patients who received Medicaid were less likely to have video visits than White patients, patients who did not need an interpreter, and patients who did not receive Medicaid, respectively ($P=.003$, $P=.01$, $P<.001$, respectively).

Conclusions: Although clinicians spent more time on video visits than telephone visits, more than half of this study's older patients did not use video visits, especially if they were from racial or ethnic minority backgrounds or Medicaid beneficiaries. This potential health care disparity merits greater attention.

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KEYWORDS

telemedicine; telehealth; telephone; videoconferencing; health care disparities; older adults; geriatrics; advance care planning; advanced directives; COVID-19; coronavirus pandemic; SARS-CoV-2; primary care

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Introduction

The COVID-19 pandemic presents multiple challenges for older adults with regard to medical care access. This population is at the highest risk for morbidity and mortality from coronavirus infection [1]. Furthermore, physical distancing efforts to reduce this risk have disrupted medical care for more than half of all adults over 70 years of age [2]. These interruptions are particularly problematic, given the high prevalence of multimorbidity and frailty in this population [3]. More than 1 in 7 older adults have experienced a disruption in what they considered essential medical services due to the pandemic [2].

One approach to maintaining access to care while reducing the risk of community spread is telemedicine appointments [4]. Telemedicine, which is sometimes used interchangeably with telehealth, refers to using electronic information and communication technologies to provide health care when distance is a barrier [5]. These telecommunication systems can range from messages through electronic patient portals to live, synchronous interactions through audio and video communication [6]. Although telemedicine services have been used prior to the COVID-19 pandemic, they were not reimbursed at the same rate as in-person visits [7]. In response to the rapid expansion and use of telemedicine services during the rise of the pandemic, the Centers for Medicare and Medicaid Services expanded the scope and rate of telemedicine reimbursement, including equivalent reimbursement for telephone and video visits to match payments for similar outpatient visits [6].

Systematic reviews of telemedicine use in older adult populations suggest that older adults generally accept, and are satisfied with, the use of telemedicine [8-10]. However, most telemedicine studies with this population have had a small number of participants, have been performed within the Department of Veterans Affairs, or have focused on specific problems (ie, dementia) rather than the management of multimorbid patients [9-15]. The types of telemedicine services (ie, video visits and phone visits) that can meet the needs of geriatric patients in clinical practice has not been evaluated [16].

The ability of older patients, family care partners, and health care providers to discuss common medical issues, such as management of multiple chronic conditions and advance care planning via either type of telemedicine visit, is unknown. Addressing disease-related vulnerabilities and advance care planning is particularly important in the setting of the COVID-19 pandemic, as the risk of critical illness has become more imminent [17]. However, advance care planning and other conversations about serious illness can be difficult for patients and their families, as they often require significant time and attention to emotional cues and may be limited by telemedicine visits.

Although video-based visits, compared to telephone visits, may improve communication through the addition of facial cues, they may be especially difficult for older adults because they require specific equipment, internet access, and technology navigation [10]. The increased prevalence of impaired cognition, hearing, vision, and dexterity in this population also poses particular problems [10,16]. However, the expanded reimbursement policy for telemedicine significantly favors video visits (ie, two-way, synchronous communication with audio and video) over audio-only communication (ie, telephone visits) [6].

The principal aim of this study was to describe the rapid transition to telemedicine (ie, telephone and video visits) to meet the needs of geriatric primary care patients during the COVID-19 pandemic. We hypothesized that video visits might have more capacity to address multimorbid disease (as indicated by visit duration and number of visit diagnoses) and advance care planning discussions. We also explored whether there were health disparities between video visits and telephone visits based on patient sociodemographic factors.

Methods

Design and Setting

In this retrospective, cross-sectional study, we performed an electronic health record (EHR) review of charts used in video and telephone appointments at 2 primary care clinics in Colorado for patients aged 75 years or older (ie, enrollment age for the clinics). Neither clinic offered telemedicine appointments prior to the COVID-19 pandemic. One clinic is located directly at a large academic medical center with 13 geriatric medicine clinicians, 4 geriatric fellows, and 1 psychologist working a total of 6 full-time equivalents. The other clinic is located at a free-standing outpatient center with 3 geriatric medicine clinicians and 1 psychologist working a total of 1 full-time equivalent. Both clinics use the same EHRs and have the same capacity for telemedicine visits. Patients who requested a routine or acute care visit were offered a choice between video and telephone-based visits. This evaluation was conducted as part of the Comprehensive Primary Care Plus' quality improvement activities, and institutional review board approval was not required.

Participants

In total, approximately 25% of the patients who had telephone and video appointments with the clinics from April 23 to May 22, 2020 were included in this study. Participant selection was performed by first identifying all patient encounters and then using a computerized randomization process to select patients who would go through manual chart review by 4 authors. In Colorado, in-person clinic visits stopped on March 16, 2020, due to the community spread of COVID-19. The starting date for chart review was 6 weeks after both clinics converted to conducting telemedicine visits. This start date allowed for data collection from appointments that occurred after addressing the initial challenges of rapidly implementing video and telephone visits. In order to ensure that the analysis only included unique patients, only 1 visit encounter was allowed per patient. Although the number of patients who visited multiple times during the study period is unknown, none of the randomly selected visits for chart review were from repeat visits.

Data Collection

We extracted patient and visit characteristics from EHRs using a standardized data collection tool. Study data were managed using the REDCap (Research Electronic Data Capture;

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Vanderbilt University) electronic data capture tools at the University of Colorado [18]. Patient characteristics included age, gender, race, ethnicity, insurance status, need for an interpreter, patient portal account status (ie, active or inactive), and specific impairments that might affect telemedicine (ie, cognitive, auditory, and visual impairment), which were determined based on the presence or absence of the impairment in our ICD-10 (International Statistical Classification of Diseases, 10th Revision)–based problem list. Cognitive impairment was determined by diagnoses that involved dementia, memory loss, or cognitive impairment. Auditory impairment was determined by diagnoses that involved hearing aids or hearing impairment. Visual impairment was determined by the diagnoses listed in the "Eye" section of patients' active problem list, and included a wide range of diagnoses common among older adults.

Visit characteristics, which were obtained from the prompts in the note template of EHRs, included type of visit (ie, telephone or video), provider type (ie, behavioral health or geriatric medicine), type of video system used (eg, health system's patient portal video function or other video systems, such as the Doximity Video [Doximity Inc]), and reasons for why a video system was not used for the visit, if applicable. An acute visit was determined by the presence of specific symptoms in the "reason for visit" section, which was documented by medical assistants during phone calls with patients conducted prior to appointments. Clinician notes were reviewed for documentation on vital signs, which were measured at patients' homes, and the presence of a care partner during the visit. For video visits, documentation from the physical exam was reviewed to determine whether there were findings that relied on visual observation and could not have been assessed with audio-only communication. These visual observation-dependent findings could either be visual observations that were noted outside of the constitutional section or descriptions of patients' home environment. The number of medication changes was determined from documentation automatically created by the EHR based on clinicians' orders during the encounter, which includes medications that are started, changed, or stopped. Data on whether patients viewed the after-visit summary through the patient portal were recorded automatically by the EHR in the encounter documentation.

The outcomes (ie, visit duration, number of visit diagnoses, and presence of advance care planning discussions) were obtained from clinical documentation. Visit duration was based on clinician documentation and was in line with reimbursement requirements at the time of this study. Specifically, the time documented reflected the time spent with the patient and associated counseling or coordination of care. This study was completed prior to the new documentation guidance, which stated that telehealth visits could include reimbursement for the provider's total time spent, including preparation, visit, and postvisit times on the same day. The number of visit diagnoses was based on clinicians' ICD-10 diagnoses during the encounter. The visit note template used by both clinics prompted clinicians to discuss advance care planning (eg, discussions on choice of medical power of attorney and code status preferences). These types of advance care planning discussions reflected documentation that was present in the specific visit, but did not reflect whether a patient had prior advance care planning discussions or documentation in the EHR or at home.

Statistical Analysis

We compared descriptive statistics for patient and visit characteristics between telephone visits and video visits, using *t* tests for continuous variables and Chi-square tests for categorical variables. Continuous and categorical variables were expressed as means with standard deviations and percentages, respectively. Multivariable linear and logistic regression models were used to evaluate the relationship between visit type (ie, the independent variable) and the following 4 dependent variables: visit duration, number of diagnoses, discussion of medical durable power of attorney, and code status discussion. These models were adjusted for the following covariates: age, need for an interpreter, Medicaid beneficiary status, and presence of a care partner. All tests for statistical significance were two-tailed, and a P value of <.05 was considered statistically significant. All statistical analyses were done using SAS version 9.4 (SAS Institute).

Results

In a 6-week period during the COVID-19 pandemic, during which almost no in-person clinic visits were possible, the clinics had a combined total of 424 scheduled telephone visits and 384 scheduled video visits (Figure 1). After March 18, 2020, the daily no-show rate ranged from 0% to 14%, which was similar to the pre-COVID-19 no-show rate. This overall volume of visits represents 85% of visits prior to the COVID-19 pandemic. Of the 25% of visits randomly selected for inclusion in this study, 9 appointments were excluded from chart review because 7 patients did not arrive for their appointments and 2 appointments were only brief follow-up phone calls for recent appointments, not full appointments. In total, 190 appointments underwent chart review, including 100 telephone visits and 90 video visits.

Of the 190 appointments (Table 1), 70% (n=133) of patients were female, 15.8% (n=30) were Black, 13.2% (n=25) needed interpreters, and 18.9% (n=36) had Medicaid coverage. The average age was 82.5 years (SD 6.2 years). There was a high prevalence of hearing, vision, and cognitive impairment. Caregivers were present for 25.3% (n=48) of appointments. The number of caregivers present prior to the COVID-19 pandemic is unknown. Most patients (137/190, 72.1%) had active electronic patient portals, regardless of whether they had a telephone or video visit. Patients who had video visits were younger (mean 81.3 years, SD 6.4 years vs mean 83.5 years SD 5.9 years; P=.01), more likely to have an active patient portal account (n=81, 59.1% vs n=56, 40.9%; P<.001), and more likely to have a caregiver present during the visit (n=31, 64.6% vs n=17, 35.4%; P=.01) compared to patients who had telephone visits. Non-White patients, patients who needed an interpreter, and Medicaid beneficiaries, were less likely to have video visits than White patients, patients who did not need an interpreter, and non-Medicaid beneficiaries (P=.003, P=.01, P<.001, respectively). There were no differences in the likelihood of video visits based on cognitive, auditory, or visual impairments.

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Figure 1. Stacked histogram showing the percentage of visit types over time from March through May 2020. There were no video or telephone visits prior to March 17, 2020 when the clinic initially began to implement telemedicine appointments in response to the COVID-19 pandemic. For the first several weeks after implementing telemedicine appointments, the majority of visits were done by telephone. Video visits rose in prevalence throughout April.

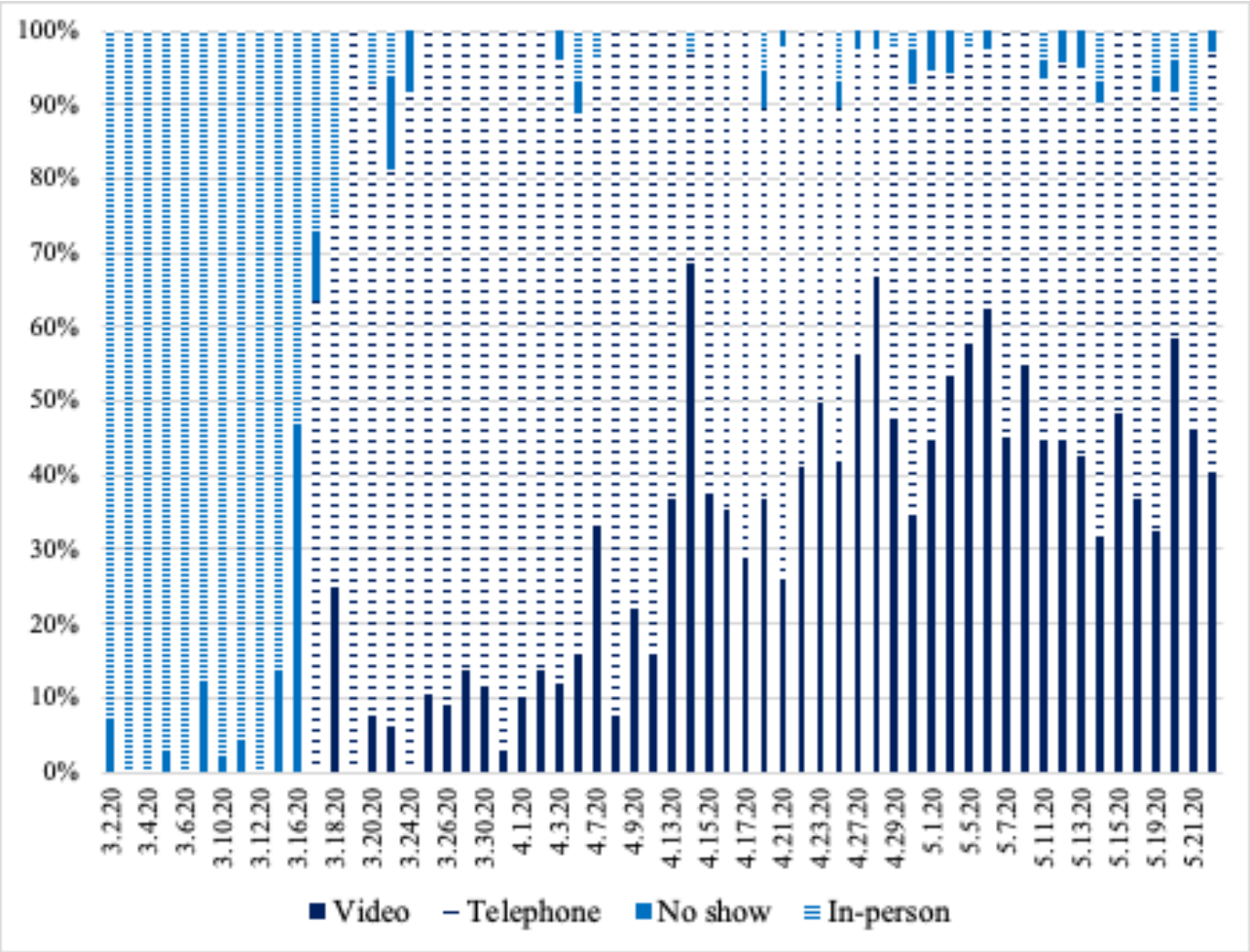

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Table 1. Patient and visit characteristics of appointments reviewed listed by visit type (N=190).

Patient and visit characteristics	All visits	Telephone visit[a] (n=100)	Video visit[a] (n=90)	*P* value
Age, years (mean, SD)	82.5 (6.2)	83.5 (5.9)	81.3 (6.4)	.01
Sex - Female, n (%)	133 (70)	68 (51.1)	65 (49.9)	.53
Race, n (%)				.003[b]
Asian	18 (9.5)	12 (66.7)	6 (33.3)	N/A[c]
Black	30 (15.8)	24 (80)	6 (20)	N/A
White	127 (66.8)	55 (43.3)	72 (57.7)	N/A
Other	14 (7.4)	8 (57.1)	6 (42.9)	N/A
Patient declined to answer	1 (0.5)	1 (100)	0	N/A
Ethnicity, n (%)				.68[d]
Non-Hispanic	178 (93.7)	93 (52.2)	85 (47.8)	N/A
Hispanic	12 (6.3)	7 (58.3)	5 (41.7)	N/A
Use of an interpreter during visit, n (%)	25 (13.2)	19 (76)	6 (24)	.01
Medicaid beneficiary, n (%)	36 (18.9)	30 (83.3)	6 (16.7)	<.001
Active patient portal account, n (%)	137 (72.1)	56 (40.9)	81 (59.1)	<.001
Presence of caregiver during visit, n (%)	48 (25.3)	17 (35.4)	31 (64.6)	.01
Specific functional impairments, n (%)				
Hearing problems	87 (45.8)	51 (58.6)	36 (41.4)	.13
Vision problems	123 (64.7)	69 (56.1)	54 (43.9)	.20
Cognitive problems	65 (34.2)	38 (58.5)	27 (41.5)	.25
Provider type for visit, n (%)				.12[e]
Behavioral health	17 (8.9)	12 (70.6)	5 (29.4)	N/A
Geriatric medicine	173 (91.1)	88 (50.9)	85 (49.1)	N/A
Acute visit	83 (43.7)	40 (48.2)	43 (51.8)	.28
Vitals obtained during visit, n (%)				
Blood pressure	56 (29.5)	26 (46.4)	30 (53.6)	.27
Heart rate	28 (14.7)	10 (35.7)	18 (64.3)	.05
Temperature	14 (7.4)	7 (50)	7 (50)	.84
Oxygen saturation	11 (5.8)	3 (27.3)	8 (72.7)	.08
Weight	19 (10)	13 (68.4)	6 (31.6)	.15
After visit summary viewed by patient, n (%)	85 (44.7)	20 (23.5)	65 (76.5)	<.001
Number of medication changes (mean, SD)	0.87 (1.3)	0.8 (1.1)	1.0 (1.5)	.33

[a]Percentages were calculated using the values in the All Visits column as the denominator.

[b]*P* value is based on a comparison between White patients and non-White patients in terms of whether they had telephone or video visits.

[c]N/A: not applicable.

[d]*P* value is based on a comparison between Hispanic patients and non-Hispanic patients in terms of whether they had telephone or video visits.

[e]*P* value is based on a comparison between behavioral health and geriatric medicine in terms of which provider type was used for telephone or phone visits.

With respect to visit characteristics, almost half (83/190, 43.7%) of the visits were for acute reasons. The majority of appointments (173/190, 91.1%) were with medical clinicians instead of psychologists (17/190, 8.9%). The average duration of visits was 33.6 minutes (SD 10.4 minutes). The most common vital sign reported was blood pressure (56/190, 29.5%), whereas only 7.4% (14/190) and 5.8% (11/190) of appointments recorded temperature and oxygen saturation, respectively.

Of the 190 reviewed visits, 47.4% (n=90) of appointments used video. Of these visits, 56.7% (51/90) used Doximity, an independent HIPAA-secure video platform, 42.2% (38/90) used the video platform in the EHR, which was accessed via an active

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patient portal account, and 1.1% (1/90) used FaceTime. The physical exam for 71.1% (64/90) of these visits included visual observation-dependent findings. The main reason cited for not using video was a lack of equipment (54/100, 54%). Other common reasons for not using video included patient preference (32%, 32/100) and cognitive problems (23%, 23/100). Of the 100 telephone visits, 56% (n=56) of patients had active patient portals.

With regard to the visit outcomes (Table 2), video visits were an average of 7 minutes longer (mean 37.3 minutes, SD 10 minutes) than telephone visits, after adjusting for age, use of an interpreter, Medicaid coverage, and presence of a caregiver (P<.001). On average, video visits documented 20% more visit diagnoses than telephone visits, after adjusting for age, use of interpreter, Medicaid coverage, presence of caregiver (P=.001). The rates of advance care planning discussion between video and telephone visits did not significantly differ.

Table 2. Telemedicine visit outcomes listed by visit format (N=190).

Variable	All visits	Telephone visit[a] (n=100)	Video visit[a] (n=90)	*P* value[b]
Duration of visit, minutes (mean, SD)	33.6 (10.4)	30.3 (9.7)	37.3 (10.0)	<.001
Number of visit diagnoses (mean, SD)	5.1 (2.8)	4.5 (2.5)	5.7 (3.0)	.001
Medical power of attorney discussion, n (%)	31 (16.3)	19 (61.3)	12 (38.7)	.29
Code status discussion, n (%)	32 (16.8)	18 (56.3)	14 (43.7)	.65

[a]Percentages were calculated using the values in the All Visits column as the denominator.

[b]Adjusted for age, use of an interpreter, Medicaid coverage, and presence of a caregiver.

Discussion

We described the rapid implementation of telemedicine visits that utilized both telephone and video visits to meet the needs of geriatric primary care patients early in the COVID-19 pandemic. Nearly half of the telemedicine visits conducted were video visits, and the 7-minute difference between video visit duration and telephone-only visit duration may represent a clinically meaningful difference. In other contexts, longer visit durations improve patient satisfaction [19], and many additional interventions, such as smoking cessation counseling, can be done with longer visits [20]. The higher number of visit diagnoses during video visits supports the notion that longer visit duration is related to an increased number of problems addressed in an appointment.

Despite the shorter duration, telephone visits had similar rates of advance care planning to those in video visits. This suggests that clinicians are comfortable with having these discussions during either visit type, even without visual cues. In the setting of the COVID-19 pandemic, Medicare has temporarily extended the coverage of advance care planning to audio-only visits [18]. Our findings support this policy change and suggest that this coverage should be continued after the pandemic.

Although most studies on videoconferencing visits have included the home monitoring of vital signs [9,10,12,16], most appointments in our study lacked vital sign monitoring. When vital signs were available, they were frequently limited in number. As such, increasing access to vital sign monitoring at home is necessary to put current telemedicine research into practice.

Although our findings demonstrate that some older adults were able to use video visits, a slight majority of patients were unable to access this visit format, as over half of visits were audio-only. The limited use of videoconferencing compared to telephone visits was also described in recent data from the Veterans Health Administration [21], a multisite geriatric clinic in Michigan [22], and the Centers for Medicare and Medicaid Services [23]. Social factors had the biggest association with the visit format. Racial and ethnic minority patients, those without caregivers present at visits, those requiring interpreters, and those with Medicaid were significantly less likely to have videoconferencing visits. Based on the results of this study, further work and policy changes are needed to ensure that racial and ethnic minority patients and those with fewer resources have access to video visits in order to minimize the risk of further exacerbating health disparities within underserved groups.

Interestingly, 40.9% (56/190) of patients that had telephone visits had active electronic patient portals. This suggests that having access to the equipment required for this portal (ie, a computer or smart phone with internet access) is not sufficient in navigating the videoconference platforms. A lack of training for electronic patient portals is a common barrier for patient use [24]. An alternative explanation is that patients' family and caregivers, rather than the patients themselves, set up the portal to communicate with patients' medical teams on their behalf. Since clinician documentation does not routinely describe whether another person assisted patients with video visits, we also did not know the role that family caregivers and other home-based supporters may have had in facilitating the visits.

There are notable limitations in this study. Chart review limited the scope and precision of the data collected and subjected results to errors in documentation. The results of this study may not apply to older adults seen in nongeriatric practices, those who have fewer comorbidities, and those with limited access to clinical resources for supporting telemedicine visits, such as patient portals. Furthermore, our study population was predominantly White and without Medicaid, and therefore may have more access to technology than other populations.

There are calls for increasing the role of telemedicine, even after the pandemic [23,25], but there is still much to learn about telemedicine appointments, including their potential impact on the quality of care and patient satisfaction. Future investigations

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should focus on addressing disparities in accessing videoconferencing, the quality of virtual and nonvirtual visits measured by patient satisfaction surveys and other methods, and optimal platforms and clinical implementation requirements for virtual visits. Furthermore, given the potential of ongoing reimbursement for telemedicine visits, there will also be opportunities to study the early adopters of older adults with multiple medical conditions who routinely use video visits to better understand patient, caregiver, clinic, health system, and community-level facilitators that may promote the ongoing uptake of video visits. This study provides insights on the use of video and telephone visits for geriatric patients that will be important as we continue to deliver telemedicine care remotely.

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Authors' Contributions

CHS contributed to the design, data acquisition, interpretation of data, drafting and revision of the manuscript, and approval of the final version. PS contributed to the analysis and interpretation of data, manuscript revisions, and approval of the final version. AJ, RCA, and CEK contributed to the data acquisition, manuscript revisions, and approval of the final version. BLP contributed to the design, manuscript revisions, and approval of the final version. MMV, SAF, and PPB contributed to the design, manuscript revisions, and approval of the final version. HDL contributed to the conception, design, data acquisition, interpretation of data, drafting and revision of the manuscript, and approval of the final version.

Conflicts of Interest

None declared.

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Abbreviations

EHR: electronic health record
ICD-10: International Statistical Classification of Diseases, 10th Revision
REDCap: Research Electronic Data Capture

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Review

Emerging Technologies With Potential Care and Support Applications for Older People: Review of Gray Literature

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Abstract

Background: The number of older people with unmet care and support needs is increasing substantially due to the challenges facing the formal and informal care systems. Emerging technological developments have the potential to address some of the care and support challenges of older people. However, limited work has been done to identify emerging technological developments with the potential to meet the care and support needs of the aging population.

Objective: This review aimed to gain an overview of emerging technologies with potential care and support applications for older people, particularly for those living at home.

Methods: A scoping gray literature review was carried out by using the databases of 13 key organizations, hand searching reference lists of included documents, using funding data, and consulting technology experts. A narrative synthesis approach was used to analyze and summarize the findings of the literature review.

Results: A total of 39 documents were included in the final analysis. From the analysis, 8 emerging technologies were identified that could potentially be used to meet older people's needs in various care and support domains. These emerging technologies were (1) assistive autonomous robots; (2) self-driving vehicles; (3) artificial intelligence–enabled health smart apps and wearables; (4) new drug release mechanisms; (5) portable diagnostics; (6) voice-activated devices; (7) virtual, augmented, and mixed reality; and (8) intelligent homes. These emerging technologies were at different levels of development, with some being trialed for care applications, whereas others being in the early phases of development. However, only a few documents mentioned including older people during the process of designing and developing these technologies.

Conclusions: This review has identified key emerging technologies with the potential to contribute to the support and care needs of older people. However, to increase the adoption of these technologies by older people, there is a need to involve them and other stakeholders, such as formal and informal carers, in the process of designing and developing these technologies.

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KEYWORDS

artificial intelligence; internet of things; mobile phone; robotics; emerging technologies; older people; care and support

Introduction

Background

Many older people are likely to require care and support in their later lives due to living with limiting long-term conditions [1,2]. These include support with activities related to mobility, daily living, and social life [2]. In the United Kingdom, for instance, it is estimated that around 20% of men and 30% of women aged 65 years and above currently require care and support with at least one activity of daily living (ADL), such as bathing and dressing [3]. In addition, many older people who require care

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and support prefer to continue living in their own homes, which is also a priority to several local authorities in the United Kingdom [4]. However, many of those are left with unmet needs due to the challenges facing the formal and informal care systems in the United Kingdom, such as limited funding to health and social care and physical and mental burden on family carers [5-7]. For example, a recent analysis of data from wave 7 of the English Longitudinal Study of Aging revealed that 55% of older people who have difficulty with at least one ADL received no formal or informal support [6]. Addressing the care and support needs of an aging population has, therefore, become an urgent health and social care priority, given the negative impact unmet needs have on older people as well as on the care systems [5,6].

There is a growing body of evidence demonstrating the potential of technology to meet older people's care and support challenges. For example, data from recent systematic reviews have demonstrated the positive impact of a number of technologies on the physical and mental health of older people as well as on the social aspects of their lives [8-12]. Recent reports have also shown that older people enjoy the experience of using technology, are willing to engage with technology-based interventions, and tend to acknowledge its importance as a means to facilitate daily activities and communication [13-15]. However, older people adopt technology at lower rates compared with other age groups [16,17]. For example, more than 60% of internet nonusers in the United Kingdom are adults aged 75 or above [17]. Some of the main barriers that could influence and predict technology adoption by older people include lack of confidence in digital skills and lack of understanding of perceived value and positive impact of technology on their quality of life [13,14,16,18-22]. Many older people also face physical changes, such as cognitive decline, memory problems, and motor and sensory changes, that limit their use of available technologies [16,21,22]. A possible way to facilitate successful implementation of technologies targeting the care and support challenges of older people is to address the barriers to adoption during the process of technology design and development [23-26]. To achieve this, it will be important first to gain an overview of early phase technologies with potential care and support applications for older people. These technologies are increasingly referred to as emerging technologies [27].

Emerging technologies are early stage technological developments with high potentials that are yet to be demonstrated [27]. In recent years, the use of the term has encountered significant growth, paralleled with efforts to define what characterizes an emerging technology [28]. One of the main characteristics of emerging technologies commonly mentioned in the literature is their ability to provide investing bodies a change in *status quo* by exerting economic or social impact [27,29-31]. In addition, two other characteristics that have general agreement among academic scholars are growth or increase over time and novelty or newness [28,32,33]. These attributes were acknowledged in a notable definition of emerging technology in the literature by Rotolo et al [28]. Rotolo et al [28] analyzed 12 definitions from the social science domain and identified 5 key attributes of an emerging technology: (1) radically novel, (2) relatively fast growing, (3) coherence persisting over time, (4) potential to have socioeconomic impact, and (5) uncertainty and ambiguity about potential applications [25]. However, despite these efforts, the challenges of defining and operationalizing the detection of emerging technologies are well acknowledged in the literature [27,28,32,33]. For example, using traditional quantitative measures, such as patent analysis, to examine the potential socioeconomic impact is acknowledged to be challenging [28]. Similarly, operationalizing all key attributes of emerging technologies at the same time is considered to be difficult, given that the available data sources can carry different pieces of information [32]. Overall, it is acknowledged that the concept of emerging technology and methods of operationalizing the term is still evolving [27,28,32,33]. Therefore, methods to identify emerging technologies will depend on the study objectives and information and data sources. For the purpose of this review, the term *emerging technologies* has been operationalized as *technological developments that are novel and rapidly growing and have a potential socioeconomic impact*.

Some emerging technologies may help overcome common barriers of engagement with technology for older people. For example, recent advances in artificial intelligence (AI)–based conversational platforms are said to simplify end users' engagement with digital technologies by reducing the need for complex skills to navigate websites or other interfaces [34,35]. Arguably, this could help address older people's limited digital skills. Similarly, self-driving vehicles have seen significant advances recently and could soon help address mobility needs of older people [36]. However, despite these potential benefits, there is limited evidence synthesis that focuses on identifying emerging technologies with potential care and support applications for older people. Most of the recent works have focused on exploring the effectiveness and perceptions of specific technologies among older people [12,14,25,37-40]. In one of the few recent reviews on this topic, Sapci and Sapci [41] investigated current research evidence on elderly care technology, in particular novel remote monitoring technologies [41]. They reported an increased interest in recent years on exploring the potential of sensor-based smart homes, robotic technologies, and AI to support elderly care. They also highlighted that the latter would play an increasing role in remote monitoring technologies. However, their review focused mainly on monitoring technologies. Arguably, there is a need to gain an overview of recent technological developments, given that other technologies might play a role in elderly care in the future. An overview of emerging technologies could also help identify developments that might not be currently used to meet the care needs of older people but could potentially meet their needs in the future.

Therefore, a scoping review was conducted to gain an overview of emerging technologies with potential care and support applications for older people, particularly for those living at home. Literature searching was restricted to gray literature documents. This is because most of the overviews and analyses around emerging technologies tend to be found in the gray literature documents, such as funding bodies and science and technology institutes' reports [42-44]. For example, the World

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Economic Forum and the Massachusetts Institute of Technology, renowned institutes in science, business, and technology, publish regular reports on emerging technologies [35,36]. In addition, most of these reports focus on emerging technologies with potential social or economic impact, which could provide insights into an attribute that is difficult to operationalize in empirical literature [28]. Analyzing these reports could also provide timely information about emerging areas of technological developments, given the quick nature of publishing in gray literature as opposed to research literature [45-47].

Methods

Study Design

A scoping review design based on the Arksey and O'Malley original and enhanced framework was used to conduct this review [48,49]. A scoping review design was deemed appropriate as this method allows to search the literature systematically and summarize and disseminate the findings of the literature search [48,49]. Following a systematic approach in searching gray literature documents was important to improve the reproducibility of the review and overcome some of the challenges encountered when conducting gray literature searches, such as lack of standard indexing and nontraditional formats of documents [50,51]. The Arksey and O'Malley original and enhanced framework recommends 6 steps in conducting a scoping review: (1) identifying the research question; (2) identifying relevant documents; (3) selecting the documents; (4) charting the data; (5) organizing, summarizing, and reporting the findings; and (6) consulting stakeholders (optional). The following sections describe the methods used to conduct the first 5 steps.

Identifying the Research Question

This review aimed at answering the following research question: *What is known from the existing gray literature about emerging technological developments that could have potential care and support applications for older people living at home?*

Identifying Relevant Documents

Identifying information sources for gray literature review depends largely on the objective of gray literature search [45,46,50]. For this review, reports from key organizations and data on ongoing research were deemed suitable to gain an overview of emerging technologies with potential care and support applications for older people. Several strategies have been used to identify relevant documents and minimize potential bias resulting from using a single search strategy for gray literature reviews [45,50]. First, key organizations were identified by running a Google search and based on their potential to publish documents related to the investigated topic. The web pages of these organizations were then searched for relevant documents using publication databases or free text search engines. Table 1 summarizes the strategies used to search each database.

In addition, reference lists of included documents were hand-searched to identify more relevant documents. Technology experts were also consulted to identify organizations and key publications on the topic of emerging technology. Funding data were used as a complementary resource to understand ongoing research activities and provide timely information about technology developments [28]. Data from the Engineering and Physical Sciences Research Council (EPSRC) were identified for this purpose. EPSRC was selected as it is the main funding body for engineering and physical sciences research in the United Kingdom [52]. Data identified included research projects currently funded in relevant research areas, including engineering, information and communication technologies, health care technologies, AI, robotics, human-computer interaction, pervasive and ubiquitous computing and sensor and instrumentations, assistive technology, rehabilitation, and musculoskeletal biomechanics. The funding amount of the key research areas and EPSRC experts' magazine (*Pioneer*) were also analyzed for the last 5 years (2015-2019).

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Table 1. Search strategy conducted on websites of key organizations.

Organizations	Search methods	Search terms
Deloitte	The website search engine was used to look for publications. The date was limited to after January 2015.	"Emerging" or "new" technologies were used as search terms.
Department of Health and Social Care	The website search engine was used to look for publications. The date was limited to after January 2015.	"Emerging" or "new" technologies were used as search terms.
NHS[a]	The website search engine was used to look for publications. Date was limited to after January 2015.	"Emerging" or "new" technologies were used as search terms.
Nuffield Trust	Search was limited to "Health and Social Care finances and reform," "Older people and complex care," and "New models of Healthcare delivery."	"Emerging" or "new" technologies were used as search terms.
MIT[b]	All issues of MIT's Technology review were screened from January 2015.	N/A[c]
World Economic Forum	All reports under the publication and white paper sections were screened from January 2015.	N/A
King's Fund	All publications under the publication section were screened. No restriction was made on the topic. The date was limited from January 2015.	N/A
Nesta	All publications in the health, AI, data analytics, and future scoping sections were screened. The date was limited from January 2015.	N/A
Gartner	All reports in the special reports section were screened. In addition, an advanced search was conducted using the website search engine using "Hype cycles" and "Knowledge and Innovation" filters.	N/A
European Parliament and Commission	All publications, research, and reports under the EU[d] publications section were screened from January 2015.	N/A
Royal Society	All reports under the publications section were screened from January 2015.	N/A
United Nations	All publications in the multimedia library of the Economic and Social Affairs were screened. The date was limited from January 2015.	N/A
World Health Organization	List of publications in Health Technologies was screened from January 2015.	N/A

[a]NHS: National Health Service.

[b]MIT: Massachusetts Institute of Technology.

[c]N/A: not applicable.

[d]EU: European Union.

Selecting the Documents

Documents were selected as per predefined inclusion and exclusion criteria. In brief, documents were selected if they described an emerging technological development that could potentially be used to meet the care and support needs of older people living in their own homes. This review focused on the following care and support domains: mobility, self-care and domestic life, social life and relationships, psychological support, and access to health care. These domains were identified in recent research as important areas of care and support for older people living at home [2]. It is important to also note that the technology did not necessarily need to be developed for older people. This is because emerging technologies are in early development stages, and some ambiguity might still be associated with their potential users [28]. Textbox 1 summarizes the inclusion and exclusion criteria.

Documents were screened in 3 steps: (1) screening the headings or titles of the documents; (2) screening the summaries of the documents such as executive summaries, overviews, and key findings; and (3) screening full text of the documents. The screening process was conducted primarily by the first author (SA). An opinion from a second reviewer (LW or MH) was sought in case of uncertainty. A PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart was used to summarize the screening and selection process.

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Textbox 1. The inclusion and exclusion criteria used to select documents.

Documents were included if they

- Described an emerging technology and used the term "emerging" explicitly or mentioned attributes of an emerging technology such as fast, new, novel, rapid, or potential societal or economic impact;
- Described a potential application of the emerging technology in one of the following care and support domains: mobility, self-care and domestic life, social life and relationships, psychological support, and access to health care;
- Described technological development that could potentially be used to support older people in their own homes or within a community setting;
- Were reports or reviews published by the identified key organizations;
- Publication date between January 2015 and July 2019;
- Were published in English

Documents were excluded if they

- Described technical developments without mentioning potential applications;
- Described non care and support applications (eg, water/food security, business, and marketing);
- Focused exclusively on technologies used in a clinical setting (eg, during surgery or in hospitals). However, technologies used in clinical practice with potential uses in home such as remote monitoring were included;
- Were blogs or news articles;
- Were documents with highly restrictive use policy

Charting the Data

Data were extracted from documents deemed eligible for the final analysis using a data extraction form on Microsoft Excel. The form included the following information: the name of the organization, the year and title of the publication, the purpose of the document, methods used or sources of evidence, description of the technology, and potential care and support applications for technological development.

Organizing, Summarizing, and Reporting the Findings

The data extracted were summarized using a narrative synthesis approach [53]. The analysis started with the development of an initial description of the key findings of the included documents. To facilitate this step, a summary table was developed listing the main emerging technologies and application areas mentioned in each document. The next phase aimed to identify the categories of emerging technologies with potential care and support applications. It involved comparing and contrasting findings within each document as well as across the full data set. This phase of analysis revealed the complexity of the topic investigated. For example, some technologies were identified as emerging breakthroughs in some documents, whereas in other documents, these were identified as use cases or application areas of other technologies. This necessitated the distinction between emerging technologies that have enabled recent technological advances (enabling technologies) and those that could be used to meet the care and support needs of older people. This review focuses on reporting the findings of the latter. A description of each of these technologies was developed. Some examples were also provided on how these technologies were enabled by the emerging enabling technologies.

Results

Summary of Literature Search

A total of 2158 records were screened from organizations' websites, of which 58 were found eligible and were included in the full-text assessment phase. In addition, 23 records were identified from other sources and were screened for eligibility (5 from hand searching-included documents, 3 from speaking to experts, and 15 from funding data). A total of 39 documents were included in the final analysis. Figure 1 summarizes the screening and selection process using a PRISMA flowchart. The characteristics of the documents included in the final analysis can be found in Multimedia Appendix 1 [54-92].

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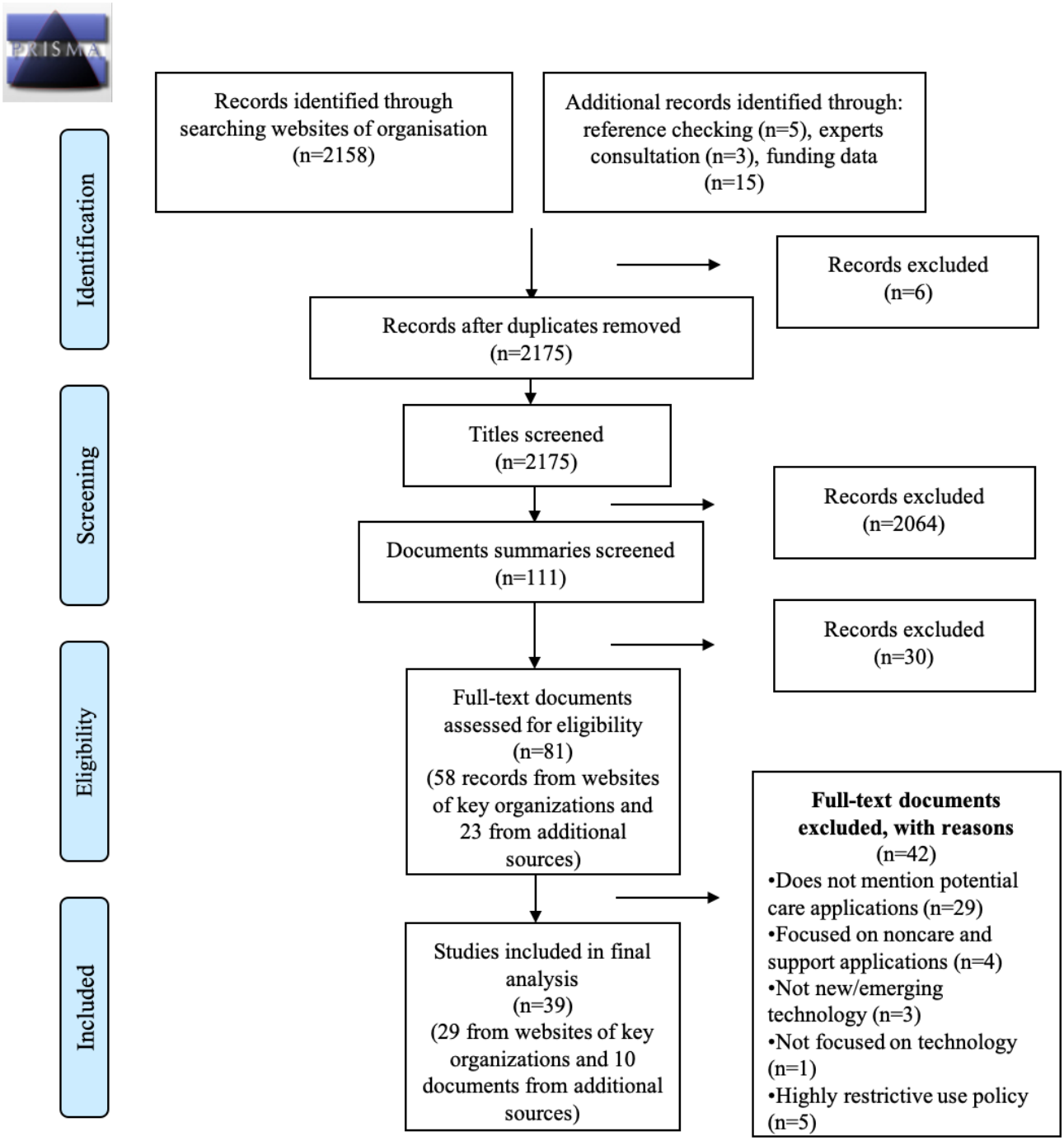
Figure 1. A summary of the screening and selection process using a PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart.



Key Findings

The analysis identified the following 8 emerging technologies that could have potential care and support applications for older people: (1) assistive autonomous robots; (2) self-driving vehicles; (3) AI-enabled health smart apps and wearables; (4) new drug release mechanisms; (5) portable diagnostics; (6) voice-activated devices; (7) virtual reality (VR), augmented reality (AR), and mixed reality (MR); and (8) intelligent homes. These technologies were mainly enabled by advances occurring in the fields of AI and subset technologies (eg, natural language processing [NLP], computer vision, and speech recognition), robotics, sensor technology, and advances in connectivity and computing (eg, fifth-generation cellular wireless [5G] and edge computing). The following sections provide a summary of each of these emerging technologies.

Assistive Autonomous Robots

Assistive robotics is a field within robotics concerned with developing robots that can assist people to manage their physical and social difficulties [54]. Assistive robotics was identified in some documents as one of the main emerging robotic developments with potential care and support applications [55-58]. This increased interest could be largely attributed to advances in AI, sensors, and human-computer interfaces [56-58]. For example, robotic dexterity, or the ability to grasp or

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manipulate objects, has recently experienced significant development owing to improvements in AI systems' ability to learn via trial and error [56]. If these learning abilities are significantly improved in the future, robotic dexterity might be able to support some household and self-care tasks for older people, such as getting out of bed and assembling gadgets [56]. Wearable robotics, including suits and exoskeletons, are also expected to be used for mobility needs of older people in the near future because of reductions in the cost and size of these technologies [57,59,60]. In addition, brain-computer interfaces, one of the recent advances in human-computer interfaces, are also allowing new ways to control robotic prostheses and exoskeletons by creating neural bypasses [58,61]. These interfaces could enable potential applications for assistive robots in the rehabilitation of patients with severe paralysis, although they are still in the early stages of development [58,61]. Various ongoing projects are also capitalizing on AI and other enabling technologies to improve the autonomy of robots in real-life situations as well as to improve verbal and nonverbal interactions with end users, including older people [61]. For example, one research project is currently working on improving the image sensing and vision processing and control systems of robots, whereas another project is improving robots' ability to analyze sounds in the environment [61]. Some of these efforts could translate into more autonomous robots in the future that are adaptive to older people's environment and needs.

Self-Driving Vehicles

Self-driving vehicles were described in the reviewed documents as an emerging technology that could create new models of transportation, improve road safety, and reduce traffic congestion [57-59,62-65]. This technology could, therefore, potentially contribute to some of the transportation needs of older people in the future. However, some of the potential benefits of self-driving vehicles will depend largely on the level of automation that can be achieved. To date, significant progress has been made in creating semiautonomous vehicles (eg, Tesla autopilots), where the vehicle performs some automated functions; however, the driver's engagement is still necessary [57,63]. A significant amount of work is also ongoing to achieve higher levels of automation [57,62-64], with some progress made recently in vehicles' capabilities to perform all driving tasks in predefined geolocations (eg, Waymo's autonomous taxis) [62]. However, developing fully autonomous vehicles, where they can perform all driving tasks in any environment, is complex and might be difficult to achieve in the near future [57].

AI-Based Health Apps and Wearables

AI and other enabling technologies are driving the development of new generation of smart apps and wearables [56,66-74]. These apps and wearables can potentially support older people to meet their needs in psychological support, self-care, and access to health care domains. For example, AI-based chatbots are at the core of a new wave of smart apps designed to provide advice to support treatments of chronic conditions, such as cognitive behavioral therapy for mental health [56,63,70]. Some of these AI chatbots also offer medical triage and advice about possible disease diagnosis before seeing doctors (eg, the Babylon app and Ada Health Companion) [69,70]. In addition, wearables such as smart watches and textiles are moving from only tracking fitness and physical activities to measuring physiological parameters and vital signs such as heart rate, electrocardiogram, and blood oxygen [56,63,74]. These developments allow wearables linked to smart apps and AI-based systems to detect early signs of disease exacerbation and help prevent further health deterioration [56,74]. The role of this new generation of wearables in the remote care of long-term conditions, including chronic obstructive pulmonary disease and mental health, is currently being investigated in several research projects in the United Kingdom [61,75].

New Drug Release Mechanisms

The analysis identified emerging drug release mechanisms that could offer new ways for administering medications [76-78]. Some of these drug release mechanisms are enabled by developments in sensors, AI, and other enabling technologies. For example, digital pills have been developed to deliver drugs automatically using a system that involves biosensors, smart apps, and wearable sensors [77]. This development was identified in 2016 as a trend that could have transformative impact on health [77], although it has not been widely discussed in the subsequent years. DNA origami is another development that could have potential drug delivery applications in the future [76]. These nanolevel DNA folded structures could benefit from developments in AI and sensors to act as nanorobots that could be programmed to deliver targeted therapy [76]. However, these developments are still in the early stages.

Portable Diagnostics

Emerging developments of point-of-care diagnostics, particularly those using smartphones, could facilitate access to health care for older people [55,57,77,79,80]. Significant work is currently ongoing to enhance sensors' ability to detect various metabolites in body fluids and to enable spectroscopy in diagnostic devices [79,80]. These projects are paralleled with efforts to improve the detection speed, size, cost, and accuracy of these sensors [80]. Portable diagnostics equipped with these kinds of sensors are expected to bring disease diagnosis closer to patients, for instance, in the home environment [55,57,80]. However, it was not clear from the reviewed documents whether end users of these diagnostics will include patients themselves. In addition, the need to improve the diagnostic process and link data from these devices to care services and pathways has been identified [55]. Improving the process of diagnosis is also an area where AI advances hold some promising potential [71,75].

Voice-Activated Devices

Voice-based interfaces are one of the main emerging user interfaces identified in the documents, enabled by advances in numerous technological fields, including AI, speech recognition, and NLP [57,81-83]. These interfaces, sometimes referred to as conversational interfaces, virtual personal assistants, chatbots, or digital helpers, use end users' speech or voice as a means to interact with the technology [57,81-83]. Voice-based interfaces have the potential to support older people in the self-care, access to health care, and social life domains. For example, voice-activated devices, such as Google Assistant and Amazon's

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Alexa, can act as home digital helpers that assist older people with tasks such as providing information, medication reminders, video calling, and home entertainment [82]. These devices can also be used as platforms to control various home appliances and contribute to creating automated home experiences [82]. Significant work is also ongoing to enable voice-based interfaces to assist with more complex tasks such as web-based medical triage and self-management of chronic conditions [58,69,71,73].

Virtual, Augmented, and Mixed Reality

VR, AR, and MR are other emerging user interfaces identified from the analyzed documents [64,73,81,83-88]. These interfaces use a virtual world (VR) or a combination of virtual and real worlds (AR or MR) to enable immersive digital experiences [57,59,84-86]. VR, AR, and MR have the potential to support older people in social life, psychological health, and domestic life domains. For example, these emerging user interfaces are expected to enable more immersive experiences in various aspects of everyday life, including web-based home shopping, leisure activities, and communication, through the use of devices such as headsets, smart glasses, and new generations of smartphones [83,87,88]. An increased interest is also observed recently on the potential of VR, AR, and MR to support the management of mental health conditions [55,83]. Emerging advances in connectivity (eg, 5G mobile network) are also expected to improve users' experience with VR, AR, and MR interfaces by enabling visual data transfer and processing without lags [81,88].

Intelligent Homes

Intelligent homes that are adaptive to users' needs and preferences is an emerging technology that could have potential care and support applications for older people [61,82,85,87-90]. Intelligent homes are largely enabled by the internet of things (IoT) technology—a system that transfers and processes data from a group of internet-connected physical devices [63,91]. For example, IoT home systems enable automated home experiences by allowing home devices, such as lights, heat, voice-activated devices, and even mobile robots, to connect and exchange information with each other [76,82,85,91,92]. IoT systems could also be used for remote health monitoring in the home environment through monitoring and detecting changes in health and activity patterns [54,63,90,91]. Home automation experience is also expected to improve in the near future owing to advances seen in network connectivity and computing paradigms (eg, 5G and edge computing) [81,89]. In addition, artificial emotional intelligence, an emerging field within AI concerned with detecting emotions, could potentially enable the development of intelligent home devices that can adapt to users' verbal and nonverbal behaviors [84].

Discussion

Principal Findings

The aim of this review was to gain an overview of emerging technologies with potential care and support applications for older people. The analysis identified 8 emerging technologies that could potentially be used to meet older people's care needs in self-care, domestic life, mobility, psychological support, social life, and access to health care. These emerging technologies were assistive autonomous robots; self-driving vehicles; AI-based health apps and wearables; new drug delivery systems; portable diagnostics; voice-activated devices; intelligent homes; and VR, AR, and MR. Some of these technologies are recognized in the empirical literature as emerging developments that could have care applications for older people. For example, Sapci and Sapci [41] identified smart homes as an innovative assistive technology that could support aging in place. VR, self-driving vehicles, and IoT-enabled home devices were also identified in a more recent study as emerging technologies that could support older people manage health and maintain their independence [93]. Similarly, increased interest has been observed in the literature in recent years to explore the potential of assistive robots, smart homes, and voice-activated devices to support the care of older people [94-100]. It is also worth noting that many of the care applications of the emerging technologies identified in this review were health related. This might be because of the interests of the organizations included in this review. However, it could also mean that some ambiguity is still associated with potential uses of these emerging technologies in other care domains. Ambiguity regarding potential applications is indeed one of the main characteristics of emerging technologies [28] and could have influenced the applications presented in this review.

This review also highlighted that emerging technologies are at different levels of development. Some, for instance, are at early phases of development such as DNA origami, whereas others are being trialed for care applications such as using AI chatbots and VR for mental health management. However, despite many documents discussing the potential of these technologies to support various care and support domains, very few have mentioned the inclusion of older people in the design of these technologies. The needs and functional preferences of older people can indeed be overlooked during the development and design of technology [36,101]. This could result in the development of technology products that do not meet the care needs of older people, hindering their adoption by this population [93]. Using human-centered design principles and involving older people during the different stages of technology design and development will therefore be important to develop products that are desirable and usable by older people [25,101,102]. Emerging technologies identified in this review, in particular, offer an exceptional opportunity to achieve this, given that many are still in the early phases of development. In addition, it will be important to involve other stakeholders in the design process, such as family carers and care professionals, to ensure that the developed products are supported by older people's formal and informal care systems [102].

This review also highlighted the complexity of recent technological developments, requiring a distinction to be made during the analysis phase between enabling technologies and those that could potentially be used to meet care needs of older people. Recent waves of technological developments are well recognized for their interdependencies, where new innovations are often the outcome of interactions between various fields [103,104]. Self-driving vehicles and intelligent homes, identified in this review, are good examples of innovations resulting from

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interactions between various technological fields, including sensors, AI, robotics, and advanced network connectivity.

These complex interactions will need to be taken into account when developing technology products targeting older people, as this could mean the need to draw on knowledge from various technological fields.

This review has several strengths. One of the strengths is following a systematic approach to search the gray literature. This systematic approach might have overcome some of the challenges associated with searching gray literature and reduced the possibility of missing key documents. Another strength is disentangling some of the complexities associated with recent technological developments to provide an overview of emerging technologies with potential care and support applications for older people. In addition, the inclusion of technological developments that were described only with the key attributes of emerging technologies may have helped overcome some of the inconsistencies associated with defining the term in the reviewed documents.

Finally, this review was exploratory in nature, where it aimed to identify emerging technological developments that could potentially be used to meet the care and support needs of older people. Therefore, issues around technology acceptability, feasibility, adoption, and ethical considerations were beyond the scope of this review. However, the results of this review will inform future work that will explore some of these issues and investigate which of the technologies identified in this review has most potential to meet the care and support needs of older people. It will involve working closely with a panel of technology experts to prioritize these technologies. This review also resulted in some implications for future research. It reinforced the importance of co-designing technology solutions and involving older people and other stakeholders, such as carers and care professionals, at various stages of technology design and development. In addition, research and development related to emerging technologies might need to be interdisciplinary, given the interdependencies and complexity of recent technological advances.

Limitations

There are some limitations that need to be acknowledged. The search and analysis processes were conducted primarily by the first author (SA). There is a possibility that this was influenced by the author's own perceptions and interpretations. However, the process of the search and analysis was discussed regularly with the research team to minimize potential bias. There is also a possibility that the search strategies missed key literature in other languages. In addition, many of the included documents were published in the United Kingdom and the United States; therefore, there is a possibility that this review missed some technological developments occurring in other parts of the world. Finally, there might be a need to consolidate the review findings with experts' consultations or studies from peer-reviewed literature, as some gray literature sources do not go through a rigorous review process.

Conclusions

In summary, this review provided an overview of emerging technologies with potential care and support applications for older people. A total of 8 emerging technologies were identified, including self-driving vehicles, assistive autonomous robots, intelligent homes, VR and AR, AI-enabled apps and wearables, voice-activated devices, portable diagnostics, and new drug release mechanisms. These technologies were at different levels of development, with some being trialed for care applications, whereas others are in the early stages of development. The results of this review can be used by researchers, designers, and developers to gain an overview of the topic investigated as well as co-design applications of some of the technologies identified with older people. Formal and informal carers might also be interested in exploring some of the technologies identified to meet the care needs of their care recipients. The findings of this review will be used by the research team to investigate which of the emerging technologies identified has the most potential to meet the care and support needs of older people.

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Authors' Contributions

SA took the lead in developing the review protocol. MH and LW reviewed and approved the protocol. SA drafted the manuscript, and MH and LW contributed significantly to the subsequent drafts and the final manuscript. All authors have reviewed and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Characteristics of the documents included in the final analysis.
[DOCX File , 47 KB - aging_v3i2e17286_app1.docx]

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Abbreviations

5G: fifth-generation cellular wireless
ADL: activity of daily living
AI: artificial intelligence

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AR: augmented reality
EPSRC: Engineering and Physical Sciences Research Council
IoT: internet of things
MR: mixed reality
NLP: natural language processing
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
VR: virtual reality

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Original Paper

Inferring Destinations and Activity Types of Older Adults From GPS Data: Algorithm Development and Validation

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Abstract

Background: Outdoor mobility is an important aspect of older adults' functional status. GPS has been used to create indicators reflecting the spatiotemporal dimensions of outdoor mobility for applications in health and aging. However, outdoor mobility is a multidimensional construct. There is, as of yet, no classification algorithm that groups and characterizes older adults' outdoor mobility based on its semantic aspects (ie, mobility intentions and motivations) by integrating geographic and domain knowledge.

Objective: This study assesses the feasibility of using GPS to determine semantic dimensions of older adults' outdoor mobility, including destinations and activity types.

Methods: A total of 5 healthy individuals, aged 65 years or older, carried a GPS device when traveling outside their homes for 4 weeks. The participants were also given a travel diary to record details of all excursions from their homes, including date, time, and destination information. We first designed and implemented an algorithm to extract destinations and infer activity types (eg, food, shopping, and sport) from the GPS data. We then evaluated the performance of the GPS-derived destination and activity information against the traditional diary method.

Results: Our results detected the stop locations of older adults from their GPS data with an F1 score of 87%. On average, the extracted home locations were within a 40.18-meter (SD 1.18) distance of the actual home locations. For the activity-inference algorithm, our results reached an F1 score of 86% for all participants, suggesting a reasonable accuracy against the travel diary recordings. Our results also suggest that the activity inference's accuracy measure differed by neighborhood characteristics (ie, Walk Score).

Conclusions: We conclude that GPS technology is accurate for determining semantic dimensions of outdoor mobility. However, further improvements may be needed to develop a robust application of this system that can be adopted in clinical practice.

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KEYWORDS

outdoor mobility; older adults; GPS; life space; activity types; machine learning

Introduction

With the growing population of older adults, the notion of *aging in place*, defined as "the ability to live in one's own home and community safely, independently, and comfortably," is of increasing importance [1]. Aging in place is desirable from both individual quality-of-life and public health perspectives. Many older adults prefer to age in place because it enables them to preserve their independence, autonomy, and social connection [2]. Furthermore, aging in place is favored by policy makers and health providers because keeping people in their homes for as long as possible can reduce institutional care costs [3]. Although most studies on aging in place focus on the home environment, there is rising recognition about the importance of neighborhoods and communities in older adults' ability to age in place [3-5]. Thus, many clinicians and researchers in the field of environmental gerontology are in search of a better understanding of older adults' travel patterns in the outdoor environment, a concept that will be referred to as *outdoor mobility* throughout the rest of this paper.

A commonly used model that focuses on older adults' outdoor mobility is *life space*, which is defined as the geographical area through which an individual moves [6]. To measure life space, the spatial environment is divided into several concentric zones (eg, bedroom, home, neighborhood, town, and out of town) and frequency of travel into each zone is recorded. Life space is traditionally measured through self-reported daily diaries or recall-based questionnaires [6,7]. The traditional life-space measures have many limitations. Travel diaries, for example, place the burden of data collection on study participants, which results in participants not recording trips that are too short or are made at inconvenient times. On the other hand, questionnaires require study participants to recall their movements during the month prior to the assessment date, which is particularly challenging for the cognitively impaired population. To overcome these limitations, more recent studies have used GPS data to create mobility indicators to assess life space, including maximum distance travelled, number of trips away from home, and area [8-11]. While most life-space studies rely only on a few indicators that represent spatial and temporal aspects of an individual's mobility [12-14], it has become clearer that mobility is a multidimensional construct [12,15,16]. Thus, in order to understand the full range of properties that emerge from mobility patterns, the construct must encapsulate the spatial, temporal, and semantic dimensions. In the current life-space mobility measures, semantic dimensions that would enable an exploration of the reasons behind the patterns that emerge in space and time are not included.

According to the *travel demand model*, travel is a derived demand, meaning that individuals travel to specific destinations in their environment in order to participate in certain activities [17]. Older adults' specific types of destinations and activities are indicative of their financial, psychosocial, physical, and cognitive status [18]. For example, participation in cognitively demanding activities, such as going to a bank, or physically demanding activities, such as playing tennis, can relay information about the cognitive or physical health of the individual, respectively. Furthermore, an understanding of relevant destinations and activities of older adults is required to design environments that support and target effective interventions that promote older adults' outdoor mobility [18]. Therefore, examining the destinations that are relevant to older adults, as well as activities that older adults conduct at those destinations, is critical to the comprehensive understanding of their mobility behaviors.

However, the raw positioning data collected by GPS devices do not provide any additional contextual information, such as the places that people visit or the activities they perform. In travel behavior research, this information is traditionally collected through questionnaires where users are asked to annotate their trajectories. In the last few years, studies have increasingly aimed at automatically annotating raw GPS data with activities performed by users. The most popular method for automatically annotating GPS data in the existing travel behavior research is the rule-based method [19-23]. The available studies utilizing a rule-based method matched the GPS data with a series of predefined heuristic rules to determine the appropriate activity type. For example, Bohte and Maat [22] used a distance measure as a rule to determine the location that is being visited and the type of activity. They first obtained the location where a trip ends. If this location was within a radius of 50 m from a known location, it is assumed that this is the location that the user visited; otherwise, it was flagged as unknown. Furthermore, a number of studies used a probabilistic method to infer activity type [24-26]. These studies calculated the probability of participating in each of the potential activities according to a predefined measure and then selected the most probable activity type. For example, Furletti et al [27] used car trajectories to infer the *point of interest* the user has visited. They then inferred the activity performed using the category of the point of interest and a probability measure based on the gravity law. These existing studies, however, have only focused on identifying destinations and inferring activity types at the aggregated level and have failed to examine mobility at individual levels.

Furthermore, there has been little work done to date on characterizing older adults' outdoor mobility according to its semantic aspects, such as destinations and activities. One approach entailed collecting activity-type information using self-report questionnaires [28]. This approach depends on the motivation and ability of the person to answer the questions accurately. An alternative approach has been to use ecological momentary assessments (EMAs) to classify types of activities. For example, in one study, activities of older adults within both residential and nonresidential environments were analyzed using EMAs [4]. That study was conducted during the course of 4 days, where EMA questions appeared as text on participants' iPhone screens for them to answer. The data in this study included a sample of participants' locations and activities within particular time windows and, therefore, was not comprehensive.

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In addition, EMA procedures can be burdensome and time consuming if the frequency of prompts increases [29]. Finally, both traditional questionnaires and EMAs are usually completed only a few times with each person and cannot effectively provide a comprehensive and objective assessment over time [30]. To date, however, no study has used an automated GPS-based approach to characterize older adults' outdoor mobility according to its contextual information, such as destinations and activities. This study aims to develop and validate an inclusive and automated GPS-based outdoor mobility model for older adults that (1) extracts ones' destinations and (2) infers activity types conducted at the most relevant destinations.

Methods

Data Collection

A total of 5 individuals [31], 65 years of age or older, were recruited from a registry of potential research participants that is maintained at Baycrest Health Sciences in Toronto, Ontario. Exclusion criteria included cognitive impairment as determined by a Montreal Cognitive Assessment score of less than 26 [32], significant functional limitations in activities of daily living (ADL) or instrumental activities of daily living (IADL) [33], and residing in assisted-living or senior housing. Informed consent was obtained from all participants. Ethics approval was obtained from the Baycrest Hospital Ethics Committee and the University Health Network Ethics Committee.

Participants were introduced to the SafeTracks Prime Mobile GPS device (SafeTracks GPS Canada) and instructed on how to use and charge it. The Prime Mobile device is small (3 cm × 5 cm × 2 cm) and light (less than 100 g). It automatically starts tracking when turned on, and its battery life lasts for about 8 hours of continuous tracking. Participants were asked to place these devices in their pockets, purses, or bags, or to wear them around their neck as a pendant. They were also provided with a small booklet and were instructed to record details describing all excursions from their home, including time and destination information. All participants completed 4 weeks of GPS data collection and travel diary recording. The 4-week study period was selected based on the time period used in the traditional life-space assessments [6,7].

The GPS device recorded location (ie, longitude and latitude coordinates), speed, and heading direction with corresponding time and date stamps. While in the *motion state*, the device provided sensor readings at a frequency of one reading per minute, and while in the *nonmotion state*, the device transitioned into standby mode until motion was detected. Textbox 1 introduces the definitions and notations that are used throughout this paper.

Textbox 1. Terminology used in this paper.

Definition 1: *GPS Record (P)* is the spatiotemporal location of the user in the form of (*Lat*, *Lon*, *t*, and *v*), where *Lat* and *Lon* are the latitude and longitude coordinates, *t* is the date-time stamp, and *v* is the instantaneous speed.

Definition 2: *Trajectory (T)* is a set of GPS records that are ordered based on their date-time attributes *t*,

$T = \{P_0, P_1, \ldots, P_n\}$, where $t_0 < t_1 < \ldots < t_n$

Definition 3: *Stop (S)* is a location at which the individual stays for more than a predefined time,

$S = (Lat, Lon, \Delta t)$

where Δt is the time the individual spent at the location, and the *Lat* and *Lon* coordinates are the centroid of all GPS points collected at the stop.

Since the stop measurements in the same location can vary, a stop cluster is defined.

Definition 4: *Stop Cluster* is a set of stops that belong to the same location.

Stop Detection

Algorithm

Two types of stops were considered when constructing a system to find the geographical locations of relevant destinations (ie, stops): (1) *full signal* and (2) *no signal* (see Figure 1). A *full-signal* stop was a stop location that contains a set of consecutive GPS records with no signal loss. The latitude and longitude of a full-signal stop was the centroid of all the GPS records in the stop. On the other hand, a *no-signal* stop was detected in two cases: (1) at areas with obstructed GPS signal and (2) when no motion is detected and the GPS device transitions into power-saving mode. This stop type consists of two GPS points: one immediately before and one immediately after the signal loss. The distance between these two adjacent points must be smaller than 150 meters. Otherwise, the signal loss can be due to underground transportation. The latitude and longitude of a *no-signal* stop was the centroid of the two GPS records in the stop. The velocity threshold was neglected because the GPS records in a no-signal stop may belong to the trip prior to the stop and poststop.

The stop-detection method used three threshold values. First, the time threshold (δ_t) was set to 3 minutes to disregard short stops, such as stops at traffic lights, and to only detect the more meaningful destinations. Second, the distance threshold (δ_d) was selected to be 150 meters based on the average block size in the Greater Toronto Area. Third, the speed threshold (δ_v) was set to 2 m/s based on the SafeTracks GPS device speed–recording accuracy and the average walking speed for community-dwelling older adults ranging from 0.9 to 1.3 m/s [34].

To detect *full-signal* stops, initially, the first GPS record in the trajectory is added to the cluster. Then, each time a GPS record (P_i) is read, three measures are evaluated: (1) the time interval between the last GPS record (P_{i-1}) in the cluster and P_i, (2) the distance between P_{i-1} and P_i, and (3) the speed at P_i. If all values

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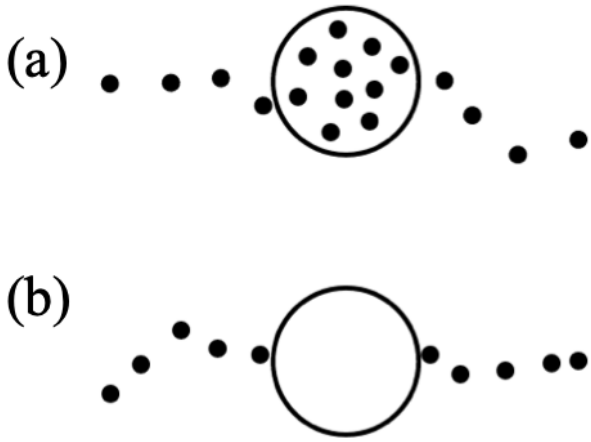
are less than their corresponding thresholds (δ_t, δ_d, and δ_v), the GPS record (P_i) is added to the cluster. Otherwise, we add the cluster to the list of stops (S), set the previous cluster to be the current cluster, and empty the current cluster.

To detect *no-signal* stops, we compute the distance and time interval between each GPS record and its previous record in the trajectory; if the extracted distance is less than the distance threshold and the time interval is more than the time threshold, a cluster of the two GPS records is added to the stop list.

Finally, when a cluster is added to the stop list, the distance and time interval between the centroid of the cluster and the previous cluster is computed; if the values are less than the corresponding thresholds, the two clusters are merged, the previous cluster is set to the new merged cluster, and the current cluster is emptied.

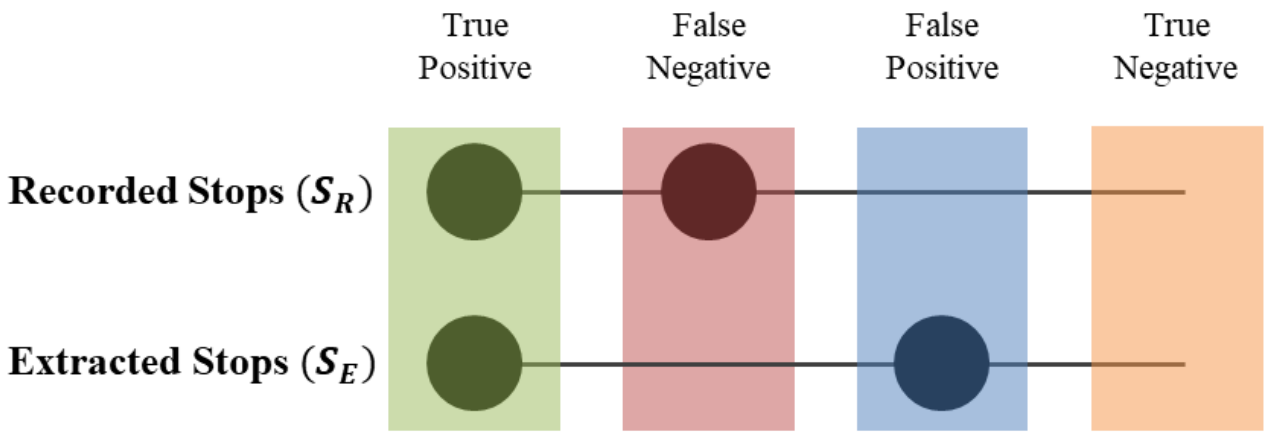
Figure 1. Stop types: (a) full-signal stop and (b) no-signal stop.



Evaluation

To evaluate the performance of the stop-detection algorithm, the stop points recorded in the travel diary (S_R) are compared with the stop points extracted from the GPS data (S_E). Figure 2 demonstrates different stop conditions. A *true positive* (TP) refers to a stop location recorded in the travel diary that correctly matches with a stop location extracted from the GPS data. We find a match if the distance between the recorded stop and the extracted stop is smaller than 150 meters. A *false negative* (FN) stands for a stop point recorded in the travel diary that is not extracted from the GPS data (ie, the algorithm considers it to be part of a trip or the user forgot to take the GPS device). A *false positive* (FP) refers to a stop point extracted from the GPS data but not recorded in the travel diary. Finally, a *true negative* (TN) occurs when no stop is extracted or recorded.

Figure 2. Comparison of the stops recorded in the travel diary versus the stops extracted from the GPS data.



Using the four stop conditions (ie, TP, TN, FP, and FN), the F1 score is determined to evaluate the performance of the stop-detection algorithm:

$$F1\ score = (2 \times precision \times recall) / (precision + recall)$$

where precision is TP/(TP + FP) and recall is TP/(TP + FN).

Activity Inference

Algorithm

Home

To infer the home location of each participant, the algorithm for density-based spatial clustering of applications with noise (DBSCAN) was used [35]. DBSCAN has been successfully used to find stop points with the most visits in GPS trajectories [36]. Two parameters that affect the results in DBSCAN are the

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cluster radius (*Eps*) and the minimum number of points required to form a cluster (MinPts). The MinPts parameter was set to 4 as suggested in Ester et al [35] for 2D data. To obtain the optimal *Eps* value for each participant, we draw a k-distance plot for k=4 and find the *knee*, which corresponds to a sharp change of gradient along the curve [37]. The fourth-nearest neighbor distance plot for participant 1 is presented in Figure 3. The knee point, which represents a change in density among the stop points, is selected as the optimal *Eps*. Table 1 demonstrates the optimal *Eps* value for each participant.

Figure 3. Participant 1's fourth-nearest neighbor distance. *Eps*: cluster radius.

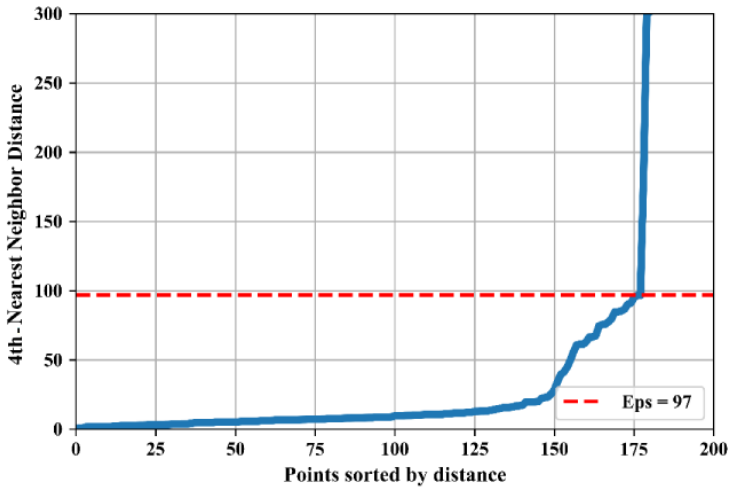

Table 1. Optimal cluster radius (*Eps*) value for each participant.

Participant	*Eps*, m
1	97
2	94
3	59
4	32
5	95

Other Activities

The activity-inference algorithm takes as input the list of stops and outputs the most probable activity type at each stop location. For each stop point (S_i), a Nearby Search was invoked from the Google Places application programming interface (API). The search returned a list of places within a 150-meter radius of the S_i. Then, for each place, a Place Details search was invoked, which returned details including place name, type, and opening hours. The place was only considered if it was open during the stop. Next, the place types were mapped into activity types according to Table 2. If the Nearby Search returns nothing or if the place type does not fall into any of the listed categories, it would be placed into the *Other* category. To find the most probable activity type at each stop, the gravity model was implemented [27]. This model associated a probability to each possible activity by taking into account the distance of each place from the stop and the general characteristics of the stop location. For example, if a stop is in an area with many places that are mapped to food and few places that are mapped to medical services, the gravity model gives more weight to food as compared to medical services.

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Table 2. Mapping between place types and activities.

Activity category	Place type
Food	Bakery, bar, cafe, food, meal takeaway, restaurant, and meal delivery
Daily shopping	Grocery and supermarket
Shopping	Bookstore, clothing store, convenience store, hardware store, electronics store, furniture store, shopping mall, liquor store, pet store, shoe store, and department store
Services	ATM (automatic teller machine), bank, car rental, car repair, finance, insurance, gas station, travel agency, post office, accounting, beauty salon, courthouse, and laundry
Leisure	Bowling alley, casino, library, movie rental, movie theater, museum, park, spa, stadium, and lodging
Medical services	Dentist, hospital, pharmacy, physiotherapist, chiropractor, psychologist, naturopath, walk-in clinic, sleep lab, LifeLabs[a], and Dynacare[a]
Religious	Church, Hindu temple, synagogue, and mosque
Sport	Gym and YMCA

[a]LifeLabs and Dynacare are medical laboratory services companies based in Ontario.

Evaluation

From the TP stops, the ones annotated by the activity-inference algorithm are compared to the ones declared by the participant in the travel diary. For the activities annotated as *Activity at Home*, the distances between the participant's actual home location and extracted home locations are computed.

Results

Participants

A total of 5 cognitively intact, community-dwelling individuals completed 4 weeks (ie, 28 days) of GPS monitoring and travel diary recording. Table 3 presents the summary statistics of the travel diary recordings for each participant.

The average age of participants in the study sample was 73 years (SD 6) (range 68-80); participants lived within the Greater Toronto Area and were all active drivers. Study participants had an average Montreal Cognitive Assessment (MoCA) score of 27.8 (SD 1.8). All 5 participants received a score of 6 in ADL and 8 in IADL, indicating the highest level of function. For more details of the sample's demographic characteristics, including the Walk Score [38], refer to Table 4.

The sample of 5 consisted of 4 retired older adults (80%) (Participants 2-5) and 1 older adult (20%) with a part-time job (Participant 1). It should be noted that although employed, Participant 1 was not working during the 4 weeks of the study.

Table 3. Summary statistics of 4 weeks of travel diary recordings for the participants.

Participant	Number of stops	Stops per day, mean (SD)
1	117	5.6 (2.5)
2	89	3.4 (1.5)
3	88	3.5 (1.8)
4	124	4.6 (1.9)
5	108	4.2 (1.9)

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Table 4. Sample demographic characteristics.

Participant	Age in years	MoCA[a] score	Sex	ADL[b] score	IADL[c] score	Employment status	Driving status	Walk Score[d]
1	68	26	Female	6	8	Employed part time	Driving	65
2	70	26	Female	6	8	Retired	Driving	30
3	78	30	Female	6	8	Retired	Driving	57
4	68	29	Male	6	8	Retired	Driving	94
5	80	28	Female	6	8	Retired	Driving	69

[a]MoCA: Montreal Cognitive Assessment.

[b]ADL: activities of daily living. ADL scores ranged from 0 (lowest level of function) to 6 (highest level of function).

[c]IADL: instrumental activities of daily living. IADL scores ranged from 0 (lowest level of function) to 8 (highest level of function).

[d]Walk Score is a measure of access to walkable amenities, ranging from 0 (Car-Dependent) to 100 (Walker's Paradise) [38].

Stop Detection

We reached a global stop-detection F1 score of 87% for all participants. The F1 score of each participant was computed and presented in Figure 4. The scores suggest that destinations of individuals can be detected with reasonable accuracy.

We further evaluated the stop detection by analyzing the mobility patterns. Figure 5 shows the distribution of stop locations recorded in the travel diary (left) versus the ones extracted from GPS data (right) for Participant 1 over the 4 weeks of the study. Additionally, an envelope was built around all stop points using the convex hull algorithm to represent the extent of travel into the environment (ie, life-space area). From Figure 5, it is clear that the two distributions are similar, although some stop points are missing in the diary plot.

Figure 4. Stop-detection F1 scores for participants 1 to 5 (P1-P5).

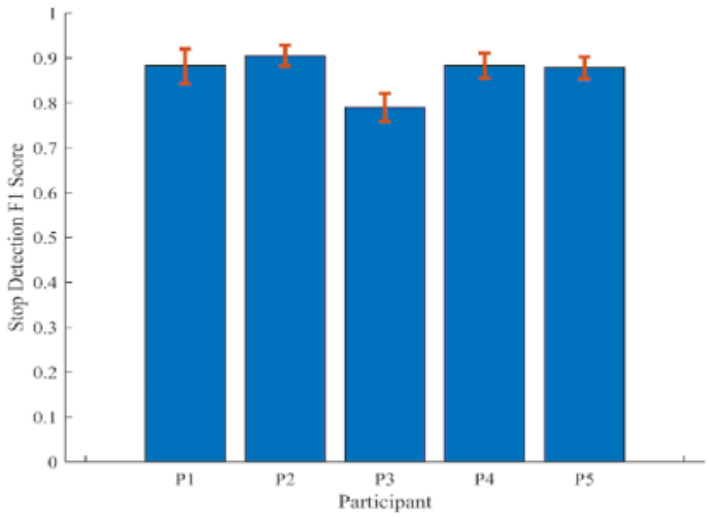

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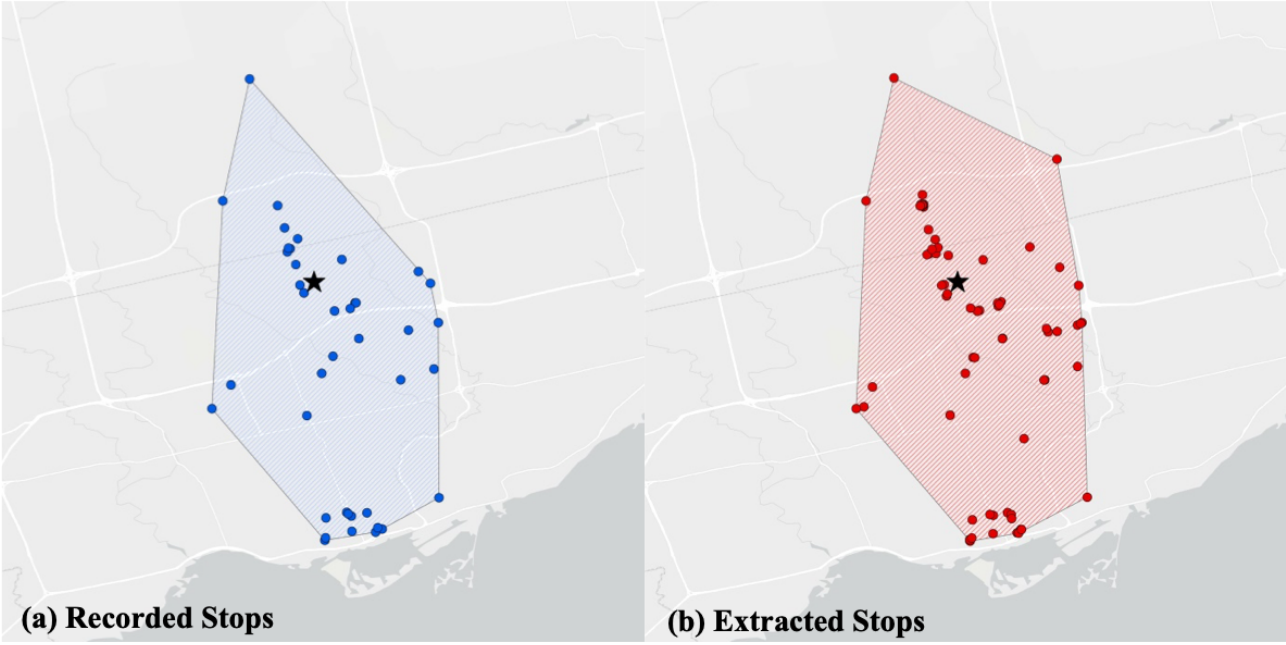
Figure 5. Comparison of (a) stops recorded in the travel diary versus (b) stops extracted from the GPS data for Participant 1.



Home and Activity Inference

Table 5 presents the distances between the participants' actual home locations and extracted home locations. On average, the extracted home locations were within a 40.18-meter (SD 1.18) distance of the actual home locations.

For all activity types including activities at *home*, F1 scores were obtained, which determine the percentage of activities correctly classified with respect to the activities recorded in the travel diary. Each participant's score is presented in Table 6. A global F1 score of 86% was reached for all participants.

Table 5. Distances between the actual home locations and extracted home locations.

Participant	Distance, m
1	6.60
2	50.3
3	19.9
4	20.4
5	76.7

Table 6. Activity inference's F1 score.

Participant	F1 score	Number of stops
1	0.89	74
2	0.90	79
3	0.86	101
4	0.79	95
5	0.86	87

The scores suggest that we can infer activity types with reasonable accuracy for all participants. It can be demonstrated that the algorithm reached its lowest score for Participant 4. To understand the reason behind this, the neighborhood characteristics of each participant's destinations were examined using Walk Score, a measure of access to walkable amenities, ranging from 0 (Car-Dependent) to 100 (Walker's Paradise) [38]; the distribution of scores are shown in Figure 6. It can be demonstrated that for Participant 4, all destinations are located in neighborhoods with Walk Score values of greater than 80.

Furthermore, for personalized evaluation of the activity-inference algorithm, plots showing the percentage of activities that were inferred from the GPS data and declared in the travel diary for all 5 participants and each activity category are presented in Figure 7. In general, the percentage of inferred activities and percentage of declared activities follow a similar trend.

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Figure 6. Distribution of Walk Scores of each participant's (P) destinations, as calculated by Walk Score [38]. A score of 0-24 or 25-49 is considered Car-Dependent, a score of 50-69 is considered Somewhat Walkable, a score of 70-89 is considered Very Walkable, and a score of 90-100 is considered Walker's Paradise.

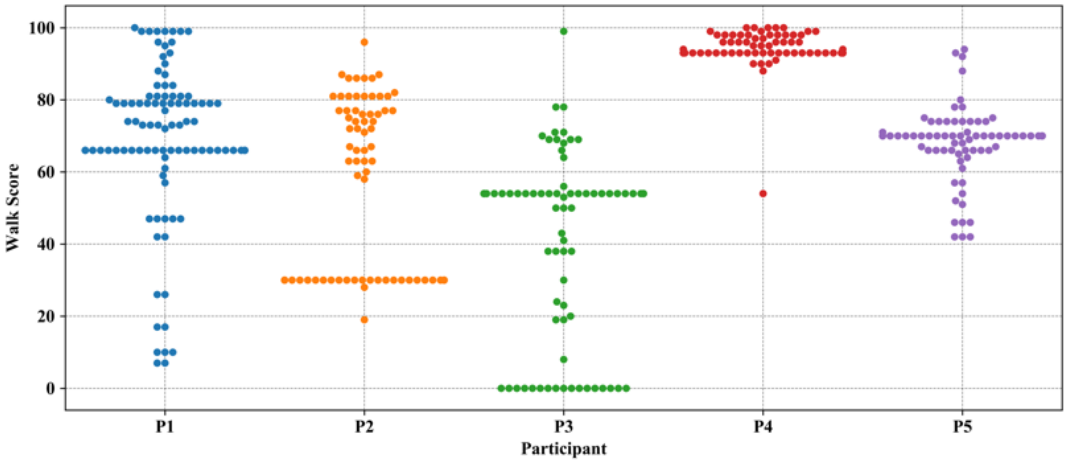
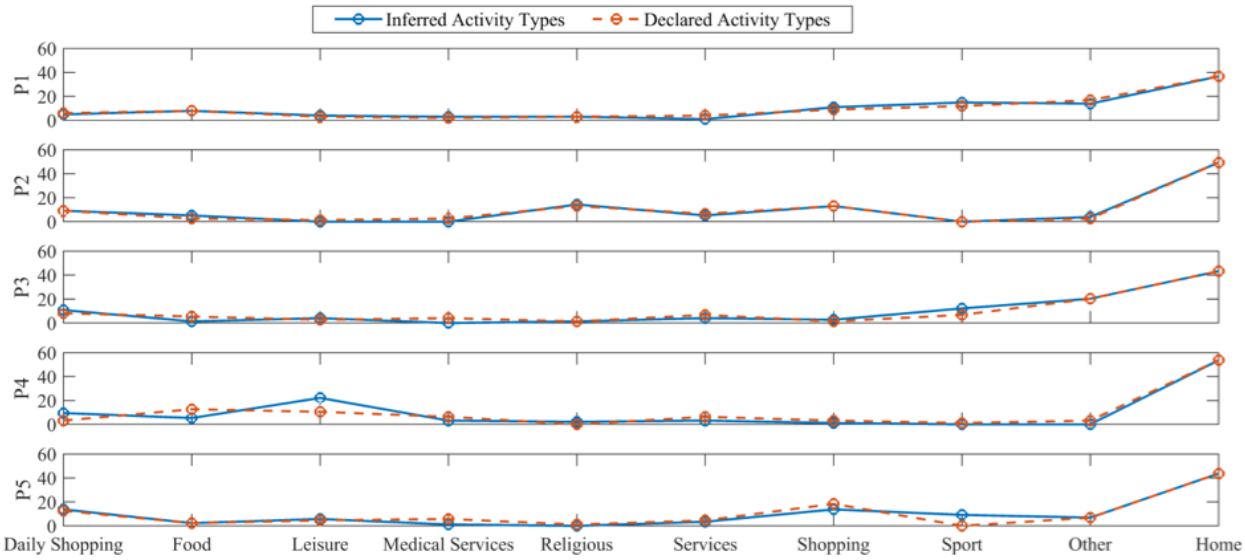


Figure 7. Comparison of the number of activity types in the travel diary versus the ones inferred from the GPS data for Participants 1 to 5 (P1-P5).



In order to further demonstrate the effects of neighborhood characteristics on the performance of activity inference, the out-of-home destinations were first placed into five groups according to their Walk Score [39]: (1) Walker's Paradise (90-100), where most errands can be accomplished on foot, and many people get by without owning a car; (2) Very Walkable (70-89) areas, where it is possible to accomplish most errands without driving; (3) Somewhat Walkable (50-69) areas, where some amenities are within walking distance, but many daily errands still rely on public transportation or driving; (4) Car-Dependent (25-49) areas, where a few destinations are within walking distance, but most activities require driving or public transportation; and (5) Very Car-Dependent (0-24), where no neighborhood destinations are within walking range. Then, the average F1 score of the activity-inference algorithm in each group was determined. Table 7 illustrates that by moving from neighborhoods with a high density of amenities to neighborhoods with a low density of amenities, the performance of the activity-inference algorithm improves.

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Table 7. Effects of Walk Score on performance of the activity-inference algorithm.

Category	Walk Score[a]	F1 score	Number of stops
Walker's Paradise	90-100	0.58	58
Very Walkable	70-89	0.76	87
Somewhat Walkable	50-69	0.83	46
Car-Dependent	25-49	0.79	22
Very Car-Dependent	0-24	0.96	24

[a]Walk Score is a measure of access to walkable amenities [38].

Discussion

Principal Findings

This paper presents a framework that allows classification of semantic aspects of outdoor mobility including destination and activity type. This framework is complementary to the GPS-based mobility indicators used in the literature to assess spatial and temporal facets of outdoor mobility and can enhance the understanding of older adults' outdoor mobility behavior.

The results show that, on average, 86% of activity types, including home activities, recorded in the travel diaries were correctly inferred. The performance of the activity-inference algorithm, however, depends on the neighborhood characteristics of destinations. If a destination is in a neighborhood with a high Walk Score (ie, Very Walkable or Walker's Paradise) where places are densely positioned, the algorithm can have difficulty identifying the correct places and the corresponding activity types; however, for destinations in less-walkable neighborhoods with a low Walk Score (ie, Very Car-Dependent, Car-Dependent, or Somewhat Walkable), the algorithm performed better. This pattern further hinders the performance of the algorithm when a participant's primary residence is in a high–Walk Score neighborhood, where their destinations are mostly concentrated within the same area, as illustrated with Participant 4's results in Figure 6. This renders the algorithm unable to precisely draw inferences, given the high-density life space, ultimately resulting in a lower F1 score. Furthermore, looking into the Walk Score of each participant's destinations (see Figure 6), it can be observed that among our 5 participants, Participant 4's destinations were positioned in locations with a higher Walk Score, and the algorithm reached the lowest activity-inference F1 score for this participant.

It is important to note that there are challenges associated with using travel diaries as ground truth. Participants' compliance with the diaries tends to decline over time. Due to the burden of manual data recording, participants may avoid or forget to record trips that are too short or that are made at inconvenient times. By examining the distributions of recorded and extracted stop locations in Figure 5, it can be observed that more stops were extracted from the GPS data in comparison to the stops recorded in the diary, suggesting that some stops in the GPS data were not recorded in the travel diary.

Furthermore, travel diaries included the street addresses of the destinations. In order to build ground truth of the destinations, we first geocoded each street address using the Google Maps API. Given a street address, Google Maps API returned the latitude and longitude coordinates. However, this process is not always straightforward. For example, in the cases where the recorded address in the diary is incomplete, the correct coordinate may not be determined. To minimize these ambiguities, during the digitizing process of the travel diaries, the recorded addresses were verified. Since a verified address corresponds to a unique geographical coordinate, the destinations that were visited multiple times had the exact same latitude and longitude coordinates and are completely overlapping in Figure 5. This is not the case for the stops extracted from the GPS data. The GPS device does not record exactly the same coordinate for a unique destination. Even if the participant is staying at the same location for some time, the GPS records can vary by up to 15 meters. Therefore, in the GPS data, the coordinates corresponding to the same physical location can vary. This can be clearly observed in Figure 5 where there are multiple stops in close proximity belonging to the same location.

The mapping between the place types and activity categories is another important issue. The activity categories are inferred based on the place types available on the Google Maps. However, there are some occasions where the activities conducted at a specific place cannot be uniquely determined. For example, playing golf with some friends can be considered as *Sport* or *Leisure* activity. On the other hand, due to the limitations of GPSs in indoor settings, for some multipurpose locations the correct activity type cannot be inferred. For example, a movie theater inside a shopping center can be identified as a *Shopping* activity instead of a *Leisure* activity. This issue can be addressed in future studies by having a hybrid system that relies on a Wi-Fi positioning system for indoor tracking and GPS for outdoor tracking.

Our proposed model outperforms the existing activity-inference techniques. One major advantage of the proposed model is that it does not require any prior information regarding users' most-visited destinations. Most of the available techniques for inferring activity types from raw trajectories involve some initial data collection at the time of recruitment. These studies collect the addresses of each participant's most-visited locations, such as home, workplace, school, or the frequently used grocery stores [20-22], and claim that these locations yield more than 60% of each participant's activities [21]. Our presented model, however, is fully autonomous and uses a density-based clustering method to extract the most-visited destinations of each participant. This improvement is particularly important for exploring activity profiles of the older adult population

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because their most-visited destinations are not always an educational establishment or workplace. Another advantage is that while most of the prevailing techniques use a small list of points of interest to infer activity types [20,22], our model takes advantage of the Google Places API system, which is currently the most comprehensive dataset of points of interest. Additionally, while most studies use a uniform probability measure to select the most appropriate activity category [21,22,25], our model implemented a gravity-based approach similar to the method introduced in Furletti et al [27] to select the most probable activity category for each destination.

Furthermore, most studies that present empirical results of activity-inference methods only focus on car trips [24,26,27]. The GPS data used in this study were collected by participants during their out-of-home trips using various modes of transportation. It is worth noting that although the gravity-based probability measure used to infer activity types in our study was similar to the approach introduced in Furletti et al [27], our results achieved a higher accuracy. This is because in Furletti et al [27], they used positioning data collected by tracking devices installed in cars. In this case, the identification of the stop locations can become problematic because a car usually cannot enter inside the stop location, meaning that the participant needs to park the car and then walk to the destination, which will not be tracked by the GPS device. In our study, however, the GPS devices were being carried by the participants inside all the stop locations they visited. Furthermore, our activity-inference algorithm also discusses the detection of the home location, which was not included in Furletti et al [27].

Limitations

The findings should be understood in light of some inherent limitations within this study, which can be addressed in future research. First, the small sample size in this study, although effective for demonstrating the feasibility of the developed algorithms [31], is not representative of the population and is, thus, not suitable for statistical analysis of the population. Further studies on larger sample sizes are required in order to comprehensively analyze the activity profiles of older adult populations. Second, a cutoff of 65 years of age was used in this study, resulting in a sample age range of 68-80 years. This wide age range along with the small sample size prohibited analysis on age-related changes in the activity profiles of older adults. Future studies can divide the older adult population into three subgroups—the young-old (65-74 years), the middle-old (75-84 years), and the old-old (over 85 years)—and investigate the mobility and activity profile of each subgroup separately. Third, all the participants were from the Greater Toronto Area. Further research is required on older adults from a set of representative locations that reflect the climatic, socioeconomic, and geographic diversity of the older adult population. Finally, due to recruitment challenges, our sample contained an unbalanced sex distribution (ie, 1 male and 4 females), which prohibited any statistical analysis by sex or gender. Future studies should examine gender differences, since they may be attributable to a variety of interrelated factors, including differences in perceptions of safety and cultural norms regarding outdoor mobility.

Conclusions

In environmental gerontology research, GPS devices are becoming increasingly more common to accurately and continuously measure older adults' outdoor mobility, thereby addressing limitations of traditional self-reported measures, such as recall biases. Outdoor mobility, however, is a multidimensional concept and it is challenging to characterize it comprehensively with only spatiotemporal indicators derived from GPS data.

In this paper, we extend the literature on older adults' mobility models through development and validation of a framework that relies on GPS data to capture older adults' travel destinations (ie, stop points) and activity types. We have performed a comparison with ground truth based on travel diaries, and we have evaluated in detail the performance of the implemented stop-detection and activity-inference algorithms. Our results indicate that it is possible to extract destinations and infer activity types from GPS data with reasonable accuracy.

This paper encourages incorporation of GPS-based mobility indicators that reflect the semantic dimension of individuals' outdoor mobility into future health- and aging-related research. This approach fosters a better understanding of what aspects of mobility are key to healthy aging. It also shows great potential in examining the impact of interventions and long-term monitoring of social connection, functionality, and quality of life. Future research should aim to utilize GPS technology to assess older adults' transportation modes in order to provide insights about different ways of conceptualizing older adults' environmental exposure.

Acknowledgments

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Conflicts of Interest

None declared.

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Abbreviations

ADL: activities of daily living
AGE-WELL NCE: Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life Networks of Centres of Excellence
API: application programming interface
ATM: automatic teller machine
CCNA: Canadian Consortium on Neurodegeneration in Aging
DBSCAN: density-based spatial clustering of applications with noise
EMA: ecological momentary assessment
***Eps*:** cluster radius
FN: false negative
FP: false positive
IADL: instrumental activities of daily living
MinPts: minimum number of points required to form a cluster
MoCA: Montreal Cognitive Assessment
TN: true negative

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TP: true positive

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Original Paper

Artificial Intelligence–Powered Digital Health Platform and Wearable Devices Improve Outcomes for Older Adults in Assisted Living Communities: Pilot Intervention Study

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Abstract

Background: Wearables and artificial intelligence (AI)–powered digital health platforms that utilize machine learning algorithms can autonomously measure a senior's change in activity and behavior and may be useful tools for proactive interventions that target modifiable risk factors.

Objective: The goal of this study was to analyze how a wearable device and AI-powered digital health platform could provide improved health outcomes for older adults in assisted living communities.

Methods: Data from 490 residents from six assisted living communities were analyzed retrospectively over 24 months. The intervention group (+CP) consisted of 3 communities that utilized CarePredict (n=256), and the control group (–CP) consisted of 3 communities (n=234) that did not utilize CarePredict. The following outcomes were measured and compared to baseline: hospitalization rate, fall rate, length of stay (LOS), and staff response time.

Results: The residents of the +CP and –CP communities exhibit no statistical difference in age (P=.64), sex (P=.63), and staff service hours per resident (P=.94). The data show that the +CP communities exhibited a 39% lower hospitalization rate (P=.02), a 69% lower fall rate (P=.01), and a 67% greater length of stay (P=.03) than the –CP communities. The staff alert acknowledgment and reach resident times also improved in the +CP communities by 37% (P=.02) and 40% (P=.02), respectively.

Conclusions: The AI-powered digital health platform provides the community staff with actionable information regarding each resident's activities and behavior, which can be used to identify older adults that are at an increased risk for a health decline. Staff can use this data to intervene much earlier, protecting seniors from conditions that left untreated could result in hospitalization. In summary, the use of wearables and AI-powered digital health platform can contribute to improved health outcomes for seniors in assisted living communities. The accuracy of the system will be further validated in a larger trial.

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KEYWORDS

health technology; artificial intelligence; AI; preventive; senior technology; assisted living; long-term services; long-term care providers

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Introduction

Advances in public health and medical treatment over the past century have increased the average life expectancy in the United States by 30 years [1,2]. The number of people aged 65 years and older in the US is projected to more than double from 46 million today to 98 million by 2060 [3]. Individuals aged 85 years and older are the most rapidly growing age segment and have a growth rate that is four times that of the total population [4]. This age group is projected to triple from 6 million today to nearly 20 million by 2060, and this demographic shift is driving unprecedented needs for eldercare [5,6].

Older adults are disproportionally affected by chronic conditions, where 77% have at least two, and 65% have four or more chronic diseases [7-10]. Consequently, older adults tend to have the highest disability rate, the greatest need for long-term care services, and are more likely to be widowed and without someone to assist with activities of daily living [10,11]. Adults that suffer from chronic diseases that affect their mobility, independence, and ability to perform activities of daily living tend to require personal assistance in their home from either paid or unpaid caregivers, and if their needs are extensive may require relocation from their home to senior assisted living communities [5,10,12].

Assisted living is a long-term care option that combines housing, personal assistance with activities of daily living, and supportive specialized services and therapy. In the US, approximately 812,000 older adults live in nearly 29,000 assisted living communities [13-15]. Assisted living residents are, on average, 87 years of age, suffer from multiple chronic conditions, and nearly 75% require assistance with at least one activity of daily living [13-16]. Assisted living communities are beginning to utilize various types of technologies to maintain the health of their residents and increase their length of stay in the community [17]. Unplanned hospitalizations lead to decreased lengths of stay and are one of the primary causes of residents moving out of assisted living communities [18]. Hospitalizations are also a strong predictor of future nursing home admission and are associated with health declines, lower quality of life, and greater health care costs [18]. Falls are one of the leading causes for the hospitalization of residents in assisted living communities [19-24], and over the past decade, the fatality fall rate for adults age 85 and older has increased 41% [25,26]. Incident fall rates in assisted living communities range between 1.07 and 3.5 falls per person per year [23,27,28], and falling once doubles an older adult's risk of falling again [29]. The fear of falling can also drive seniors to limit their activities, which can result in further physical decline, depression, and social isolation [30]. Fall detection technologies have improved in recent years; however, considering that 20-30% of falls are preventable [25,26], technologies are needed to predict and prevent falls [20,31-33].

Many caregivers in assisted living communities rely solely on their observational powers to detect health changes in older adults in their care. As the number of residents requiring more assistance is increasing in these communities, the number of available caregivers is decreasing dramatically. Technologies can be utilized to augment and force-multiply human observation and provide quality care. Such solutions can provide continuous observation, detecting changes in activity and behavior patterns that may be indicative of a change in health status—information that cannot be provided by intermittent human observation. Artificial intelligence (AI) can be used to bridge the caregiver-senior ratio gap and augment occasional human observation with continuous machine observation and deep learning neural nets to predict when interventions are needed.

A growing body of evidence demonstrates that sensor-laden wearables utilizing AI, and in particular machine-learning algorithms, can detect an individual's daily activity and behavior [17,34-41]. In 1995, Celler et al developed the first telemonitoring system that could remotely monitor an older adult's functional health status by continuously measuring their interactions over time [42]. The system measured a user's mobility, sleep patterns, and utilization of cooking, washing, and toilet facilities to identify changes in functional health status [42]. In recent years, several monitoring technologies have been developed: radar sensing systems, passive infrared motion sensors, body-worn wearables, camera and video monitors, pressure sensors, and sound recognition [36,43-45]. Passive, ambient nonwearable based systems have found utility in home settings where one individual resides; however, such systems have difficulty accurately identifying a unique individual's activity and behavior in a senior living community where many residents and staff members work and live [43]. The CarePredict AI-powered digital health platform, wearable device, and location system was developed for the autonomous, continuous, longitudinal measurement of activity and behavior patterns for multiple older adults and caregivers in a community setting [46-48]. The system measures a senior's activity and behavior and can detect when such behavior is outside of their individual baseline. Caregiving staff can use the system to identify residents that may have an increased probability for a fall, depression, or urinary tract infection (UTI), and thereby give them time to provide a proactive intervention, protecting seniors from conditions that, left untreated, could result in hospitalization.

In this study, we tested whether the use of the CarePredict system could effectively improve the care provided in senior living communities. Specifically, we assessed the impact on hospitalization rate, fall rate, length of stay, and staff response time in each assisted living community.

Methods

Study Design and Population

The study was designed to assess facility-level and resident-level outcomes for communities that utilized CarePredict's AI-powered digital health platform, wearable device, and real-time location system. Retrospective analysis of anonymized resident data was collected from six assisted living communities in three states over 24 months. A study flow chart is provided in Figure 1. Data were analyzed for 472 residents in year 1 and 490 residents in year 2. The participants agreed to the collection of data presented in this publication by signing the terms and conditions for use, and data were anonymized for statistical

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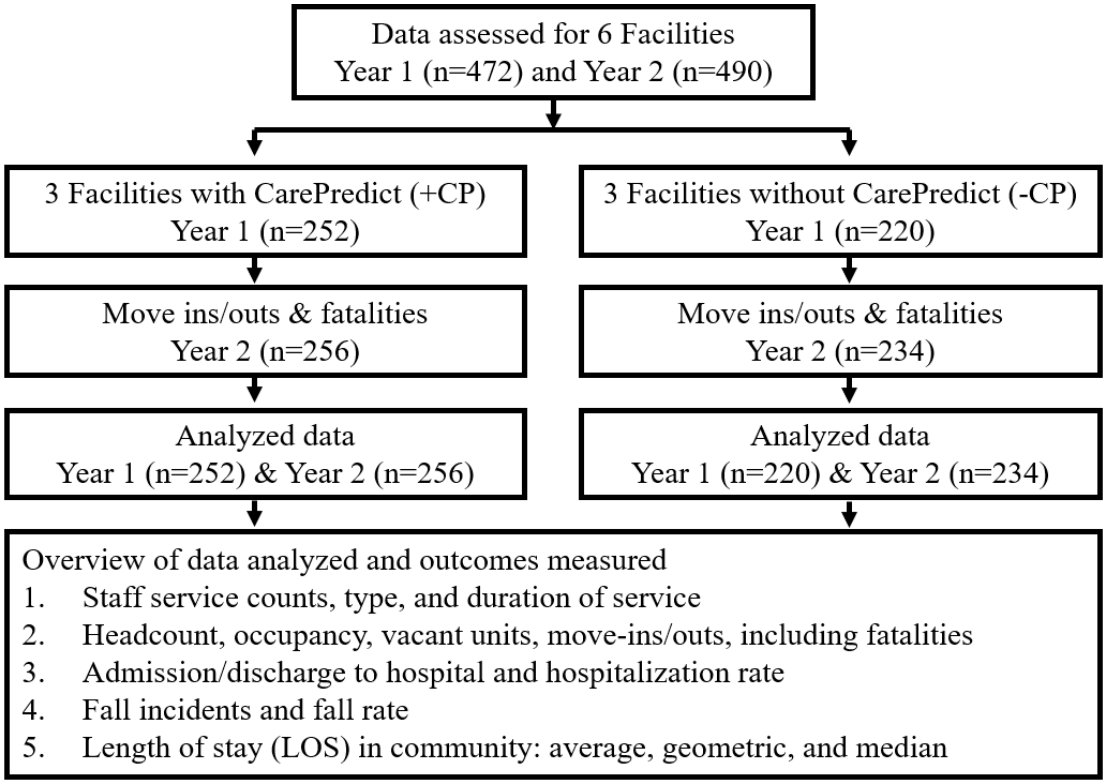
analysis. Due to the nonexperimental, retrospective, de-identified, and anonymized study design, no ethical approval was needed.

Figure 1. Workflow of data collection and analysis.



Data Collection

All de-identified data analyzed in this study were collected and reported by facility staff using each community's online electronic healthcare software platform. The same software was used in all communities. CarePredict employees were provided access to the extracted anonymized data for scientific evaluation. No identifiable resident information has been or will be shared.

Equipment and Process

The CarePredict system consists of a wrist-worn wearable device, context beacons for room location, and a cloud-based AI-powered platform (Figure 2A-B). The wearable is worn on a user's dominant arm, measures changes in their wrist kinematics, and autonomously quantifies gestures and activities of daily living such as eating, bathing, walking, bathroom visits, and sleep duration (Figure 2A-B). The wearable uses wireless communication to transfer data to the cloud over an encrypted connection and supports two-way audio that allows the resident to communicate to staff using mobile apps on iOS and Android devices. The wearable supports radio-frequency identification (RFID) protocols to allow integration with electronic door access systems enabling the resident to use their wearable for safe, secure, and convenient access to their apartment. The wearable measures 50 × 33 × 17.7 mm, weighs 40 g, and includes a six-axis accelerometer, a microprocessor, RFID, Bluetooth 4, Wi-Fi 802.11 b/g/n, and 1 Gb of onboard storage capable of storing 6 days of data. The wearable has a swappable battery, so the device does not need to be removed for charging. The battery is a 380mAH Li-ion 10.6g Polymer battery with 50 to 110 hours of battery life. The wearable has an operational temperature range of –20°C to +55°C, water-resistant to IP67, and the following certifications: FCC, CE, TELEC, RoHS, REACH, WEEE, Bluetooth.

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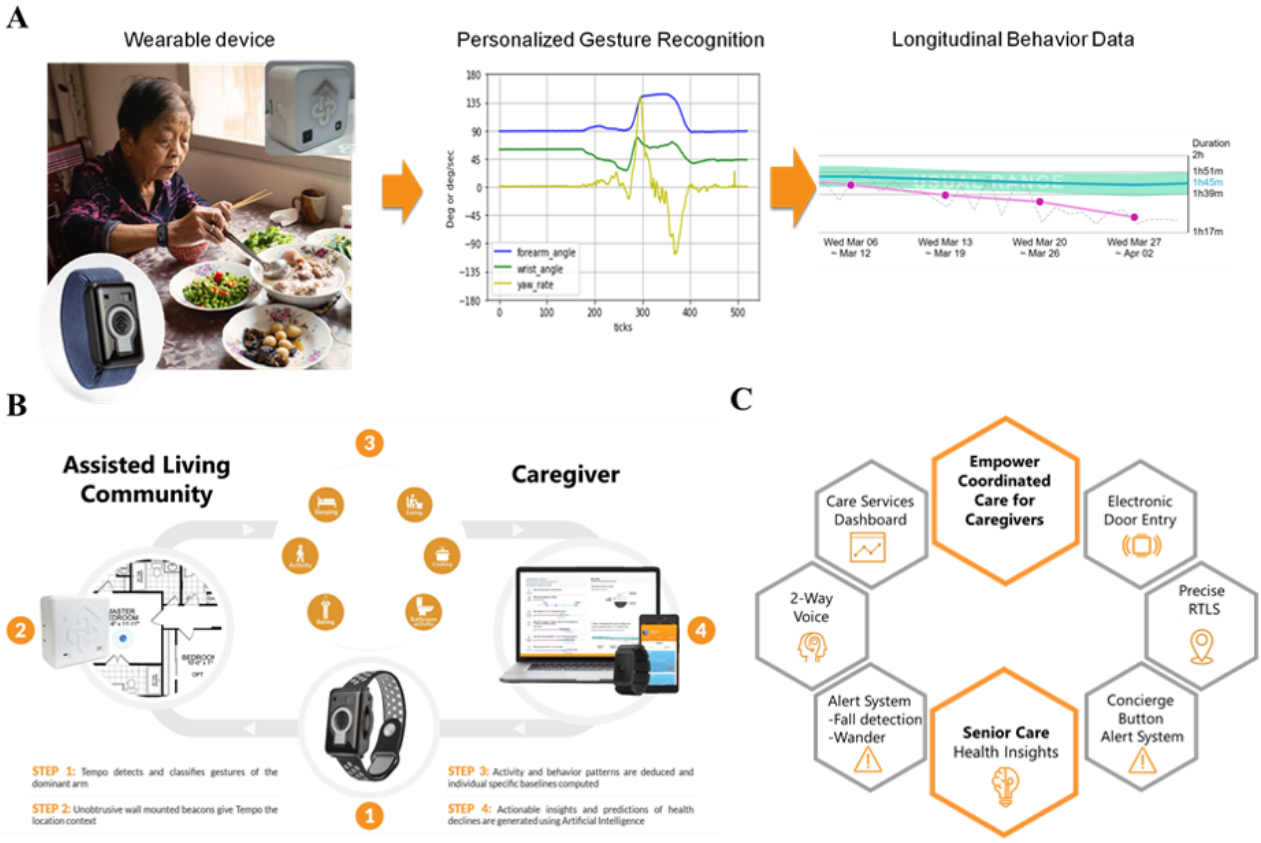
Figure 2. AI-powered digital health platform, wearable device, and room location system. A. Wearable device and sample representation of gesture recognition and activity detection. B. System architecture and overview of the data collection process. C. Summary of the product's primary functions.



The real-time location or context beacons enhance the accuracy of the wearable's gesture recognition engine by bringing in room type data and permitting accurate room-level location tracking in an indoor setting [47]. Each beacon measures 52.1 × 52.1 × 28.0 mm, weighs 78 g, and uses Lithium CR123A batteries. The beacons utilize a proprietary line-of-sight technology to allow for real-time location monitoring on multi-floor levels with room-level accuracy and no bleed-throughs [46-48]. The CarePredict product is used in assisted living communities to provide five key functions (Figure 2C).

Actionable Insights

The system collects unique and rich data sets to train deep learning neural nets to surface crucial insights that correlate with an increased risk for a fall, UTI, or depression. A few correlates used in the system include the following: increased fall risk due to malnutrition, skipping meals, increased nightly get up count, reduced sleep duration, and decreased physical activity level; the increased probability for a UTI due to increased frequency or duration in bathroom visits, unusual toileting patterns, increased nighttime bathroom patterns, and reduced activity level; early signs of depression due to increased frequency of skipping meals, restless sleep, avoidance of bright lights and sunshine, and reduced physical activity levels. Further details on this system and established correlations are provided here [1,46-52]. All of these insights are generated without requiring self-reporting by the senior or need for another human observer. The power of this unique data set coupled with AI essentially provides a 24/7 net of continuous observation for the senior, giving caregivers insight into the evolving health of the senior so that proactive measures can be taken to avert a more severe health issue. A supplementary overview video on the system is provided in Multimedia Appendix 1 [53].

Real-Time Location System

Operators and staff both benefit from the use of an accurate real-time location system. First, staff can know the location of a resident who has pressed the button on their wearable to call for assistance, enabling the closest staff member to attend to a resident quickly. Second, historical insights allow the operators to assess previous shifts' activities to improve staffing efficiencies. Such information may serve to facilitate improved response times, care coordination, and optimal workforce distribution. In addition, geofence alerts provide an added safety measure against wandering and elopement risks of residents with Alzheimer's and dementia.

Documentation of Care Services

With a surge in acuity levels across senior living communities, providers need to have visibility into the amount of care required and provided to its residents. This solution allows caregivers to document at the point of care what services were rendered and a suite of reports that provide response time to alerts, time spent with residents on various direct care activities, and insights regarding quantity and the quality of care provided.

Two-Way Voice Communication

The wearable provides two-way voice communication that allows residents to communicate directly with the caregiving

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staff. Staff can prioritize alerts and respond appropriately. As a single communication platform for residents and staff, the wearable eliminates the need for multiple devices and provides tracking and reporting capabilities for staff efficiency.

Keyless Access Control

The wearable is integrated with passive RFID technology so it can be used for keyless door entry, providing convenience and safety to residents and staff and assuring consistent adherence of use.

Outcome Measures

Facility staff at each community collected and reported the following data daily: occupancy, headcount, number of vacant units, unit move-ins and move-outs, staff service counts, duration, and type (such as dressing, bathing, grooming, transferring, and toileting), length of stay, fall incidents, emergency department and/or hospital admissions/discharges. Resident incident reports were utilized to document hospitalizations and fall incidents. The headcount, hospitalization, and fall incident numbers were used to compute both a hospitalization and fall rate. The hospitalization rate was defined as the number of hospitalization incidents per headcount in the facility, and the fall rate as the number of falls recorded per headcount per year. The average "baseline" rates for each community were measured from the first quarter of the study; the average "end of study" measurement was collected in the 8th quarter of the study. The average rate of change between these periods was computed between these two periods. Staff response times were automatically measured in this study using the CarePredict system. Residents trigger an alert and call for staff assistance by depressing the button on their wearable, and a staff member acknowledges the alert using the CarePredict software. We analyzed both the duration of time the staff required to acknowledge an alert and then to reach the resident. The residents' length of stay in each community was also measured. Length of stay is defined as the number of months a resident resides in a given community. The average, geometric, and median length of stay were analyzed, and detailed descriptions are provided in the supplementary materials section (Multimedia Appendix 2).

Statistics

Descriptive statistics, including means, standard deviations, and distributions, were provided for all study variables and compared across groups (+CP vs. –CP communities). Study variables were compared to baseline measurements for each group. A two-sample, two-tailed, t-test was applied for metric variables to test for significant differences between groups. A P value <.05 was considered statistically significant.

Compliance with Ethical Guidelines

Informed consent was obtained from the communities and participants included in the study.

Results

Resident Demographics

The resident demographic data (age, sex) and facility staff service time were assessed. The average resident ages were 87.3 years (SD 1.2 years) for the +CP communities and 88.1 years (SD 1.6 years) for the –CP communities (Table 1). The percent of female residents was 66.2% (SD 3.8) in the +CP and 69.2% (SD 8.2) in the –CP communities. The +CP and -CP communities exhibited no statistical difference in resident age (P=.64) and gender (P=.63). The average staff service time (hours per headcount per month) for each +CP and -CP community is shown in Table 2. The average staff service hours per resident per month were statistically similar for the +CP and –CP communities (P=.94).

Table 1. Resident age in the CarePredict and control assisted-living communities.

Age group	CarePredict (N=252), n (%)	Control (N=220), n (%)	*P* value
Below 75 years	12 (4.76)	21 (9.55)	.64
75-80 years	40 (15.87)	26 (11.82)	.47
81-85 years	74 (29.37)	55 (25.00)	.44
86-90 years	69 (27.38)	60 (27.27)	.62
Over 90 years	57 (22.62)	58 (26.36)	.72

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Table 2. Average staff service time (hours) spent per headcount per month. There was no significant difference between groups (*P*=.94).

	Hours
CarePredict Community, mean (SD)	76.7 (20.9)
1	81
2	54
3	95
Control Community, mean (SD)	77.6 (2.6)
1	59
2	71
3	103

Outcome Measures

Hospitalization and Fall Rates

The hospitalization and fall rates for the six assisted living communities are provided inTable 3. The average baseline hospitalization rates for the +CP and –CP communities were 48.8% (SD 7.3) and 39.1% (SD 2.5), respectively. Compared to baseline, the average change in hospitalization rate decreased by 15.0% (SD 8.51) for the +CP communities and increased 34.5% (SD 7.24) for the –CP communities (*P*=.04). Thus, the hospitalization rate for the +CP communities was 39.8% lower than the –CP communities, 33.8% (SD 6.0) versus 73.6% (SD 18.1), respectively (*P*=.02). The average fall rate (number of total fall incidents per headcount per year) and change in fall rate compared to baseline was measured for both the +CP and –CP communities (Table 3). There was no significant difference between the groups' initial baseline fall rates (*P*=.3). Compared to baseline, the fall rates for the +CP communities decreased 1.01 (SD 0.57), and the –CP communities increased 0.82 (SD 0.55). These changes are statistically significant (*P*=.05). The average fall rate for the +CP communities was 69% lower than for the –CP communities, 0.97 (SD 0.28), and 3.11 (SD 0.75), respectively. The normalized fall rate between groups was statistically significant (*P*=.01).

Table 3. Outcomes: hospitalization and fall rates for six assisted living communities.

Community	CarePredict (+/-)	Hospital incidents per headcount, N=490			Falls per headcount, N=490		
		Baseline, n (%)	Change from baseline, (%)	End of study, n, % (SD)	Baseline, n, fall rate	Change from baseline	End of study, n, fall rate (SD)
1	–	70 (42.0)	18.7	74, 60.7 (11.2)	70, 2.46	1.38	74, 3.84 (0.5)
2	–	70 (37.2)	57.1	78, 94.3 (12.7)	70, 2.31	0.81	78, 3.12 (0.8)
3	–	80 (38.1)	27.8	82, 65.9 (3.1)	80, 2.11	0.28	82, 2.39 (0.1)
4	+	80 (45.1)	–18.2	84, 26.9 (6.7)	80, 1.92	–0.65	84, 1.27 (0.8)
5	+	84 (57.2)	–19.4	84, 37.8 (18.9)	84, 2.40	–1.67	84, 0.73 (0.5)
6	+	88 (44.0)	–7.3	88, 36.7 (10.1)	88, 1.62	–0.72	88, 0.90 (0.7)
Mean (SD)	–	39.1 (2.5)	34.5 (7.24)	73.6 (18.1)	2.29 (0.18)	0.82 (0.55)	3.11 (0.75)
Mean (SD)	+	48.8 (7.3)	–15.0 (8.51)	33.8 (6.0)	1.98 (0.39)	–1.01 (0.57)	0.97 (0.28)
Delta		9.7	–49.5	–39.8	0.16	–1.83	–2.14
P value		.21	.04	.02	.30	.05	.01

Length of Stay in Assisted Living Communities

The median, geometric, and mean length of stay in the CarePredict and control communities are provided in Table 4. Length of stay was significantly greater in the CarePredict communities than in the control communities.

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Table 4. Length of stay in CarePredict and control communities.

Community	CarePredict	Control	Difference in CarePredict vs control (%)	*P* value
Median length of stay (SD)	214 (38)	128 (8.7)	67	.03
Geometric mean length of stay (SD)	178 (46)	92 (8.6)	93	.04
Mean length of stay (SD)	268 (42.4)	192 (18)	40	.03

Staff Response Time

The average time to alert acknowledgment improved by 230 seconds (*P*=.03), and staff response time improved by 263 seconds (*P*=.02) (Table 5).

Table 5. Average acknowledgment and response times at baseline and the end of the study.

Response	Baseline, seconds, mean (SD)	End of study, seconds, mean (SD)	Improvement (%)	*P* value
Acknowledge alert	580 (42)	349.5 (82)	40	.03
Reach resident	763.5 (78)	500 (35)	37	.02

Discussion

Principal Findings

In this pilot study, we assessed whether the use of a wearable device and AI-powered digital health platform could provide improved health outcomes for older adults in an assisted living community. We found that the communities with CarePredict (+CP) exhibited a 40% lower hospitalization rate, 69% lower fall rate, and 67% greater length of residence stay compared to control communities (–CP). Overall, the use of CarePredict technology in assisted living communities appears to contribute to improved outcomes and shows promise as an effective tool to provide a higher quality of care.

There are several possible explanations for these findings. First, since both the residents and staff wear the CarePredict device, it functions as both an effective communication platform and resident alert system allowing for the coordination of prompt care. The system also provides robust staff performance metrics, which can be used to encourage continually improving staff response times to residents who need aid. The alert system prevents minor situations from escalating to emergent situations requiring hospitalization. Residents desire prompt, attentive care in assisted living communities, and the CarePredict system helped contribute to the facility staff acknowledging alerts 40% faster and reach residents in response to those alerts in 37% less time [54,55]. The CarePredict system appears to provide community staff with an increased awareness of residents' needs and allows them to provide more prompt care, and thus may directly contribute to the improved outcomes observed.

Second, the system provides the community staff with detailed information regarding each resident's activities and behavior. Changes in an adult's activity and behavior are well-characterized to precede health declines; therefore, staff can use this information to quickly identify older adults that are at an increased probability for a health decline and intervene much earlier [49,50]. For example, such information can be used to identify and flag older adults that show the earliest sign of a urinary tract infection (UTI). In particular, the CarePredict system identifies a new or marked increase in urination urgency or frequency, both well-established indicators for a symptomatic UTI [49-51]. These older adults can then be assessed, and if diagnosed with a UTI, can be provided antibiotics to treat the UTI before it may result in hospitalization [51]. This increased visibility provided by the system may also have contributed to the observed lower hospitalization rates and increased LOS.

Fall rates also appear to be positively impacted by the use of the CarePredict solution. The data shows that +CP communities exhibited a 69% lower fall rate than the –CP communities. Fall rates are known to increase steadily with age [20], and the rates vary considerably for older people in different settings. Lower fall rates (0.3-1.6 per person per year) are typically reported in independent living communities with relatively healthy adults (age ≥65 years), whereas higher fall rates (0.6-4.05 per person per year, mean 1.7) are observed in assisted living, memory care, and long-term care institutions [24,56,57]. In a recent systematic review on falls, the mean rate of falls was found to vary between 1.07 falls per person per year for a low-risk population, and up to 3.5 falls per person per year for a high-risk population [23]. The CarePredict solution appears to contribute to an observed fall rate (0.97) that is lower than average incident fall rates reported in the literature [23,27].

By identifying older adults whose activity and behavior pattern indicates decreasing mobility, staff can take pre-emptive action to mitigate senior fall risk, UTIs, or other incidents that may have required hospitalization. Reducing hospital admissions also helps to maintain census, reduce resident turnover, and increase resident LOS in the community. The data shows that +CP communities exhibited a nearly 40% lower average hospitalization rate than the –CP communities (33.8% versus 73.6%). Several senior living outcomes studies by Zimmerman et al and Hedrick et al reported average annual hospitalization rates of 51% and 40%, respectively [29,58]. The +CP communities exhibited hospitalization rates that were 18% and 7% lower than the averages reported by Zimmerman and Hedrick et al, respectively [29,58].

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Limitations

There are several limitations to this pilot study. First, the study was conducted at six assisted living communities with less than 500 total residents. This study needs to be replicated and results confirmed using a larger sample size of individuals. Second, the –CP communities did not use an alert response technology system in this study, and thus staff response times could not be collected and analyzed for the –CP communities. As a result, the impact that the CarePredict technology had on staff response times was only measured and analyzed for the +CP communities. We, therefore, could not compare the staff response times between the +CP and –CP communities, and rather only measured the response times for the +CP communities at baseline and end of the study. Third, staff in the +CP communities used the CarePredict technology system for multiple purposes: to acknowledge and respond to resident alerts, to communicate to residents and other staff members, and to autonomously collect resident activity and behavior data. Since Carepredict served multiple functions, it is difficult to attribute which of these system capabilities and data sets directly contributed to the improved outcomes.

Future Studies

To better understand the mechanisms by which these improvements were provided, in future studies, we plan to include a control group of communities that only utilize the CarePredict system for alerting and communication purposes. The added value provided by the predictive analytics feature will then be easier to assess and quantify directly. These results will also allow us to assess the impact that the proactive, actionable data generated by the CarePredict system will have on identifying and preventing high-risk residents from being hospitalized. Finally, although the six communities assessed in this study had comparable resident demographics (age, gender) and staff service hours per resident, other factors like residents' hospital and fall history, and quality of care indicators may also have contributed to the differences observed in the measured outcomes.

Conclusions

The leading cause of residents moving out of assisted living communities is unplanned hospitalization [18]. Hospitalizations are a strong predictor of nursing home admission and are associated with health and disability declines, lower quality of life, and greater health care costs [29,58]. The findings of this study highlight that the CarePredict AI-powered digital health platform, wearable device, and location system shows promise to support caregiving staff in identifying older adults that have an increased probability for a health decline, and thereby give staff time to provide a proactive intervention and thus reduce the number of hospitalizations. AI-powered platforms and wearable devices show promise as assistive tools for senior living organizations to deliver improved outcomes. In future studies, we plan to explore the variables and specific mechanisms by which this technology can directly contribute to each performance metric and outcome.

Conflicts of Interest

GJW, KD, JG, GZ, and SM are employees of CarePredict. HMF is an advisor to CarePredict.

Multimedia Appendix 1
Overview video on AI-powered digital health platform and wearable.
[MP4 File (MP4 Video), 193738 KB - aging_v3i2e19554_app1.mp4]

Multimedia Appendix 2
Definitions and methods for calculating length of stay.
[DOCX File , 29 KB - aging_v3i2e19554_app2.docx]

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Abbreviations

AI: artificial intelligence
+CP: community with CarePredict
–CP: community without CarePredict (control)
LOS: length of stay
RFID: radio-frequency identification
UTI: urinary tract infection

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Original Paper

Age and Attitudes Towards an Internet-Mediated, Pedometer-Based Physical Activity Intervention for Chronic Obstructive Pulmonary Disease: Secondary Analysis

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Abstract

Background: Chronic obstructive pulmonary disease (COPD) is prevalent among older adults. Promoting physical activity and increasing exercise capacity are recommended for all individuals with COPD. Pulmonary rehabilitation is the standard of care to improve exercise capacity, although there are barriers that hinder accessibility. Technology has the potential to overcome some of these barriers, but it is unclear how aging adults with a chronic disease like COPD perceive technology-based platforms to support their disease self-management.

Objective: Guided by the unified theory of acceptance and use of technology, the current retrospective secondary analysis explores if age moderates multiple factors that influence an individual with COPD's openness toward an internet-mediated, pedometer-based physical activity intervention.

Methods: As part of an efficacy study, participants with COPD (N=59) were randomly assigned to use an internet-mediated, pedometer-based physical activity intervention for 12 weeks. At completion, they were asked about their experience with the intervention using a survey, including their performance expectancy and effort expectancy, facilitating conditions (ie, internet use frequency and ability), and use of the intervention technology. Logistic regression and general linear modeling examined the associations between age and these factors.

Results: Participants ranged in age from 49 to 89 years (mean 68.66, SD 8.93). Disease severity was measured by forced expiratory volume in the first second percent predicted (mean 60.01, SD 20.86). Nearly all participants (54/59) believed the intervention was useful. Regarding effort expectancy, increasing age was associated with reporting that it was easy to find the time to engage in the intervention. Regarding facilitating conditions, approximately half of the participants believed the automated step count goals were too high (23/59) and many did not feel comfortable reaching their goals (22/59). The probability of these perceptions increased with age, even after accounting for disease severity. Age was not associated with other facilitating conditions or use of the technology.

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Conclusions: Age does not influence performance expectancy or use of technology with an internet-mediated, pedometer-based physical activity intervention. Age is associated with certain expectations of effort and facilitating conditions. Consideration of age of the user is needed when personalizing step count goals and time needed to log in to the website.

Trial Registration: ClinicalTrials.gov NCT01772082; https://clinicaltrials.gov/ct2/show/NCT01772082

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KEYWORDS

aging; COPD; chronic conditions; physical activity; eHealth

Introduction

Chronic Obstructive Pulmonary Disease and eHealth

Chronic obstructive pulmonary disease (COPD), prevalent mainly in older adults, is the fourth leading cause of death in the United States [1]. Independent of lung function, physical inactivity in COPD is associated with poor outcomes, worse health-related quality of life [2,3], higher health care use [4], and mortality [5]. Physical activity is recommended for all individuals with COPD [6,7]. Pulmonary rehabilitation is the standard of care to increase physical activity and exercise capacity; however, there are barriers to conventional pulmonary rehabilitation, including distance and time required to travel to medical center–based in-person sessions.

Technology or eHealth can potentially be used to overcome many barriers to accessibility. Technology-based interventions may support self-management behaviors, such as engagement in physical activity [8]. Randomized controlled trials (RCTs) have demonstrated the efficacy of these interventions in persons with COPD [3,9-12]. However, implementation into usual care has been slow [13]. One of the factors impeding implementation might be the concern that increasing age may be associated with lower technology knowledge and use. Understanding what influences one's acceptance and use of technology can help select effective implementation strategies [14].

Among patients with chronic diseases, such as COPD, it is unclear if age influences attitudes toward web-based platforms to support disease self-management. Some literature suggests that increasing age is negatively associated with effort expectancy and use of technology [15-17], but other studies suggest that age does not impact technology acceptance [18]. Additionally, there is a perceived decreased rate of technology ownership among older individuals, although reviews have found that a significant portion of older adults already use technology and that rates of ownership are increasing every year across all age groups [18,19]. Finally, age-related visual, motor, or cognitive limitations may make it difficult for an older adult to efficiently use some technologies, which subsequently discourages interest and use [18]. In order to provide an optimal context in which eHealth interventions can effectively improve self-management behaviors and health outcomes, it is important to understand the potential factors that influence attitudes towards technology acceptance and use among aging patients in this population [18]. Careful consideration of how age influences these factors can be used to develop or adapt the technology to better meet the needs of patients with COPD.

Theoretical Background

The unified theory of acceptance and use of technology (UTAUT) provides a conceptual framework for predicting (1) behavioral intention to use a technology and (2) technology use behavior [20,21]. These factors include performance expectancy, effort expectancy, facilitating conditions, and social influence. Performance expectancy refers to the degree to which an individual believes that using the system will help him or her. Effort expectancy refers to the degree of ease associated with using the technology. Facilitating conditions refer to conditions that may support acceptance and use of the technology. Social influence refers to what degree an individual feels that others believe he or she should use the new technology [20]; due to the retrospective nature and data limitations of the current study, we were unable to examine social influence. Figure 1 shows the UTAUT constructs we were able to assess in the study. The UTAUT posits that facilitating conditions have a direct effect on use behavior. Internet efficacy, or digital literacy, has been identified as a facilitating factor predicting the use of eHealth [22]. Early UTAUT research focused primarily on predicting behavioral intention to use a technology and actual technology use, primarily in organizational contexts. Since then, Venkatesh et al [20] encouraged extensions in new contexts, user populations, and cultural settings. The current study continues this extension by examining technology acceptance from the individual's perspective in a Veteran COPD population.

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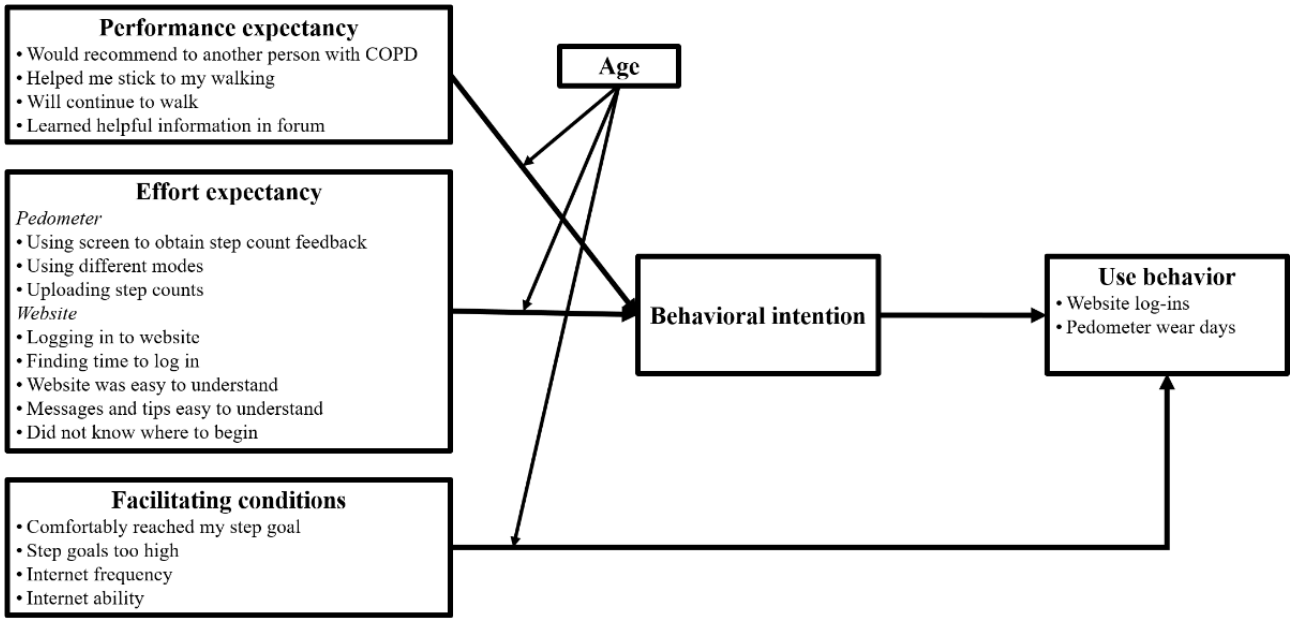
Figure 1. Conceptual framework of the unified theory of acceptance and use of technology, modified to represent the current study and the corresponding items assessed. COPD: chronic obstructive pulmonary disease.



Current Study

Using the UTAUT, the current secondary analysis explored whether age moderated factors associated with behavioral intention to use technology by persons with COPD who used Every Step Counts (ESC). ESC is an internet-mediated, pedometer-based physical activity intervention that we have previously shown to be efficacious in Veterans with COPD [12]. We hypothesized that increasing age would be associated with decreased performance expectations, increased effort expectations, decreased facilitating conditions, and decreased use (website log-ins and pedometer wear days) of a technology-based physical activity intervention for participants with COPD.

Methods

Design

This secondary analysis used data from a previously reported RCT registered on ClinicalTrials.gov (NCT01772082) [12]. The RCT was approved by the Veterans Affairs Boston Healthcare System Institutional Review Board (Protocol No. 2328). All participants gave written informed consent. Participants with COPD, defined as a ratio of forced expiratory volume in the first second to forced vital capacity (FEV_1/FVC) less than 0.7 or emphysema on clinical chest computed tomography, were randomly assigned to use either a website coupled with a pedometer (ESC intervention) or a pedometer alone. The sample of the current analysis includes only the participants who were randomly assigned to use the ESC intervention (n=59).

Intervention

ESC is a multicomponent, internet-mediated, pedometer-based physical activity intervention. ESC was developed based on the theory of self-regulation, which emphasizes an iterative approach to behavior change using personalized goals, iterative step count feedback for self-monitoring, educational tips, and motivational messages to enhance disease self-management and self-efficacy, as well as an online community forum for social support. Participants were asked to use ESC for 12 weeks and to wear a pedometer (Omron HJ-720 ITC; Omron Healthcare Inc). Participants were asked to wear the pedometer daily, clipped to their clothing around their waist. Use of the pedometer also required participants to ensure the pedometer had sufficient battery power. Participants could view their steps on the face of the pedometer and change the pedometer display (steps, aerobic steps, calories, miles) by pressing buttons. Additionally, participants had to navigate the website to upload their step count data from their pedometer, view their feedback graphs and weekly step count goals, and access the educational tips, motivational messages, and online forum. After the 12-week intervention, as part of their visit, they were asked for feedback using a survey about their experience using the pedometer and website.

Measures

Age, measured continuously and assessed at study entry, was included as an independent variable in the analyses. Marital status, race, and disease severity were included as covariates in all analyses. Marital status was measured categorically: single/never married, separated, divorced/annulled, widowed, or married. FEV_1 percent predicted (FEV_1% predicted), a spirometric measurement of airway obstruction, was used to characterize disease severity [23,24].

Performance Expectancy

Participants were asked about how useful they found the intervention to be for increasing their physical activity. They were asked whether they agreed (true or false) with the following statements: (1) “I would recommend the Every Step Counts for Lung Health walking program to another person with COPD”; (2) “The Every Step Counts for Lung Health program helped me stick to my walking for exercise”; (3) “I

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will continue to walk for exercise after the research study ends"; and (4) "I learned helpful information when I used the online community forum." Responses to the statements were examined individually.

Effort Expectancy

Participants were asked about their experience using the technology (pedometer and website). Regarding the pedometer, participants were asked whether they agreed (yes or no) that during a typical week during the research study, they regularly (4-7 days/week) had any of the following problems using the Omron pedometer: (1) "difficulty using the Omron screen to obtain step-count feedback"; (2) "difficulty using the different Omron 'modes' (steps, aerobic steps, kcal, miles)"; and (3) "technical difficulty uploading step-count data from the Omron pedometer to my computer."

Regarding the website, participants were asked whether they agreed (yes or no) that they regularly (defined as more than half of the times they accessed the site) had any of the following experiences using aspects of the website: (1) "Problems with logging in to the website"; (2) "It was easy for me to find the time to log in to the website once a week"; (3) "The Every Step Counts for Lung Health website was easy to understand"; (4) "The motivational messages and educational tips were easy to understand"; and (5) "After I logged in to the website, I did not know where to begin to use it."

Facilitating Conditions

Participants self-reported facilitating conditions that could influence their use and self-efficacy using the intervention. Regarding the website-generated, personalized, and iterative step goals, participants were asked whether they agreed (yes or no) with the following statements: (1) "I was able to comfortably reach my step-count goal each week as directed by *Every Step Counts*" and (2) "The daily step-count goals were too high for me to walk each day." Other facilitating conditions included internet use and competence; these were measured ordinally. Participants were asked how often they use the internet on a scale from 1 (never) to 4 (every day) and how they would rate their ability to use the internet on a scale from 1 (no ability) to 5 (expert ability).

Use Behavior

Use behavior, or use of the technology-based components of the intervention, was measured continuously. The number of days participants wore the pedometer over the study period was used to measure use of the pedometer. The number of times the participants logged on to the website over the course of the study was used to measure use of the website.

Statistical Analyses

We used descriptive statistics to examine the frequency of responses to the different UTAUT constructs. We used logistic regression to estimate the odds ratio (OR) to measure the association between age and dichotomous variables that examined performance expectancy and effort expectancy. ORs were considered significant if the 95% confidence interval did not include 1.00 and the *P* value was less than .05. General linear modeling was used to examine the association between age on the continuous and ordinal outcome variables that measured facilitating conditions and use behavior (ie, pedometer wear days and website log-ons). General linear model estimates were considered significant if the 95% confidence interval did not include 0.00 and the *P* value was less than .05. Marital status, race, and FEV_1% predicted were included as covariates in all models. All analyses were performed using SAS 9.4 (SAS Institute).

Results

Participant Characteristics

Table 1 displays participant characteristics. Participants ranged in age from 49 to 89 years (mean 68.66, SD 8.93). Most of the participants were male (58/59, 98%), White (55/59, 93%), married (26/59, 44%), and retired (35/59, 59%), and most earned an annual income of at least US $30,000 per year (38/59, 65%). There was a statistically significant difference in age between reported employment categories ($\chi^{2(3)}$=8.7; *P*=.03). The mean age of retired participants was 70.1 years (SD 7.9) compared with 61.8 years (SD 6.1) who indicated they were working full time.

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Table 1. Characteristics of study participants (N=59).

Characteristics	Statistics
Demographic characteristics	
Age (years), mean (SD)	68.66 (8.93)
Gender, n (%)	
Male	58 (98)
Female	1 (2)
Race, n (%)	
White	55 (93)
African American	3 (5)
American Indian or Alaska Native	1 (2)
Income (US), n (%)	
<$15,000	10 (17)
$15,000-$29,999	11 (19)
$30,000-$49,999	18 (31)
$50,000 or more	20 (34)
Marital status, n (%)	
Single/never married	6 (10)
Separated	1 (2)
Divorced or annulled	20 (34)
Widowed	6 (10)
Married	26 (44)
Employment, n (%)	
Full-time job	5 (8)
Part-time job	11 (19)
Not working due to disability	8 (14)
Retired	35 (59)
Medical characteristics	
FEV_1% predicted[a], mean (SD)	60.01 (20.86)
Oxygen, n (%)	4 (7)
Comorbidities, n (%)	
Coronary artery disease	10 (17)
Diabetes	17 (29)
Arthritis	18 (31)
Previous pulmonary rehabilitation, n (%)	6 (10)
Intervention characteristics	
Change in daily step counts, mean (SD)	440.17 (1819.74)

[a]FEV_1% predicted: forced expiratory volume in the first second percent predicted.

Performance Expectancy

The majority of participants randomized to ESC believed the intervention to be useful; 95% (56/59) of the sample reported that they would recommend the intervention to other Veterans with COPD. Only 32% (19/59) found the online forum to contain helpful information, and 63% (37/59) reported that they did not use the online forum. Approximately three-quarters (45/59, 76%) believed that the intervention helped them stick to their walking, and 98% (58/59) reported that they will continue to walk. Contrary to our hypothesis, the OR of these responses did not vary by age, adjusting for marital status, race, and FEV_1% predicted (Table 2).

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Table 2. Summary of age associations on UTAUT constructs.

UTAUT[a] construct	Response	AOR[b] (95% CI)	B (95% CI)	*P* value
Performance expectancy, n (%)				
Would recommend to another person with COPD[c]	56 (95)	0.99 (0.798 to 1.235)	N/A[d]	.95
Helped me stick to my walking	45 (76)	0.95 (0.869 to 1.030)	N/A	.20
Will continue to walk	53 (90)	0.92 (0.801 to 1.057)	N/A	.24
Learned helpful information in forum	19 (32)	0.99 (0.924 to 1.070)	N/A	.88
Effort expectancy, n (%)				
Pedometer				
Using screen to obtain step count feedback	12 (20)	1.08 (0.971 to 1.200)	N/A	.16
Using different modes	6 (10)	1.12 (0.976 to 1.285)	N/A	.11
Uploading step counts	21 (36)	1.05 (0.971 to 1.133)	N/A	.22
Website				
Logging in to website	9 (16)	1.04 (0.941 to 1.142)	N/A	.47
Finding time to log in	48 (81)	1.17 (1.030 to 1.332)	N/A	.02
Website was easy to understand	54 (92)	1.01 (0.874 to 1.156)	N/A	.94
Messages and tips easy to understand	34 (58)	1.02 (0.951 to 1.094)	N/A	.57
Did not know where to begin	7 (12)	0.99 (0.880 to 1.121)	N/A	.91
Facilitating conditions, n (%)				
Comfortably reached my step goal	22 (37)	0.91 (0.827 to 0.990)	N/A	.03
Step goals too high	23 (40)	1.08 (1.000 to 1.172)	N/A	.049
Internet frequency		N/A	0.00 (0.656 to 4.897)	.90
Never	3 (5)			
≤4 times per month	8 (16)			
Several times a week	12 (20)			
Every day	36 (61.0)			
Internet ability		N/A	–0.03 (–0.063 to 0.010)	.15
None	3 (5)			
Basic	27 (46)			
Moderate	17 (29)			
Advanced	8 (14)			
Expert	4 (7)			
Use behavior, mean (SD)				
Pedometer wear days	77.2 (18.8)	N/A	0.31 (–0.345 to 0.971)	.34
Weekly number of log-ons	5.4 (3.1)	N/A	0.02 (–0.341 to 0.384)	.91

[a]UTAUT: unified theory of acceptance and use of technology.
[b]AOR: adjusted odds ratio.
[c]COPD: chronic obstructive pulmonary disease.
[d]N/A: not applicable.

Effort Expectancy

We hypothesized that higher age would be associated with increased effort expectancy. When we examined participants' perceived effort expectancy of the pedometer, 20% (12/59) thought it was difficult to obtain step count feedback from the pedometer, 10% (6/59) found it difficult to use the different modes on the pedometer, and 36% (21/59) had difficulty uploading their step count data to the website. None of these were associated with age (Table 2). When asked if it was easy to find time to use the website, 81% (48/59) agreed. Age was significantly associated with increased odds of agreeing that it

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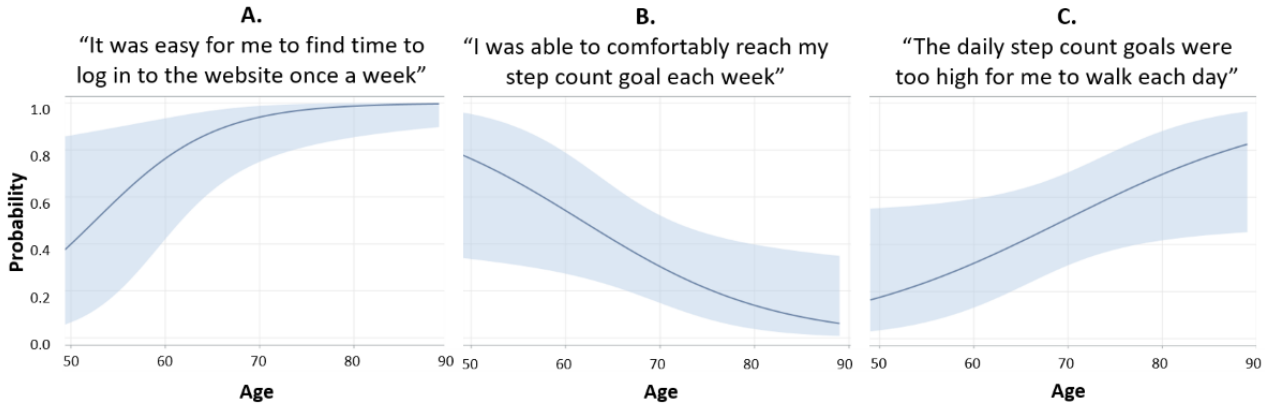
was easy to find time to use the website (OR 1.17, 95% CI 1.030-1.332; *P*=.02). As shown in Figure 2, agreement that it was easy to find time to use the website began to level off around an age of 70 years. The majority of participants (54/59, 92%) reported that the website was easy to understand. More than half (34/59, 58%) believed the motivational messages and educational tips were easy to understand; 41% (24/59) did not view these messages and tips.

Figure 2. Predicted probability (logistic regression) of agreeing that (A) "It was easy for me to find time to log in to the website once a week"; (B) "I was able to comfortably reach my step count goal each week"; and (C) "The daily step goals were too high." Figures include 95% confidence limits. Fit computed controlling for marital status, race, and forced expiratory volume in the first second percent predicted.



Facilitating Conditions

A total of 37% (22/59) of participants agreed that they were able to comfortably reach their step count goal. Increasing age was significantly associated with decreased odds of agreeing that they felt comfortable reaching their step goal (OR 0.91, 95% CI 0.827-0.990; *P*=.03; Figure 2). Similarly, 39% (23/59) of participants agreed that their daily step count goals were too high. Increasing age was significantly associated with increased odds of agreement (OR 1.08, 95% CI 1.003-1.172; *P*=.049; Figure 2). In addition, 15% (9/59) reported trouble logging in and 12% (7/59) reported not knowing where to begin on the website once logged-in. At study entry, the majority of those randomized to the ESC intervention self-reported using the internet every day (36/59, 61%). Most participants self-reported basic (27/59, 46%) or moderate (17/59, 29%) internet abilities. Age did not significantly predict self-reported frequency of internet use or perceived internet ability (Table 2).

Use Behavior

Across the 12-week, or 84-day, study period, participants wore the pedometer an average of 77.19 days (SD 18.78). Participants were asked to log on at least once a week to upload their step count data to the study website. The average number of website log-ons throughout the 12-week intervention period was 15.69 (SD 9.63). Contrary to our hypothesis, pedometer wear days and number of log-ons did not vary by age (Table 2).

Guided by the UTAUT, we examined the direct relationship between facilitating conditions and use behavior. Feeling comfortable reaching the step goals was not significantly associated with website log-ons (B=0.81, 95% CI –1.25 to 2.88; *P*=.43). Similarly, perceiving the step goals as too high was also not associated with website log-ons (B=–0.51, 95% CI –2.58 to 1.56; *P*=.63). Self-reported frequency of internet use at baseline was marginally associated with number of website log-ons during the study (B=1.10, 95% CI –0.02 to 2.22; *P*=.05). Self-reported internet ability was not significantly associated with the number of log-ons (B=0.77, 95% CI –0.15 to 1.69, SE 0.45; *P*=.10).

Feeling comfortable reaching their step goals was not significantly associated with website pedometer wear days (B=2.08, 95% CI –8.81 to 12.97, SE 5.41; *P*=.70). Similarly, perceiving the step goals as too high was also not associated with pedometer wear days (B=–0.10, 95% CI –10.62 to 10.43, SE 5.23; *P*=.99). Self-reported frequency of internet use at baseline did not significantly predict valid pedometer wear days during the study (B=–2.18, 95% CI –9.02 to 3.65; *P*=.46), nor did self-reported internet ability (B=–1.55, 95% CI –6.43 to 3.33; *P*=.53).

Discussion

Overview

The current study examined COPD patients' acceptance and use of an internet-mediated, pedometer-based physical activity intervention, ESC, using the UTAUT as a conceptual model. Results support that participants with COPD are generally able to use the technologies involved with ESC (ie, pedometer and website). An overwhelming majority of the sample reported that they would recommend the intervention to other Veterans with COPD, believed that the intervention helped them walk more, that they would continue to walk, and that the website was easy to understand. This was true for participants across all ages. There were themes from the UTAUT, such as perceiving goals as unattainable, that differed by age. This provides important information on how to improve and implement such a technology-mediated intervention in COPD.

Age Was Associated With Perceived Difficulty in Meeting Step Count Goals

Approximately 63% (37/59) of the participants did not feel they could comfortably reach their given step count goal and nearly 40% (23/59) believed that their step count goals were too high. Both perceptions increased as age increased, independent of

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disease severity as reflected by lung function. ESC used an algorithm that considered the participant's steps walked from the previous week to automatically calculate and increment their goal each week. Goals were set at the minimum value of 3 possible numbers: (1) the previous goal + 400 steps, (2) the average of the most recently uploaded 7 days of step counts + 400 steps, or (3) 10,000 steps [12]. Previous pilot work found that a weekly increase of 400 steps was an attainable goal for a COPD cohort [11]. Despite this personalization, older participants were still more likely to believe their goals were too high and felt uncomfortable reaching their step count goals. This was true over and above the severity of the participant's disease, as measured by FEV_1% predicted.

Goal setting has been a prominent intervention strategy to increase motivation and effect behavior change [25]. As done with ESC, technology can be used to set automated exercise goals in interventions that are personalized to a COPD population. Although ESC attempted to set realistic, small, and gradual goals that would be effective for long-term engagement compared with larger goals, participant feedback shows that goals need to be further tailored based on the user's age. Goal setting is strongly tied to one's self-efficacy, or confidence that they can accomplish a goal, which is directly related to one's behavior [26,27]. Setting goals that the participants perceive as unrealistic and too difficult can be detrimental to their self-efficacy [26]. Our results suggest that automated goals may need to account for age to increase effort expectancy of the intervention. Future studies could examine whether smaller weekly increments would help participants perceive the goals as being more attainable as age increases.

Increasing Age Was Associated With More Time to Engage With the Website

Increased age was associated with endorsing that it was easier to find the time to use the website. Our older participants were retired, whereas the younger, middle-aged participants were still of working age. This perceived lack of time closer to midlife is common [28], particularly for those who feel a conflict between the many goals or tasks one must achieve throughout the day (eg, finishing work, picking up children, etc). It is not surprising that as age increases, participants, who are more likely to be retired, are more likely to agree that it was easy to find the time to engage in the website. Indeed, the majority of our sample did indicate that they were retired.

Time constraints for busy adults are likely to be an ongoing obstacle to engaging in physical activity. This is an important consideration when designing alternative interventions to address barriers to activity promotion strategies. One of the barriers to conventional pulmonary rehabilitation is the time commitment, both the amount of time required to travel to attend in-person sessions and the amount of time required to complete the rehabilitation sessions [29,30]. Presumably, time is less of a burden for a web-based intervention that does not require travel or in-person sessions, although we still found that age was positively associated with believing it was easy to find time to use the website. Future work would benefit from examining and comparing participant perspectives, particularly of middle-aged participants, on the time burdens of both traditional in-person rehabilitation and technology-based interventions.

Age Was Not Associated With Use Behavior

Age was not associated with use of the technology-based intervention (pedometer wear days or website log-ons). Similarly, self-reported internet ability did not predict use of the pedometer or website. Frequency of internet use, however, was associated with more frequent log-ons to the web-based intervention. For that reason, it may be difficult to engage participants who do not use the internet in web-based interventions. However, rates of internet use are increasing every year, and, consequently, acceptance and adoption of web-based interventions are also likely to increase [31].

A fraction of participants had difficulties using the pedometer (ie, obtaining step count feedback from the pedometer or uploading their step count data to the website). This barrier did not vary by age. Our results support that persons with COPD may benefit from pedometers that are simple to use and guidance on how to use them. While communication and education can influence acceptance and use, experience is also needed. Experimental research has shown that brief use of an eHealth application can decrease the expected difficulty or effort [32,33]. Offering participants more opportunity to become acquainted with the technology at baseline, or initial clinic visits, may increase their intention to use the device in the future.

Strengths and Limitations

A major strength of this study is the use of the UTAUT conceptual framework to understand how age influences persons with COPD's acceptance and use of a technology-mediated physical activity intervention. In addition, the participants in our sample were given an opportunity to incorporate the technology into their daily lives for 12 weeks, as opposed to some technology acceptance studies that explore participants' initial impressions of technology and do not reflect actual use [34,35]. This was a secondary analysis using questions that were formed based on clinical interest and not originally based on the UTAUT. As such, the questionnaire did not use previously validated UTAUT questions. We used dichotomous survey questions to reduce participant burden and may have missed some granularity in participants' opinions.

Although we used UTAUT to guide our secondary analysis, we were limited by the data that had been collected. The UTAUT model also includes the construct of social influence, which refers to the belief that others (eg, family, providers) believe that the individual should use the new technology [20]. This was not assessed as part of the original study. Along with age, UTAUT theorizes that gender, experience, and voluntariness influence technology adoption [21]. The current sample's participants were mostly White male Veterans with COPD. Therefore, we are unable to examine if gender influences perceptions of ESC. These results might not be generalizable to others. Similarly, all patients had the same amount of experience with the intervention. Another limitation of studies of patient-facing technologies is the voluntary nature of the study; individuals who feel less comfortable with technology may be less likely to have enrolled in the study. Additionally,

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participants were asked to log on to the website at least once a week and wear the pedometer every day. Thus, these measures may also be indicative of compliance and not necessarily voluntary use of the technology. Future work would benefit from exploring these other UTAUT moderators (gender, experience, voluntariness) and age variations in technology acceptance among a more diverse sample of participants with COPD.

Another potential limitation is that these analyses include only the RCT participants randomized to the ESC intervention; there is a chance that type II error may have caused us to miss some age-related differences. A larger sample would statistically allow for more degrees of freedom within the model. However, among our sample, we were able to detect significant age-related differences for ease of finding time to engage in the intervention, belief that the step count goals were too high, and comfort reaching step goals. Therefore, we are confident we are powered to detect differences despite the small sample size.

Conclusion

Veterans with COPD are likely to accept and use technology to promote physical activity. However, not all of them can easily adopt it. Those who use the internet more will be more inclined to use the web-based intervention. Thus, familiarizing participants with the various technologies may facilitate use of the technology. To encourage positive behavior change, interventions that use incremental goal setting should consider adapting automated goals by age so that participants can perceive them as attainable. If older adults can feel encouraged and confident, they will accept and use web-based interventions.

Acknowledgments

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Conflicts of Interest

None declared.

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Abbreviations

COPD: chronic obstructive pulmonary disease
ESC: Every Step Counts
FEV1: forced expiratory volume in the first second
FEV1% predicted: forced expiratory volume in the first second percent predicted
FVC: forced vital capacity
OR: odds ratio
RCT: randomized controlled trial
UTAUT: unified theory of acceptance and use of technology

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Original Paper

Smartphone-Based Experience Sampling in People With Mild Cognitive Impairment: Feasibility and Usability Study

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Abstract

Background: Daily functioning of people with cognitive disorders such as mild cognitive impairment (MCI) is usually depicted by retrospective questionnaires, which can be memory-biased and neglect fluctuations over time or contexts.

Objective: This study examines the feasibility and usability of applying the experience sampling method (ESM) in people with MCI to provide a detailed and dynamic picture of behavioral, emotional, and cognitive patterns in everyday life.

Methods: For 6 consecutive days, 21 people with MCI used an ESM app on their smartphones. At 8 semi-random timepoints per day, participants filled in momentary questionnaires on mood, activities, social context, and subjective cognitive complaints. Feasibility was determined through self-reports and observable human-technology interactions. Usability was demonstrated on an individual and group level.

Results: Of the 21 participants, 3 dropped out due to forgetting to carry their smartphones or forgetting the study instructions. In the remaining 18 individuals, the compliance rate was high, at 78.7%. Participants reported that momentary questions reflected their daily experiences well. Of the 18 participants, 13 (72%) experienced the increase in awareness of their own memory functions as pleasant or neutral.

Conclusions: Support was found for the general feasibility of smartphone-based experience sampling in people with MCI. However, many older adults with MCI are currently not in possession of smartphones, and study adherence seems challenging for a minority of individuals. Momentary data can increase the insights into daily patterns and may guide the person-tailored development of self-management strategies in clinical settings.

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KEYWORDS

experience sampling method; mild cognitive impairment; cognition; feasibility; smartphones

Introduction

Clinical questionnaires are commonly retrospective in nature and are thus potentially affected by a memory bias and thought to have low ecological validity [1]. As already cognitively healthy individuals over or underestimate past emotions and situations [2], this method might distort reality even more when people experience cognitive deficits. Moreover, within- or between-day fluctuations of health aspects are rarely taken into account, even though emotions and well-being vary depending on daily circumstances [3,4].

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Momentary data collection, known as the experience sampling method (ESM) [5] or ecological momentary assessment [6], may offer a solution to this problem. The ESM uses diaries to gather information on symptoms, mood, activities, or social interactions in the moment they occur. Individuals fill in short questionnaires about current emotions and behaviors repeatedly over several days, which results in a high ecological validity and offers detailed insight into dynamic patterns [7]. Originally, ESM questionnaires had a paper-pencil format, but more recently, mobile devices such as smartphone apps have prevailed. Compared to paper-pencil diaries, technology-based ESM questionnaires can be filled in faster, reducing time burden and providing more details about the exact assessment time. Using the ESM, especially in combination with personalized feedback from a health care professional, increases awareness of and engagement in a healthy lifestyle and thus supports self-management [8,9]. The term self-management can be defined as "the individual's ability to manage their symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition" [10] and is a necessary skill to improve or maintain daily functioning.

A recent review reported that technology-based self-monitoring such as the ESM is already applied in various populations, including people with depression, chronic pain, or other health issues, to study behaviors and promote health [9]. In cognitively healthy older adults, momentary data collection seems feasible and acceptable [11] and is promising in individuals with brain injury [12] and after stroke [13].

One group of individuals that might also benefit from this diary approach are people with mild cognitive impairment (MCI). By definition, MCI is not thought to impact daily functioning greatly [14]; however, even small cognitive alterations can lead to changes in feelings, behaviors, self-perception, and social interactions [15]. Thus, self-management can be impaired when living with MCI.

To our knowledge, using the ESM in people with mild cognitive impairment (MCI) is rare. Daily or weekly paper-pencil diaries have been used to study momentary stressors and affect in MCI samples [16,17], but we are not aware of technology-based ESM studies in this population. Assessing the general feasibility of an unfamiliar and technology-based method is necessary, as people with MCI are commonly older and have amnestic deficits. Thus, individuals with MCI may find it challenging to process new information or handle unfamiliar technologies. Research shows, for example, that people with MCI find it more challenging to use everyday technology than older adults without cognitive impairments [18,19], which might also impact the feasibility of smartphone-based ESM. If feasible, applying ESM in people with MCI may reveal valuable insight into daily patterns of their lives that traditional assessments have been unable to depict. Furthermore, the ESM may promote awareness and self-management in this population, thus ultimately contributing to maintained or improved well-being.

This study aims to determine the feasibility and usability of smartphone-based experience sampling in people with MCI. An ESM app was installed on participants' smartphones and programmed with a high sampling frequency to capture various intra-individual states (ie, mood, subjective cognitive problems) and situations (ie, activities, social context). Self-reports of using the ESM and observations of the direct human-technology interaction were conducted as part of the feasibility assessment. Human-technology interaction refers here to the person's ability to manage the ESM smartphone app, including specific performance skills, environmental characteristics, and individual capacities.

The usability of momentary data was studied on an individual and group level, focusing on subjective cognition, daily activities, and stress experienced in relation to those activities. Studying the data on a group level can provide valuable information on the daily functioning of the MCI population in general, while individual data can illustrate within-person fluctuations. This may result in helpful person-tailored insights that not only foster individualized therapy but also the diagnostic process [20] and the monitoring of early changes in cognitive or behavioral alterations in MCI.

Methods

Sample

Participants were recruited from the memory clinic at the Maastricht University Medical Center (UMC) from June 2018 to January 2020. Inclusion criteria were (1) having a clinical diagnosis of MCI, according to Albert et al [14], (2) owning a smartphone with an Android or iOS operational system, (3) providing written informed consent, and (4) receiving written informed consent from a relevant other (ie, partner, family member, close friend) that was selected by the person with MCI and was recruited. Exclusion criteria were (1) insufficient abilities to participate in research (eg, a self-reported or relevant other–reported inability or lack of confidence to use a smartphone or to learn and remember the purpose of the study) and (2) severe health problems, such as a diagnosis of a somatic, psychiatric, or neurological disorder causing additional cognitive dysfunction. Both exclusion criteria were based on the clinical judgment of a psychologist or psychiatrist during the recruitment phase (eg, telephone conversations with a potential participant or relevant other).

The Medical Ethical Committee from the Maastricht academic hospital (azM) and Maastricht University approved the study (NL64310.068.17 / METC173055), and the protocol is registered on ToetsingOnline (64310). The authors comply with the Helsinki Declaration of 1975, as revised in 2008. All participants, including people with MCI and their relevant others, provided written informed consent before study participation.

Experience Sampling Smartphone App

The PsyMate smartphone app [21] is a cloud-based platform developed at Maastricht University and Maastricht UMC (Multimedia Appendix 1). It is a tool for repeated momentary assessments in daily life that has been extensively studied and refined in mental health care [22]. In this study, the PsyMate was programmed to prompt participants 8 times a day over 6 consecutive days with an auditory and visual signal ("beep") to fill in a short momentary assessment. A high sampling

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frequency of 8-10 beeps per day was thought to provide sufficient insight into various daily contexts while not disrupting the flow of everyday life. The duration of 6 days was chosen to capture both weekdays and weekend days. This set-up was based on previous feasibility studies [23,24]. Beeps occurred unpredictably in semirandom time blocks of 112.5 minutes between 7:30 AM and 10:30 PM and were available to be filled in for 15 minutes after the beep. In total, 27 ESM items were included and could be answered on a 7-point Likert scale or in a multiple-choice set-up (Multimedia Appendix 2) assessing mood (eg, “I feel cheerful”), physical well-being (eg, “I feel tired”), subjective cognition (eg, “Since the last beep, I had memory problems”), and context (eg, “Where am I?”). Participants classified their responses individually, meaning that “work,” for example, could mean paid employment for one individual while another individual selected this option for gardening or doing chores. A morning and evening questionnaire was also part of the ESM, asking the participant to reflect on the previous night (eg, “I slept well”) and day (eg, “Generally, I felt tense today”). These questionnaires were not prompted via beeps but were available during the morning and evening, to be filled in self-reliantly, and this data was not included in this study (Multimedia Appendix 3). The development of this questionnaire was based on previous ESM studies [22,25,26]. Questions on subjective cognition were added after consulting with ESM experts and clinicians (ie, psychologists, psychiatrists, and neuropsychologists from the UMC).

Procedure

Participants were approached via the Alzheimer Center Limburg research database, consisting of patients with cognitive impairments who had previously expressed interest in being contacted for research purposes and had been previously recruited through UMC or by their treating health care professional at the memory clinic. A member of the research team called potential participants, checked general eligibility, verbally explained the study, and sent out information sheets. Participants were called by phone 1 week later, and if willing to participate, a date for the orientation session was set. A standardized protocol was used: (1) an orientation session, (2) an ESM training session, (3) a 6-day ESM period, and (4) a debriefing session. Only the person with MCI participated in the ESM training, the ESM period, and the debriefing session, but both the person with MCI and their relevant other were present at the orientation session. Sessions took place either at the hospital or at the participant's home, depending on the participant's preference. Participants could drop out at any time without providing a reason.

Orientation Session

After the study procedure was explained once more and final questions were clarified, informed consent was signed by the person with MCI and their relevant other. Next, sociodemographic information was collected and questionnaires were filled in assessing characteristics of the person with MCI either with self- or proxy-reports. At the end of this session, a date for the ESM training session was set. The ESM training was not combined with the orientation session so as not to overburden participants (as filling in a range of questionnaires can potentially be intense, confronting, and tiring). Thereby, we hoped to prevent participants from forgetting the ESM-training instructions due to information overload.

ESM Training Session

During the 30-minute training session, the PsyMate app was installed on the participant's smartphone, and the participant was instructed on how to respond to beeps, operate the app, and interpret the momentary questions. An example ESM questionnaire was filled in to familiarize participants with the procedure. The management of the app was observed, guided by the Management of Everyday Technology Assessment (META), to get a detailed picture of the human-technology interaction and performance skills [27]. All participants were briefed individually. A leaflet containing all instructions and contact information was handed out.

ESM Period

The PsyMate started sending beeps from the moment of installation; participants could respond on this day to train for filling in the momentary assessments, but they were instructed that the official 6-day ESM period would start the following day. On the second ESM day, a researcher called to check-in and solve potential technical problems or provide clarification.

Debriefing Session

This session took place 1 day after the last day of the ESM period. Participants were asked to report their general experiences using the app, and they received travel reimbursements and a small gift after participation but no financial reward.

Instruments

Sociodemographic and Descriptive Information

Next to the sociodemographic information of the person with MCI (age, sex, education, living situation, years since first symptoms) and their relevant other (age, sex, relationship to person with MCI), reliable and valid instruments were filled in with the purpose of describing the sample. The Mini–Mental State Examination (MMSE) provided information on cognitive functioning [28]. If the MMSE had been administered by a health care professional at the memory clinic in the past 3 months, these scores were used to reduce the burden. Otherwise, the MMSE was part of the orientation session. Furthermore, the Guidelines for the Rating of Awareness Deficits (GRAD) were included as a semistructured interview to assess the degree of awareness of one’s own cognitive problems [29]; the GRAD compares the patient's information and the relevant other's view on the patient's history. Impaired awareness is defined as the absence of knowledge recognition of cognitive deficits and its impact [29]. The Hospital and Anxiety Depression Scale (HADS) was included to generate scores for generalized anxiety and depression [30,31], and the Perceived Stress Scale (PSS) measured the perception of stress [32]. The relevant other filled in the Neuropsychiatric Inventory Questionnaire (NPI-Q) for information on a variety of neuropsychiatric symptoms [33,34] as well as the Amsterdam Instrumental Activities of Daily Living (Amsterdam IADL), which specifically measures

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problems in instrumental activities in individuals with mild cognitive problems [35].

Feasibility Assessment: Self-Report

The feasibility was determined through the compliance rate of the ESM assessments and was regarded as satisfactory when >70% of the momentary questionnaires were filled in [12,23]. The subjective experience of using the ESM tool was assessed during the debriefing session through a semistructured interview, including ratings of the difficulty, time burden, interference with daily activities, and overall acceptability of the methodology. This interview followed a standardized protocol and included questions such as “Was this a normal week?” or “Did the PsyMate app hinder your daily occupations?” which were discussed and then rated by the participant on a 7-point Likert scale or categorically.

Feasibility Assessment: Observations

The Management of Everyday Technology Assessment (META) [36] was used during the ESM training session. This tool aims to identify the ability to manage technology among older adults with and without cognitive impairments by observing the direct human-technology interaction. The META consists of 4 parts, assessing (1) observable performance skills, (2) environmental characteristics, (3) the person's capacity, and (4) the perceived importance of the used technology. The fourth part (the perceived importance of the technology), as well as general information about the technology (eg, years of possession, amount of use), is answered by the individual via an interview. The first 3 parts are scored by the investigator on a 4-point scale: 4=competent handling and management (ie, no deficits in this skill disturbs or hinders the person's use of the technology; no difficulty); 3=deficits in this skill occasionally or slightly disturb the person's use of the technology (minor difficulty/problems); 2=deficits in this skill obviously disturb the person's use of the technology (major difficulty/problem); 1= deficits in this skill hinder the person's use of the technology, or the person is in need of assistance to perform the skill competently. For the first part (observable performance skills), 6 out of 11 performance skills were selected and scored, as the other 5 were not part of using a smartphone app (eg, coordinate different physical parts of the technology).

Statistical Analyses

Descriptive analyses were conducted to summarize the sociodemographic information and background questionnaire scores. The compliance rate of the ESM day questionnaires, responses to the debriefing questionnaires, and META scores of the human-technology interaction were also analyzed using descriptive statistics. For the usability demonstration, only participants who filled in at least 30% of the ESM assessments were included, as a sufficient amount of information needs to be available to describe daily patterns [37]. Thus, momentary ESM data from dropouts collected via the PsyMate were not included in this part of the analysis. The momentary data were demonstrated on a group level using mood, context, feelings of tiredness, and subjective cognition items, and analyzed with descriptive statistics to assess the usability in this population in general [12]. The variable positive affect (PA) consisted of the ESM items “I feel cheerful,” “I feel energetic,” “I feel relaxed,” “I feel satisfied,” and “I feel enthusiastic.” The negative affect (NA) included “I feel down,” “I feel insecure,” “I feel irritated,” “I feel lonely,” “I feel anxious,” and “I feel guilty.” To demonstrate elements of daily functioning, an activity-related stress (ARS) variable was generated using “I can do this well” (reversed), “This requires effort from me,” and “I would rather do something else.” The ESM data collected with the PsyMate has a multilevel structure with beeps (level 1) nested within participants (level 2). Average scores of PA, NA, and ARS were thus person-mean centered to take the within-person effect into account. Factor analyses were conducted to ensure sufficient internal validity (Cronbach α=.86, .84, and .68 for the PA, NA, and ARS, respectively). PA, NA, and ARS were average, on a person-mean level. On an exemplary level, the subjectively experienced cognitive problems of 3 participants were demonstrated with line graphs over the course of the ESM period. The 3 participants were selected without specific criteria but with the aim of showing variation, giving a general impression of the ESM data, and demonstrating how the data can be used in clinical practice prospectively. Daily functioning using ARS was also demonstrated on an individual level by using data from 3 participants exemplary. Stata statistical software (version 13.0; StataCorp) was used for statistical analyses, and Excel (version 16.16.19; Microsoft) was used to create graphic visualizations.

Data Availability Statement

The data is stored at Maastricht University. Due to ethical and legal regulations, the data is only accessible for the MUMC+ research team. Sharing data with another research team needs to be approved by the Medical Research Ethics Committee azM/UM, or participants need to sign a new informed consent sheet.

Results

Group Characteristics

A total of 152 people with MCI were approached to participate in this study; 21 people with MCI signed informed consent. The participant flow is illustrated in Figure 1. Their relevant others also agreed to participate; the relevant others of the study participants had a mean age of 63.3 (SD 8.9, range 47-78) years, 6 were men and 15 were women, and 19 were the partners of the participants while 1 was a sibling and 1 was a friend. Table 1 provides an overview of the characteristics of the total sample. Multimedia Appendix 4 shows the details of the study completers and dropouts.

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Figure 1. Flow chart of recruited participants with mild cognitive impairment (MCI). ESM: experience sampling method.

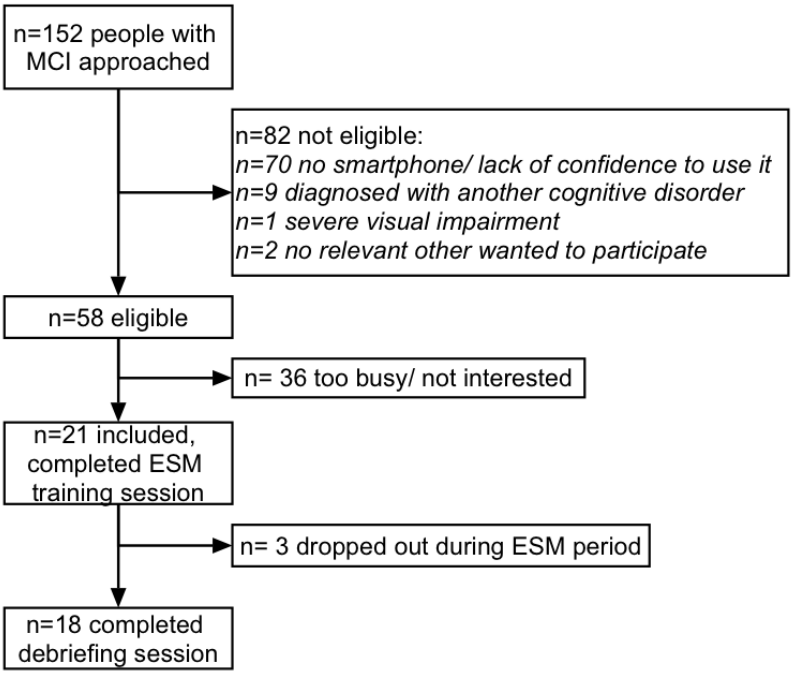

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Table 1. Descriptive information about the participants with mild cognitive impairment (n=21).

Participant characteristics	Values
Age in years, mean (SD; range)	66 (7.1; 48-79)
Sex, n (%)	
Men	16 (76)
Women	5 (24)
Level of education, n (%)	
Low (<9 years)	2 (10)
Middle (9-10 years)	11 (52)
High (>10 years)	8 (38)
Employment status, n (%)	
Retired	14 (67)
Working	3 (14)
Unemployed	4 (19)
Living situation, n (%)	
With partner	17 (81)
With partner and children	1 (5)
Alone	3 (14)
Years since first symptoms, mean (SD; range)	4.8 (4.0; 1-19)
Cognition (MMSE[a]), mean (SD; range)	28 (1.26; 27-30)
Awareness (GRAD[b]), mean (SD; range)	3.4 (0.67; 2-4)
4: Intact, n (%)	10 (48)
3: Mildly disturbed, n (%)	9 (43)
2: Moderately disturbed, n (%)	2 (10)
1: Absent, n (%)	—
Anxiety (HADS-A[c]), mean (SD; range)	11.8 (2.2; 6-15)
Depression (HADS-D[d]), mean (SD; range)	9.6 (1.4; 7-12)
Perceived stress (PSS[e]), mean (SD; range)	19.1 (4.5; 9-28)
Neuropsychiatric symptoms (NPI-Q[f]), mean (SD; range)	2.7 (2.1; 0-7)
Instrumental activities of daily living (IADL[g]), mean (SD; range)	57.2 (7.3; 45.9-69.9)

[a]MMSE: Mini–Mental State Evaluation; MMSE score range: 0-30, with higher scores indicating less cognitive difficulties.

[b]GRAD: Guidelines for the Rating of Awareness Deficits.

[c]HADS-A: Hospital and Anxiety Depression Scale–Anxiety; HADS scores range: 0-21 per scale (<7 noncases, 8-10 doubtful-cases, >11 definitive cases).

[d]HADS-D: Hospital and Anxiety Depression Scale–Depression; HADS scores range: 0-21 per scale (<7 noncases, 8-10 doubtful-cases, >11 definitive cases).

[e]PSS: Perceived Stress Scale; PSS scores range: 0-40, with higher scores indicating higher stress levels.

[f]NPI-Q: Neuropsychiatric Inventory Questionnaire; NPI-Q scores range: 0-36, with higher scores indicating a greater amount of neuropsychiatric behavior in the past month.

[g]IADL: Instrumental Activities of Daily Living; IADL *t* scores range: 20-80, with higher scores indicating better functioning; mean score=50 at memory clinics.

Dropouts, Compliance, and Self-Report

In the study, 21 individuals started the ESM period, resulting in 673 beep records; 3 participants had problems using the ESM and did not complete the ESM period. These 3 dropouts had been eager to learn the app during the training session and their MMSE, other questionnaire scores, and general impression did not deviate outstandingly from the other participants. A statistical comparison between study completers and dropouts was not performed due to the small sample size.

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The reasons for dropout were the following: Person A had problems using the right force pressing app buttons during the training session, forgot hearing aids repeatedly (according to partner) and thus did not react to the beeps, did not carry the smartphone along at all times, forgot the appointment, and seemed to generally deny cognitive problems. Person B expressed being very busy, only heard "some beeps" (no hearing problems, technical problems are unlikely according to IT specialist, reason unclear), and forgot the appointment for the debriefing session. Person C seemed generally nervous during the ESM training session (while expressing strong interest to participate), required very detailed and simple explanations of app use, and had forgotten instructions when contacted the following day. These 3 participants had not filled in the required 30% (16 beeps) to be included in the usability analysis, leading to a loss of 17 records (2.3%).

Of the 21 participants, 18 completed the ESM period and debriefing session, resulting in 656 valid beep records. On average, participants completed 38 beeps (SD 6.8; range 23-47) of the 48 beeps. The ESM compliance rate was 78.7%. Participants thought that the momentary questions reflected their experiences well (mean 4.83, SD 1.62) and that the PsyMate had little influence on their mood (mean 1.44, SD 1.15), activities (mean 1.61, SD 1.54), social interactions (mean 1.22, SD 0.73), or daily occupations (mean 1.39, SD 0.85). Filling in the momentary questions made participants marginally more aware of their activities (mean 2.17, SD 1.86) and moderately aware of their feelings (mean 3.56, SD 2.45) and memory (mean 4.56, SD 2.5). Of the 18 participants, 4 found increased awareness of their memory to be unpleasant, while 13 experienced it as pleasant or neutral. Table 2 provides detailed information on the general experience with the PsyMate and user-friendliness.

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Table 2. General PsyMate app and user-friendliness evaluation [n=18; dropouts (n=3) were not included because they did not participate in the debriefing session].

General PsyMate app and user-friendliness evaluation	Scores (1="not at all" – 7="very much")
General evaluation of PsyMate app, mean (SD; range)	
Was this a normal week?	5.06 (1.51; 2-7)
Did special events occur?	2.22 (1.73; 1-4)
Did the questions reflect your experiences well?	4.83 (1.62; 2-7)
Did the PsyMate app influence your mood?	1.44 (1.15; 1-5)
Did the PsyMate app influence your activities?	1.61 (1.54; 1-7)
Did the PsyMate app influence your social interactions?	1.22 (0.73; 1-4)
Did the PsyMate app hinder your daily occupations?	1.39 (0.85; 1-4)
Did you make mistakes when filling in the PsyMate app?	2.17 (0.92; 1-4)
Did filling in the PsyMate app make you more aware of your feelings?	3.56 (2.45; 1-7)
If so, did you experience this as pleasant? n[a]	7
If so, did you experience this as neutral? n[a]	9
If so, did you experience this as unpleasant? n[a]	1
Did filling in the PsyMate app make you more aware of your memory?	4.56 (2.50; 1-7)
If so, did you experience this as pleasant? n[a,b]	6
If so, did you experience this as neutral? n[a,b]	7
If so, did you experience this as unpleasant?[a,b]	4
Did filling in the PsyMate app make you more aware of your activities?	2.17 (1.86; 1-7)
If so, did you experience this as pleasant? n[a,b]	3
If so, did you experience this as neutral? n[a,b]	14
If so, did you experience this as unpleasant? n[a,b]	0
Evaluation of PsyMate app user-friendliness, mean (SD; range)	
Were you able to read the text on the screen well?	6.06 (1.70; 1-7)
Could you hear the beep well?	6.44 (0.86; 4-7)
Did you have problems using the PsyMate app?	1.56 (1.65; 1-5)
Were the verbal explanations regarding the PsyMate app clear?	6.67 (0.60; 5-7)
Were the written explanations regarding the PsyMate app clear?	6.67 (0.60; 5-7)
Were the questions from the PsyMate app unclear or difficult?	2.28 (1.60; 1-7)
Did you experience the use of the PsyMate app burdensome with regard to the number of beeps?	1.44 (0.98; 1-5)
Did you experience the use of the PsyMate app burdensome with regard to length of one beep?	1.44 (0.62; 1-3)
Did you experience the use of the PsyMate app burdensome with regard to the sound?	2.33 ± 2.14 (1-7)
Did technical problems hinder you from filling in the beeps?[b]	1.88 1.09 (1-4)

[a]Questions were not answered on a 7-point Likert scale but categorically.

[b]Missing response (n=1).

Observation of the Human-Technology Interaction

The META revealed that most performance steps involved in using the PsyMate did not cause any difficulties (Table 3). However, using the appropriate force, tempo, and precision caused, on average, some disturbances (mean 3.48, SD 0.51). With regard to the environmental characteristics influencing the use of the PsyMate app during the training session, the contextual influence (ie, the presence of researchers, which could be potentially stressful) was observed as not hindering smartphone use (mean 3.9, SD 0.3; range 3-4), while the technological design (ie, screen and button size) was observed as somewhat disturbing (mean 3.38, SD 0.3; range 2-4). The overall judgment of the participants' capacity to use the app was

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reflected in the capacity to recall necessary information as not disturbing (mean 3.86, SD 0.36; range 3-4), just like the capacity to pay attention and focus (mean 3.81, SD 0.40; range 3-4) and the capacity to manage stress (mean 3.76, SD 0.45; range 3-4). Of the 21 participants, most participants (12/21) had had smartphones for more than 10 years; 5 had used a smartphone for 3-9 years, 1 had used it for 1-2 years, and 2 had it for less than 1 year (1 participant could not indicate the duration). All 21 participants experienced the technology as very important and not replaceable; 18 used their smartphones daily and 2 used it at least weekly (for the remaining 1 participant, there is a missing value).

Table 3. Assessment of observable performance skills when using the PsyMate app during the experience sampling method (ESM) training session (n=18).

Performance skill	Observation score[a], mean (SD; range)
Identify service and function[b]	3.90 (0.31; 3-4)
Perform actions in logical sequence	3.95 (0.22; 3-4)
Manage series of number/letters[c]	4.0
Choose correct button or command	3.76 (0.45; 3-4)
Use appropriate force, tempo, and precision	3.48 (0.51; 3-4)
Identify information and respond adequately	3.95 (0.22; 3-4)

[a]Observation scores: range 1-4; 4=competent handling/management (ie, no deficits in this skill disturbs or hinders the person's use of the technology); 1=deficits in this skill hinder the person's use of the technology and/or the person is in need of assistance to perform the skill competently.

[b]n=1 missing, as skill was not observable.

[c]n=12 missing, as skill not observable.

Usability of the Experience Sampling Data

Daily Patterns on a Group Level Over ESM Period

In general, the 18 participants experienced a high level of PA (mean 4.95, SD 0.66; range 3.94-6.13), a low level of NA (mean 1.95, SD 0.93; range 1.07-3.92) and a low to moderate level of ARS (mean 2.73, SD 0.74; range 1.71-4.05). They felt moderately tired (mean 3.64, SD 1.39; range 1-6.29) and had low to moderate problems with their memory (mean 3.01, SD 1.11; range 1.34-5.29), language (mean 2.04, SD 1.15; range 1-5.21), and concentration (mean 2.85, SD 1.36; range 1.05-4.96). With regard to their contextual patterns, participants spent most of their time at home (72%) (other locations: transport [9%]; at family's/friend's [5%]; at work [5%]; somewhere else [5%]; public place [4%]) engaging in household (22%) or relaxing activities (29%) (other activities: eating/drinking [10%]; something else [10%]; work [8%]; nothing [6%]; traveling [4%]; in conversation [4%]; self-care [4%]; sport/physical activity [3%]), and were often in company of their partner (45%) or alone (31%) (other social company: family [8%]; colleagues [4%]; co-occupants [4%]; friends [3%]; acquaintances [3%]; strangers [2%]).

Individual Profiles

To illustrate the variability that can be studied using momentary data, several descriptive examples are presented, focusing on the subjectively experienced cognitive problems, daily activities, and activity-related stress in everyday life. These participants were selected without specific criteria but with the aim of visually illustrating fluctuations within subjects, variables, and days (Figures 2-4). An unspecified heterogeneity is present, while no statistical differences within and between subjects were tested. Some suggestions for personalized feedback conversations between health care professionals and the individuals are provided as well.

As shown in Figure 2 and Table 4, Person 1 reports mainly moderate memory problems, while language and concentration abilities are overall subjectively unimpaired. Person 1 engages in doing “nothing” 24% of the time. This activity shows personally higher levels of ARS, while “relaxing” has lower levels of ARS. The person engages in “work” (note: not necessarily paid) 10% of the time, which also shows a personally higher level of ARS. When discussing this data, increased engagement in relaxation and coping with work could be targeted.

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Figure 2. Person 1: subjectively experienced cognitive problems.

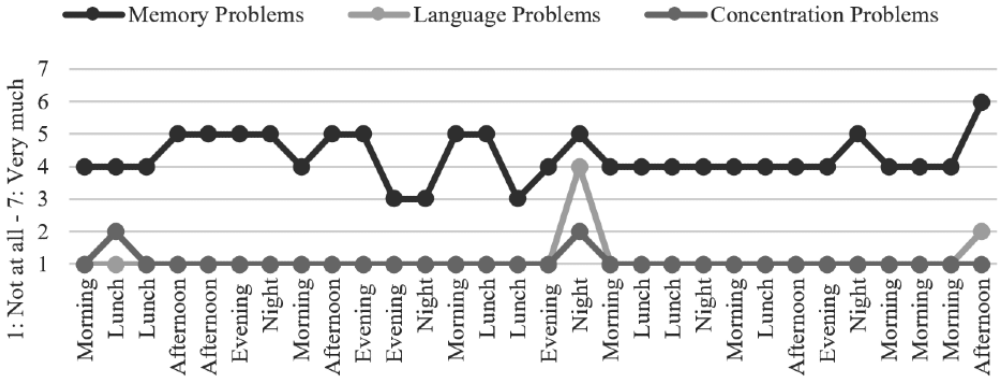

Table 4. Person 1: daily activities and levels of activity-related stress.

Daily activities	Daily time (%)	Activity-related stress level[a]
Nothing	24	3.14
Relaxing	7	1.78
In conversation	3	2
Something else	50	2
Eating/drinking	3	2
Work	10	3.67
Travel	3	2.07

[a]Scale: 1 (not at all) – 7 (very much). This data stands in relation to the fluctuations of cognition (Figure 2).

As shown in Figure 3 and Table 5, Person 2 reports cognitive problems that fluctuate across all 3 domains. Conversations (2% of activity engagement) seem to be the most stressful (personally higher level of ARS). In this case, dealing with cognitive problems and developing coping strategies for conversations might be useful for the individual.

Figure 3. Person 2: subjectively experienced cognitive problems.

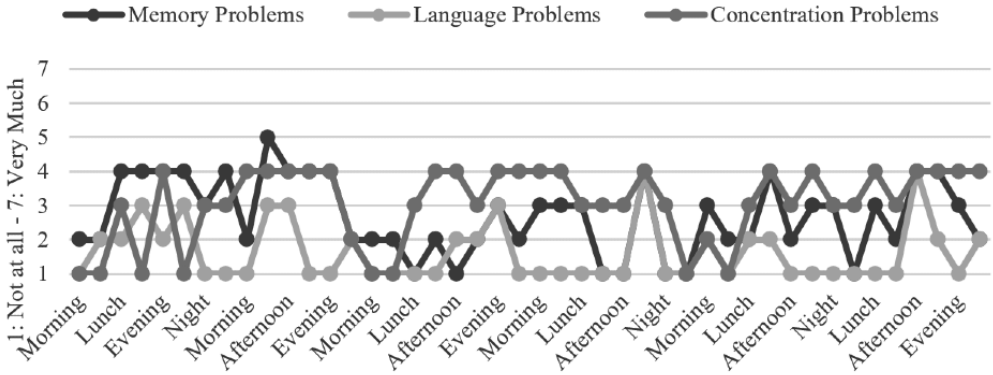

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Table 5. Person 2: daily activities and levels of activity-related stress.

Daily activities	Daily time (%)	Activity-related stress level[a]
Household	32	2.89
Relaxing	39	2.69
In conversation	2	3.33
Sports/physical activity	5	2.33
Eating/drinking	9	2.33
Work	2	2.67
Self-care	9	3.08
Traveling	2	2

[a]Scale: 1 (not at all) – 7 (very much). This data stands in relation to the fluctuations of cognition (Figure 3).

As shown in Figure 4 and Table 6, Person 3 has subjective cognitive impairments in all 3 domains that fluctuate somewhat simultaneously. On some mornings, the cognitive problems seem to be milder. Relaxation activities, which report low levels of ARS, are the main activity of Person 3 (48%). Nevertheless, doing nothing (12%) and working (7%) might be topics to discuss to optimize self-management.

Figure 4. Patient 3: subjectively experienced cognitive problems.

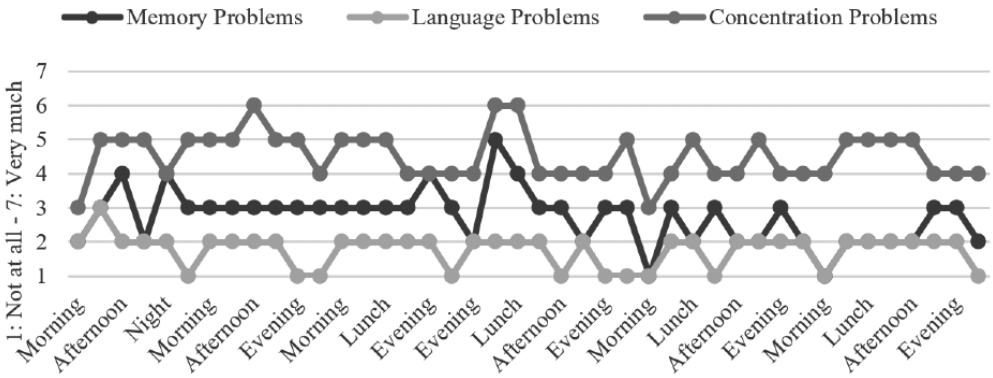

Table 6. Person 3: daily activities and levels of activity-related stress.

Daily activities	Daily time (%)	Activity-related stress level[a]
Household	5	4.17
Relaxing	48	3.3
Something else	14	3.56
Sports/physical activity	5	3.5
Eating/drinking	2	4
Work	7	4.67
Self-care	7	3
Nothing	12	5.33

[a]Scale: 1 (not at all) – 7 (very much). This data stands in relation to the fluctuations of cognition (Figure 4).

Discussion

Principal Findings

This study evaluates the feasibility and demonstrates the usability of a smartphone-based ESM in people with MCI. Several important findings emerged: (1) in study completers, the compliance rate was high and subjective ratings of the ESM procedure were positive; (2) the observable human-technology interaction between participants and the ESM app was generally unproblematic; (3) raising awareness for one's own cognitive problems through ESM can be unpleasant for some individuals; and (4) cognitive issues (eg, forgetfulness) may lead to the inability to use the ESM.

Previous research found that the compliance rate, also referred to as adherence, use, or engagement, to technology-based self-monitoring such as ESM lies between 51-86% in middle-aged and older adults [9,38]. Therefore, the reported

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78.7% of completed assessments in this study is a strong indication for the feasibility of ESM in a majority (18/21, 85%) of our MCI sample. A high sampling frequency, which was applied in this study with 8 beeps per day, is not thought to hinder ESM use, while the length of the questionnaires can increase burden [39]. The overall positive participants' feedback on the procedure, including the length and frequency, supports the chosen ESM set-up. Additionally, the human-technology interactions were observed as overall unproblematic. Occasionally, a participant's inappropriate tempo, force, or precision of clicking on app buttons disturbed usage slightly. As older adults may benefit from large buttons and screens without scroll functions [40], it would be advisable to rotate the screen, increase button sizes, or provide a touch-pen to ease the app use even further. In addition to dexterity, older adults might also have hearing issues. In this study, one of the dropouts did not wear their hearing aids, which might have contributed to their inability to use the ESM and discontinuation of the trial.

According to the social cognition theory, self-monitoring can raise awareness for one's own emotions or behaviors [41]. Repeated momentary assessments can use this increased awareness to promote behavioral changes towards healthy lifestyles [22,42] as well as improve mental well-being [43]. Within this study, there was no intention to change daily patterns, but nevertheless, participants became more aware of their memory abilities through repeated self-assessments. Of the 18 participants, 13 individuals experienced this as pleasant or neutral, but 4 reported this to be unpleasant. Similar side-effects of the ESM have previously been reported, and a suggestion could be to use positive formulations in the ESM questions [44]. For example, instead of asking about cognitive problems (eg, "Since the last beep, I had memory problems"), abilities could be targeted instead (eg, "I can remember well"). In this study, the experience of using ESM was discussed during the debriefing session, and in 1 case, a participant was advised to consult a health care professional for further treatment for cognition-related stress. In clinical settings, treating health care professionals may discuss experiences and increased awareness to develop coping strategies [45]. The individual profiles section highlights topics that may be discussed on an individual level, such as activities that elicit low stress (eg, relaxation) or the potential need for assistance or new coping strategies. Studies suggest that those feedback conversations could focus on positive emotions to increase resilience to stress [46] and stimulate goal-directed behavior [47]. This kind of feedback has shown to improve well-being, for instance, in an ESM-based intervention for carers of people with dementia [26]. The ultimate goal when using ESM is to support self-management through increase awareness for one's own abilities and orientate attention towards positive and meaningful aspects of daily life.

A small number of participants were unable to complete the experience sampling period. In older adults with undiagnosed subjective cognitive concerns, nonadherence to momentary assessments is thought to be greatly influenced by cognitive issues [48]. In this study, predicting dropouts using standardized instruments such as the MMSE was impossible. A systematic review reports that the averaged MMSE score in MCI samples seems to range from 23.1 to 28.7 [19], indicating a great variability of cognitive abilities in this population and that participants of this study potentially had relatively mild MCI. However, the MMSE has a limited discrimination between cognitively health adults and people with MCI, and other tests with a higher sensitivity (eg, Hopkins Verbal Learning Test) could have been used to determine study eligibility [49]. All participants were eager to participate, while no clear indication for exclusion could be identified. Follow-up phone calls were helpful to notice difficulties early. Dropouts seem to blame their inability to participate on the technology (eg, "It did not beep"). Admitting problems with technology might be easier than admitting other cognitive deficits, as even young and healthy individuals may occasionally face difficulties with technology. Further, reduced illness insight and cognitive deficits could have influenced the ability to use the ESM. The latter is supported by reports from participants and relevant others, stating that smartphones or hearing aids were forgotten, thus interfering with the ESM use. To prevent injustice in health care, all individuals with MCI motivated to use the ESM should be given a chance to do so, and frustration can be prevented through follow-ups, close guidance, and open communication.

Generally, the ESM group data revealed subjective problems with memory, concentration, and language in everyday life. This finding is in line with traditional neuropsychological assessments reporting a variety of cognitive deficits in MCI, of which memory is commonly most dominant [50]. A moderate level of fatigue has also been found in a healthy sample using the ESM [24] and may thus not be directly related to the cognitive deficits. To determine significant differences from healthy older adults, a control group is prospectively necessary. Furthermore, associations between daily fatigue, context, mood, and cognitive problems experienced by individuals may be studied using multilevel analysis [12].

Future Directions

On an individual level, cognitive fluctuations indicate trends of diversity both within and between subjects. The heterogeneity of the MCI group has been highlighted before [51], but this is one of the first studies to provide such a detailed insight into daily patterns using smartphone-based ESM. Next to the subjective evaluation of cognitive problems in everyday life, objective momentary cognition tasks can be added to this ESM app. The feasibility of 2 tasks has recently been tested in healthy individuals [52] and holds promise for future studies to describe a comprehensive picture of cognitive abilities. The ESM may also be useful to compare daily patterns of subjective or objective cognitive functioning in different neurological and psychiatric disorders.

Additionally, activity-related stress levels seem to vary between activities as working, for example, shows a trend for high levels of stress. This study is unfortunately not able to statistically explore activity patterns in people with MCI, but future research might follow up on this idea. Research shows that complex tasks are affected early on in the process of cognitive decline [53], and cognitive difficulties may decrease the ability of individuals with MCI to work [54]. Our understanding of necessary adjustments and ways to support working, particularly employment, when living with MCI are limited [55], but the

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insights gained from the participants in this study highlight the need to study working and employment as a potential stressor in this population further. High levels of anxiety and depression are commonly observed in MCI [56], as they were in this sample, and may also stand in relation to stress and cognitive deterioration [57]. As highlighted above, developing coping strategies and focusing on positive emotions might support daily well-being, including work-related stress. The ESM can be a useful tool to relate functional fluctuations with contexts and activities and thus understand patterns and networks in people with MCI, both on a within- and between-subject level [58].

Limitations

Some critique regarding the ESM and study limitations need to be acknowledged. It is recommended not to overinterpret single items but rather to use momentary data as a starting point for a conversation about one's self-management and coping. Generally, many people (n=70) approached for the study had no smartphone or did not feel confident to participate in a smartphone-based study. This outcome indicates that there is a bias towards individuals with a higher technology familiarity to benefit from digital innovations in research and clinical work. Over the next decade, this bias might decrease, but researchers and clinicians need to be aware of this gap to not neglect individuals in need of support. Potentially, traditional paper-pencil diaries might be an alternative for people with MCI [16,17] that cannot or do not want to use smartphones. However, cognitive problems (eg, forgetting paper diary) or hearing problems (eg, not hearing the beeps from a prompting device) could still interfere. As learning and using a new technology is an intertwined process [59], and training is a key component for older adults to increase confidence and self-efficacy when using technology [60], prospective individuals with MCI who are not confident in their abilities to use a smartphone could receive training sessions and additional guidance. Unfortunately, this study is not able to determine if individuals with MCI would also be able to learn smartphone and ESM use together. Furthermore, the findings may be affected by a sex and education bias, as 76% (16/21) were men and only 10% (2/21) were low-educated. In addition, the etiology of MCI was not determined, resulting in an unspecified heterogeneity. As indicated by the MMSE, this MCI sample might have relatively mild cognitive problems, and a replication of our findings in a broader MCI sample might be necessary to increase the generalizability of the results. Detailed descriptive information about MCI subgroups could prospectively be added. The small sample size orientated on other feasibility studies [12,61] may limit the generalizability of the results, but the great number of assessments still result in a rich data set [22]. Finally, the study represents a specific group of people with MCI in possession of their own smartphones, and this recruitment criteria needs to be kept in mind when applying the ESM in future studies or clinical settings.

Conclusion

Technology-based ESM can be a useful addition to clinical questionnaires to reveal detailed moment-to-moment fluctuations, contextual patterns, and individual differences in subjectively experienced cognitive problems, affect, and activities. This feasibility study is a relevant step to better understand and support people with MCI in their everyday lives. Momentary data may prospectively be used to study individual and group-based patterns in this population and develop person-tailored self-management strategies.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Interface of the experience sampling method (ESM) smartphone app "PsyMate.".
[PNG File , 89 KB - aging_v3i2e19852_app1.png]

Multimedia Appendix 2
Experience sampling method (ESM) item list of the day questionnaire.
[DOCX File , 15 KB - aging_v3i2e19852_app2.docx]

Multimedia Appendix 3
Morning and evening questionnaires.
[DOCX File , 14 KB - aging_v3i2e19852_app3.docx]

Multimedia Appendix 4
Descriptive information of the study completers (n=18) and dropouts (n=3).
[DOCX File , 16 KB - aging_v3i2e19852_app4.docx]

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Abbreviations

Amsterdam IADL: Amsterdam instrumental activities of daily living
ARS: activity-related stress
azM: academisch ziekenhuis Maastricht
ESM: experience sampling method
GRAD: Guidelines for the Rating of Awareness Deficits
HADS: Hospital and Anxiety Depression Scale
MCI: mild cognitive impairment
META: Management of Everyday Technology Assessment
MMSE: Mini–Mental State Examination
NA: negative affect
NPI-Q: Neuropsychiatric Inventory Questionnaire
PA: positive affect
PSS: perceived stress scale
UMC: Maastricht University Medical Center

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Original Paper

Use of an Internet-of-Things Smart Home System for Healthy Aging in Older Adults in Residential Settings: Pilot Feasibility Study

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Abstract

Background: The Internet-of-Things (IoT) technologies can create *smart* residences that integrate technology within the home to enhance residents' safety as well as monitor their health and wellness. However, there has been little research on real-world testing of IoT smart home devices with older adults, and the feasibility and acceptance of such tools have not been systematically examined.

Objective: This study aims to conduct a pilot study to investigate the feasibility of using IoT smart home devices in the actual residences of older adults to facilitate healthy aging.

Methods: We conducted a 2-month feasibility study on community-dwelling older adults. Participants chose among different IoT devices to be installed and deployed within their homes. The IoT devices tested varied depending on the participant's preference: a door and window sensor, a multipurpose sensor (motion, temperature, luminosity, and humidity), a voice-operated smart speaker, and an internet protocol (IP) video camera.

Results: We recruited a total of 37 older adults for this study, with 35 (95%) successfully completing all procedures in the 2-month study. The average age of the sample was 78 (SD 9) years and primarily comprised women (29/37, 78%), those who were educated (31/37, 86%; bachelor's degree or higher), and those affected by chronic conditions (33/37, 89%). The most widely chosen devices among the participants were multipurpose sensors and smart speakers. An IP camera was a significantly unpopular choice among participants in both phases. The participant feedback suggests that perceived privacy concerns, perceived usefulness, and curiosity to technology were strong factors when considering which device to have installed in their home.

Conclusions: Overall, our deployment results revealed that the use of IoT smart home devices is feasible in actual residences of older adults. These findings may inform the follow-up assessment of IoT technologies and their impact on health-related outcomes and advance our understanding of the role of IoT home-based monitoring technologies to promote successful aging-in-place for older adults. Future trials should consider older adults' preferences for the different types of smart home devices to be installed in real-world residential settings.

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KEYWORDS

Internet of Things; smart home; independent living; aging; healthy aging

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Introduction

Background

Aging-in-place is a concept that has been proposed to address older adults' needs and expectations of successful aging. It calls for supporting older adults' desire to remain and live in their own homes without having to relocate to support facilities such as nursing homes [1]. The importance of aging-in-place has been shown consistently across different surveys of older adults [1]. However, while older adults show a strong desire to stay independent without having to give up their own lifestyle as they age, aging-in-place can introduce some challenges. These include managing one's own health, performing various activities of daily living, and maintaining social connections while experiencing health-related changes. Previous research has shown that older adults who live alone can face issues related to isolation, mobility, hygiene, finances, health management, home management, safety, and nutrition [2-4]. Consequently, there is an increased need for interventions to support the successful aging-in-place of older adults. To this end, there has been a growing interest in the use of technologies for older adults, including those that can facilitate health monitoring of older adults in their residence to promote healthy aging in their own homes. The need for this type of technological intervention is amplified by the growing older adult population, increasing health care needs, and the desire of older adults to age in their own homes.

The Internet of Things (IoT) is a network of objects (eg, sensors, appliances, cars) equipped with internet connectivity, enabling them to send and receive data [5]. Therefore, IoT objects or devices can interact with each other and cooperate to provide value-added services to the user [6]. One of the most prominent examples of IoT is the smart home. An IoT smart home can consist of smart appliances (eg, washers, dryers, refrigerators), smart home safety and security systems (sensors, monitors, cameras, and alarm systems), and smart home energy equipment, such as smart thermostats and smart lighting. Such IoT devices can create *smart* residences that integrate technology within the home to enhance residents' safety as well as monitor their health and wellness. The residences equipped with IoT smart home devices potentially make the lives of older adults easier, more convenient, and safer. For example, older adults with limited mobility will be able to control their doors, window blinds, or light switches by simply giving voice commands. For these older adults, being empowered to perform these daily activities on their own is the difference between being able to live independently or needing assistance at home or moving to an assisted living facility. In addition, the advancement in IoT sensor technologies along with advanced data analytics presents an opportunity to support independent aging by identifying potential patterns in health, detecting anomalous activities, and prompting early intervention to prevent adverse health events [7-11].

The use of home-based sensor technologies to passively monitor activity levels of older adults is a concept that has been tested previously [10,12-22]. Previous research has shown that such technologies could accurately detect abnormal movement or behaviors [10,21-24], and older adults are interested in receiving data from sensor technologies that provide better insight into their health status [25,26]. In addition, older adults have demonstrated their belief that sensor-based passive monitoring systems in their homes have the potential to enhance their quality of life [27]. Although these projects provide initial insights into the potential of health monitoring using smart home sensors, most of these efforts were not real-world evaluation studies with older adults and did not assess older adults' preferences for diverse arrays of IoT smart home devices. In addition, previous research has used systems with hardware components that capture and transmit data but do not have ways to interact with other devices and aggregate the data in a central repository, as would be the case in an IoT-based smart home system. To our knowledge, there has been little research on real-world testing of IoT smart home devices with older adults, and the feasibility and acceptance of such tools have not been systematically examined. Therefore, the purpose of this study is to address this gap by conducting a pilot study to investigate the feasibility of using IoT-based smart home devices in actual residences of older adults.

Objectives

Our objective is to investigate the feasibility of using IoT smart home devices in real-world residential settings of older adults. To demonstrate feasibility, we assessed the following key aspects of future trial design: (1) recruitment and retention, (2) participants' preference for device choices, (3) device deployment and maintenance, (4) feasibility of data collection, and (5) acceptability of the selected health outcome measures. As this was a feasibility study, no controls or randomization was used, and no specific interventions were administered during the study. All study procedures were approved by the University of Washington, Institutional Review Board.

Methods

Study Design

This study was a 2-month feasibility study that enrolled community-dwelling older adults in the Puget Sound area to choose among different IoT devices to be installed and deployed within their homes. The devices varied depending on the preference of the participant, and options included the following: (1) a door and window sensor, (2) a multipurpose sensor (motion, temperature, and luminosity), (3) a voice-operated smart speaker, and (4) an IP video camera (see *IoT Device Description and Deployment* for more detail). Over the study period, participants were interviewed at 3 different time points: baseline, 1 month, and 2 months (study exit) to understand their thoughts about the devices.

We recruited participants through collaboration with local retirement communities in the Puget Sound area. In order to be eligible for the study, participants needed to be (1) community-dwelling older adults, (2) able to read and write English, (3) have an internet connection at their residence, and (4) choose at least one or more devices for installation in the home. Recruitment occurred at 6 different senior housing communities to include individuals across a range of lower to middle-upper socioeconomic status. The communities house

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older adults who have the capacity to live independently with minimal help in maintaining their home or activities of daily living. Working with facility administrators, we posted recruitment flyers and held information sessions that included a short presentation about the research project, followed by a question and answer session. After the presentation, interested individuals either went through an informed consent process with study team members or filled out contact information to be contacted later for enrollment in the study. In the latter case, informed consent was obtained during the baseline visit before any study procedures. We also conducted snowball sampling to identify potential participants who may be interested in participation. During the informed consent process, the subject chose the devices to be installed and indicated their choice on the form. To compensate participants for their time, we provided US $25 gift cards following the first- and second-month interview visits.

In this study, recruitment occurred in 2 different phases. For phase 1, a voice-operated smart speaker was not one of the available IoT devices, and eligible participants had to be living alone on top of the aforementioned inclusion criteria. For phase 2, we added the option of a voice-operated smart speaker and made it eligible for interested couples who live together to join the study together. The recruitment process and the study procedures remained the same between the 2 phases. In total, 37 participants were included in the study. Fifteen participants were recruited during phase 1 (12 females and 3 males) and 22 participants were recruited during phase 2 (17 females and 5 males).

IoT Device Description and Deployment

Table 1 provides an overview of the IoT devices available for the participants to choose and evaluate for this study. Figure 1 presents pictures of the devices used in the study. All the devices were commercially available. The primary investigator conducted installations of the devices and provided technical support via phone or by making in-home visits during the duration of the study when necessary. The frequency and reasons for additional visits outside the scheduled study visits were recorded. Participants were also encouraged to contact the primary investigator if they had any questions or issues related to the devices.

Table 1. Internet-of-Things smart home devices used in this study.

Device	Data collected	Data transfer protocol	Location of deployment within the home
Door and window sensor	Binary on or off signal when the switch is activated	Z-wave	Front door, refrigerator
Multipurpose sensor	Luminosity, temperature, humidity, and motion	Z-wave	Living room, bedroom
Voice-operated smart speaker	The transcripts of the questions and requests made during the study period	Wi-Fi	Living room
Internet protocol web camera	Live video streaming. No video recording was collected	Wi-Fi	Living room, bedroom

Figure 1. Device pictures.

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Door and Window Sensor and Multipurpose Sensor Deployment

Door and window sensor and multipurpose sensor: The door and window sensor record a binary on or off signal when the magnetic switch is activated. The multipurpose sensor collects data on motion, temperature, luminosity, and humidity. The door and window sensor were installed either at the front entrance of the residence or the fridge. The multipurpose sensor was installed in the living room area or the bedroom depending on the preference of the participant. To deploy these 2 sensors, we used the open source software platform called *Lab of Things* developed by Microsoft Research [28,29]. This platform was installed in a small study laptop and deployed together with a door and window sensor and a multipurpose sensor. For communication between the Lab of Things platform and the sensors, a Z-wave USB dongle was attached to the laptop. During the study, the laptop was plugged into the outlet and left on all the time for processing and sending the sensor data to our research cloud server. The laptop was closed lid and placed to be as unobtrusive as possible to the participant's home.

Voice-Controlled Smart Speaker Deployment

The smart speakers are equipped with a far-field microphone that supports voice recognition. This allows for various hands-free operations, including playing music, retrieving information, and setting reminders and alarms. For this study, we used Echo Dot, a smart speaker manufactured by Amazon. Amazon smart speakers provide capabilities or skills that enable users to try out features created by third-party designers and developers for a more personalized experience. For example, *WebMD*'s skill allows users to ask basic health-related questions. The initial training of how to use the smart speaker was provided by a member of the research team. The participants were encouraged to explore various features during the study period and consider the potential uses of a smart speaker in the management of health context. In addition to the initial training, a list of basic commands was provided to the participants to facilitate the usage of the smart speaker.

IP Web Camera Deployment

The use of an internet protocol (IP) camera allows for the synchronous monitoring of a room or other area in the home by the participants. The camera was installed in the living room area or the bedroom location according to the preference of the participants. The participants had the option to have the accompanying monitoring app installed on their mobile phone or just use a regular desktop browser to view the live feed from the camera. The research team did not monitor the live feed from the camera because providing a monitoring service was not the goal of this study. However, the participants could choose to share access to the camera with someone in their life by sharing the web address of the secured camera dashboard and the accompanying ID and password.

Procedures

Baseline Visit

Once participants agreed to participate in the study and provided written informed consent, we scheduled an in-person appointment with the participant for the baseline visit. During the baseline visit, we installed participant-selected IoT devices in the subject's residence. Installation took approximately 30-45 mins if a participant was to select all offered devices. After the installation was complete, we collected demographic data including age, gender, marital status, education, insurance status, history of chronic conditions and current medications, and the use of assistive devices. In addition, we administered the eHealth literacy scale (eHEALS) [30] to measure one's comfort level with the technology. Health-related data that incorporate physical, psychosocial, functional, and mobility-related parameters were collected using validated self-report instruments. For a complete description of instruments and the data collection schedule, see the *Data Collection and Analysis* section. After all the questionnaire data were collected, a semistructured interview was conducted to assess the initial participant perspectives on IoT smart home devices. The questionnaires and interview questions took 30-45 mins, and in conjunction with installation, the first visit lasted between 60 and 90 mins in total.

Midpoint (1-Month) Visit

During the midpoint visit, we conducted an in-person interview to assess the perceived usefulness of the installed IoT smart home technology, any challenges, privacy or other concerns, and any recommendations or feedback that subjects had at this point. During this visit, we presented participants with graphs of their own sensor data collected during the first month, asking for thoughts and feedback (see the *Smart Home Activity Data Visualization* section below). The visit lasted 30 to 45 mins.

Exit (2-Month) Visit

After 2 months, we conducted an exit visit in the subjects' homes. The installed devices were removed at the beginning of the visit. We administered questionnaires and conducted a semistructured interview to assess perceived obtrusiveness of the IoT smart home technology, any challenges, privacy or other concerns, and any recommendations or feedback (pertaining to their overall experience) subjects may have as they concluded their participation. The exit visit took approximately 60 mins. All interviews at the 3 timepoints were digitally audio-recorded and transcribed using a professional transcription service.

Smart Home Activity Data Visualization

Participants who selected motion tracking sensors (eg, a door and window sensor, a multipurpose sensor) were presented with graphs of their own sensor data obtained from the motion sensors. The line graphs and bar graphs were created by PI by aggregating the sensor data using R software to show the activity trends and pattern changes over time. The number of graphs shown to the participants varied based on the selection of devices. Participants who selected a smart speaker or an IP camera did not see the graphs, and no questions were asked related to visualization.

Data Collection and Analysis

Multimedia Appendix 1 [23-27] outlines the instruments used for this study and the data collection schedule. Instruments were selected to test for feasibility of data collection and acceptability for measuring health status outcomes for future smart home

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studies. For the analysis of demographics and the selection of IoT devices at baseline, we used descriptive statistics. In addition, we used the paired two-tailed *t* test and chi-square test to compare the pre-post assessments of participants' health-related variables in an exploratory manner, as the study was not powered to detect statistically significant changes over time. The statistical software program R was used to complete the quantitative data analyses. Interview sessions (at baseline, midpoint, and exit) were audio-recorded and transcribed. Descriptive content analysis [31] of the interview data was performed by at least two independent researchers, and the validity of the interpretations was checked by a third trained member.

Results

Recruitment and Retention

A total of 51 people inquired about the study, expressing initial interest to join after attending the recruitment information session or contacting the research team member using the recruitment flyer. Among the 51 inquiries, 47 were from the information session, 2 from the study flyer contact information, and 2 were contacts from snowball sampling from the enrolled participants. Table 2 summarizes the recorded reasons that were identified to exclude participation.

We recruited a total of 37 older adults for this study (15 in phase 1 and 22 in phase 2). For those who were recruited, one participant (ph1_p1) during phase 1 did not complete the full 2-month study, dropping out after completing the midpoint visit. This individual mentioned very low perceived utility of the devices and complained about unidentified technical issues experienced at home. Another participant (ph1_p7) was lost to follow-up for the midpoint visit but contact was re-established for the exit interview. All other participants (n=35) successfully completed all the procedures in the 2-month study.

Table 2. Reasons for exclusion.

Reasons for exclusion from the study	Number of people (n=14), n (%)
Does not live alone[a]	2 (14)
Younger than 65 years	4 (29)
No internet connection at home	5 (36)
Lost to follow-up contact or no reasons recorded	3 (21)

[a]Phase 1 required people to live alone to be eligible. This criterion was relaxed in phase 2 recruitment.

Device Selection by the Participants

Table 3 shows the choice of IoT device selection by the participants. Among the phase 1 group, the most widely chosen device was the multipurpose sensor (14/15, 93%), closely followed by the door and window sensor (12/15, 80%) in phase 1. Among the phase 2 group participants, a smart speaker (19/22, 86%) was the most widely chosen device, followed by the multipurpose sensor (18/22, 81%) and the door and window sensor (15/22, 68%). An IP camera was a significantly unpopular choice among participants in both phases (phase 1: 2/15, 13%; phase 2: 3/22, 13%). Most participants commented that the potential privacy risks deterred them from choosing the camera. For both phases, the participants had options to choose more than one device. The most frequently selected combinations of devices for phase 1 were door and window+multipurpose sensor (9/15, 60%). For phase 2, with the addition of a smart speaker in the available devices to choose from, the majority of the participants chose the combination of door and window+multipurpose sensor+smart speaker (11/22, 50%).

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Table 3. Internet-of-Things device selection by the participants.

Devices	Phase 1 (n=15), n (%)	Phase 2 (n=22), n (%)
Door and window sensor	12 (80)	15 (68)
Multipurpose sensor	14 (93)	18 (81)
IP[a] camera	2 (13)	3 (14)
Smart speaker	N/A[b]	19 (86)
Combinations of devices selected		
Door and window sensor only	1 (7)	1 (5)
Multipurpose sensor only	3 (20)	0 (0)
Smart speaker only	N/A	1 (5)
Door and window+multipurpose sensor	9 (60)	2 (9)
Door and window+multipurpose sensor+IP camera	2 (13)	0 (0)
Door and window+multipurpose sensor+smart speaker	N/A	11 (50)
multipurpose sensor+smart speaker	N/A	4 (18)
IP camera+smart speaker	N/A	2 (9)
Door and window+multipurpose sensor+IP camera+smart speaker	N/A	1 (5)

[a]IP: internet protocol.

[b]N/A: not applicable. Smart speaker was not offered during phase 1.

Device Deployment and Maintenance

Over the course of the study, the primary investigator reviewed the status of the deployed sensor system remotely. The status of the sensor devices (door and window sensor and multipurpose sensor) was managed through the cloud remote management system of the Lab of Things platform. If the deployed system was offline, the primary investigator contacted the participants to schedule a maintenance visit. We recorded 22 maintenance visits outside the scheduled study visits throughout the study. In total, 11 maintenance visits were made to reboot the netbook used in the study. The netbook was used to receive and upload the sensor data for the deployment of a door and window sensor and multipurpose sensor and had to be left on all the time, 24/7, throughout the study. On some occasions, the netbook system froze due to memory overflow, and a manual reboot of the system was necessary. This issue was less of a problem for phase 2, where newer netbooks with bigger internal memory were used for the study. A total of 8 maintenance visits were made to re-establish the internet connection. One facility went through switching the internet service provider during the study; therefore, all the participants enrolled at that time from that specific building required an additional visit for setting up the devices.

Feasibility of Data Collection

Overall, the study participants were able to easily complete the demographics and eHEALS questionnaires on their own during the baseline visit. Some participants mentioned that they were confused as several eHEALS items seemed repetitive. All health-related questionnaires (Instrumental Activities of Daily Living, Life-Space Assessment, and 12-item Short-Form Health Survey) were administered by the research team during the baseline and exit visits. There were no missing items in the questionnaire data collected. In one instance, a participant (ph2_p19) noted discomfort with the mental health–related questions in SF-12 but still provided responses. One participant (ph1_p7) declined to complete the exit questionnaires due to time constraints. Multimedia Appendix 2 shows the self-reported health-related parameters measured at the baseline and exit and the pre-post trends of these parameters. As expected, there were no statistically significant changes in any health-related variables between the 2-month study period.

Participant Characteristics

Table 4 shows the demographic information of all study participants. There were no statistically significant differences in demographic parameters between the phase 1 and phase 2 participants. Overall, the participants in the study had a mean age of 78 (SD 9) years, were likely to be female (29/37, 78%) and have a Bachelor's degree or higher (31/37, 86%). Four couples living together (n=8 married individuals) enrolled in the study together in phase 2 and the rest of the participants (n=29) in the study lived alone. The mean eHEALS score for participants was 32 out of a maximum of 40 (SD 6), indicating that the participants were generally comfortable using information technology for health situations. The majority of participants in the study had one or more self-reported chronic condition (33/37, 89%) and took more than 3 current medications (20/37, 54%). About half of the participants used some form of assistive devices (20/37,54%) such as a cane, a walker, or a wheelchair.

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Table 4. Participant characteristics.

Characteristics	Phase 1 (n=15)	Phase 2 (n=22)	Combined (N=37)
Age (years), mean (SD)	77 (11)	78 (8)	78 (9)
Female, n (%)	12 (80)	17 (78)	29 (78)
Marital status, n (%)			
Single	6 (40)	2 (9)	8 (22)
Married or partnered	0 (0)	8 (36)	8 (22)
Divorced	2 (13)	3 (14)	5 (14)
Widowed	7 (47)	8 (36)	15 (41)
Other	0 (0)	0 (0)	0 (0)
Chose not to answer	0 (0)	1 (5)	1 (3)
Education, n (%)			
Less than high school	0 (0)	0 (0)	0 (0)
High school diploma or general education development	1 (7)	2 (10)	3 (9)
Some college	1 (7)	1 (5)	2 (6)
Bachelor's degree	8 (53)	8 (38)	16 (44)
Graduate or professional degree	8 (33)	10 (48)	15 (42)
eHEALS[a] score, mean (SD; range)	35 (5; 26-40)	30 (7; 16-40)	32 (6; 16-40)
Insurance, n (%)			
Medicare	15 (100)	22 (100)	37 (100)
Medicaid	0 (0)	0 (0)	0 (0)
Private insurance	6 (40)	9 (41)	15 (42)
Other	2 (13)	9 (41)	5 (14)
Number of chronic conditions (self-report), n (%)			
0	3 (20)	1 (5)	4 (11)
1-3	7 (47)	18 (82)	25 (68)
4+	5 (33)	3 (14)	8 (22)
Number of current medications (self-report), n (%)			
None	4 (27)	2 (9)	6 (16)
1-2	2 (13)	9 (41)	11 (30)
3-4	5 (33)	4 (18)	9 (24)
5+	4 (27)	7 (32)	11 (30)
Use of assistive devices, n (%)			
Yes	10 (67)	10 (46)	20 (54)
No	5 (33)	12 (55)	17 (46)

[a]eHEALS: electronic health literacy (8-40); higher scores represent higher self-perceived eHealth literacy.

Summary of Interview Findings

In general, older adults showed a positive attitude toward IoT smart home technologies to support their health management. Many older adults commented that having such smart devices installed at their homes could help them better prepare for emergency situations. In addition, older adults showed an interest in having access to their activity level and environmental data collected by the sensors and discussed the benefits of using such data to monitor their health status and make informed decisions on their health management. Older adults who evaluated a smart speaker appreciated the convenience of a voice interface, as many used a smart speaker for setting up reminders and accessing the internet to retrieve information through the device. Along with the benefits, many noted their concern about privacy in using smart home technologies. The detailed findings of the qualitative assessment of the full interview data are beyond the scope of this paper and are presented in a separate paper (Choi et al 2020, unpublished document accepted at the *Journal of Gerontological Nursing*).

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Discussion

Principal Findings

This pilot study evaluated the feasibility of using IoT smart home devices in real-world residential settings of older adults. The specific goal of this study is to assess some key aspects of trial design to inform future intervention studies using IoT smart home devices in older adults' residences. Overall, our deployment results revealed that the use of IoT smart home devices is feasible in actual residences of older adults. Almost all participants (35/37, 95%) successfully completed the study protocol, and no major issues were identified during the study. In addition, the results show that older adults have varying degrees of acceptability to the different types of IoT smart home devices in real-world contexts. Most participants showed a preference for passive monitoring sensor devices and a smart speaker over IP cameras. Most participants considered an IP camera to be more intrusive and did not want it to be placed in their home environment. Our findings suggest that perceived privacy concerns, perceived usefulness, and curiosity to technology were strong factors when considering which device to have installed in their home. This aligns with some previous research that examined the acceptability of in-home sensor devices [14,18]. Future trials should consider older adults' preferences for the different types and services offered by smart home devices to be installed in real-world residential settings [32].

Recruitment and Retention

In this study, we collaborated with local retirement facilities in the Puget Sound area and recruited 37 people from 6 different retirement facilities. Our recruitment results show that the recruitment information session held at the retirement facilities was an effective strategy among the different recruitment activities in our study. One key benefit of the group information sessions was the reduced burden on the research team in the facilitation of the informed consent process. Future research should explore research partnerships with local retirement facilities and community agencies. The partnership could be mutually beneficial as research teams could gain easier access to potential older adult research participants, and the facilities could have increased access to innovative technology solutions and explore their potential applications in supporting their residents.

One barrier to participation was that some individuals who were interested in participating lacked internet access at home. Owing to limited funds and other practical constraints, we were not able to provide an internet connection and thus excluded those who did not have available access. This exclusion criterion could have turned away a group of participants who were not familiar with internet technology. No major challenges were noticed in our study procedures, and all but one participant failed to complete the study. The high retention could be explained by the low participant burden imposed by the study. In addition, engaging participants to choose the devices to evaluate at the start of the study may have eliminated any discomfort of having unwanted devices in their residence, in turn motivating them to remain in the study.

Deployment Management

We identified some challenges to the maintenance of the deployed devices. We recorded a total of 22 additional visits to the participants' homes outside the regular study visits. A total of 11 additional visits were necessary due to unforeseen technical issues, as we noticed that the memory overflow of the sensor data processing netbook required a manual reboot of the system. This issue was resolved through replacement of the netbook with ones with larger memory for the study. The issue of reliability and stability of the system deserves to be highlighted. The home gateway system that manages and controls interconnected IoT devices and the processing of the data received from the devices is an important central component of smart home infrastructure [33]. The reliability and stability of such home gateway systems for long-term operation is essential for designing future intervention studies that use IoT smart home technologies.

Limitations

The primary study limitation is the generalizability of our findings due to a relatively small sample size with limited diversity in demographics recruited in a single metro area. Although the study team attempted to recruit from residential facilities across a breadth of socioeconomic status, the study sample was not able to cover a wide spectrum of older adults. The recruited sample did not include Medicaid beneficiaries and were highly educated compared with the general older adult populations. Therefore, the findings of the study must be interpreted with caution as the opinions on IoT smart home devices may vary in other regions or among broader demographics. In addition, the 2-month pilot deployment period may not be enough to understand the changes in perception and adoption behaviors over the long term. Furthermore, we only offer 4 different IoT monitoring devices for older adults to choose for this pilot study. The participants' opinions might have varied had there been additional kinds of devices available for them. Despite these challenges, the data presented in this study can inform future studies exploring the use of smart home devices with older adults in their residential setting.

Conclusions

Our study is particularly unique from previous studies, in that it assessed older adults' preferences for different IoT sensor devices through real-world testing of IoT devices with older adults to address the literature gap. In addition, we combined environmental sensor data with motion sensor data to understand potential use cases of such integrated data in monitoring older adults' activities. Furthermore, to our knowledge, our study is among the first attempts to explore the use of smart speakers in a health context with an older adult population. We believe the findings from this feasibility testing of an IoT smart home sensor system may identify barriers and limitations of the technology features critical to rapid adoption among older adults. This work will inform the follow-up assessment of IoT technologies and their impact on health-related outcomes and advance our understanding of the role of IoT home-based monitoring technologies to promote successful aging-in-place for older adults.

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Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Overview of instruments and data collection schedule.
[DOCX File , 18 KB - aging_v3i2e21964_app1.docx]

Multimedia Appendix 2
Health-related variables collected at baseline and exit.
[DOCX File , 14 KB - aging_v3i2e21964_app2.docx]

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Abbreviations

eHEALS: eHealth Literacy Scale
IoT: Internet of Things
IP: internet protocol

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Original Paper

An Individual Cognitive Stimulation Therapy App for People With Dementia: Development and Usability Study of Thinkability

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Abstract

Background: There is a lack of technological resources for the mental stimulation and communication of people with dementia, which can be helpful in improving cognition and quality of life. Paper-based individual cognitive stimulation therapy (iCST) for people with dementia has the potential to be adapted to a touchscreen format. This can improve accessibility and provide mental stimulation using interactive features. There is a need for a rigorous and systematic approach toward development, leading to improved suitability and implementation of the intervention, so that more people can benefit from its use.

Objective: This study aims to develop and investigate the usability of Thinkability, an iCST app that can be used by people with dementia and carers on touchscreen tablets.

Methods: The Medical Research Council framework for evaluating complex interventions and the Centre for eHealth Research roadmap served as frameworks for the stages of intervention and technology development. The development of the iCST app itself adopted an agile approach with elements from action research. Hence, it was developed in 3 successive *sprints* and was evaluated by relevant stakeholders at each sprint. Sprint 1 included 2 patient and public involvement (PPI) consultation meetings, sprint 2 included 1 PPI consultation meeting, and 4 focus groups and 10 individual interviews were organized in sprint 3. A feasibility trial is currently underway.

Results: The findings from each sprint were used to inform the development. Sprint 1 helped to identify the relevant evidence base and explored the attitudes of people with dementia and carers toward a potential iCST app. In sprint 2, an initial prototype was evaluated in a small PPI consultation meeting. In sprint 3, feedback was gathered through a qualitative study on the quality and perceived effectiveness of the iCST app. It was well received by people with dementia and carers. A need for more updated and personalized content was highlighted.

Conclusions: This study proves that an agile approach toward technology development involving all relevant stakeholders is effective in creating suitable technology. Adding to our previous knowledge of noncomputerized cognitive stimulation therapy, the release of the iCST app will make this psychosocial intervention accessible to more users worldwide.

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KEYWORDS

dementia; cognitive stimulation therapy; eHealth; development

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Introduction

Background

The anticipated rise in the prevalence of dementia requires the development of more complex interventions to better manage the challenges of the condition [1]. To successfully implement effective interventions that are fit for purpose, there is a need for a rigorous approach toward development with the help of appropriate frameworks. The Medical Research Council (MRC) framework offers such an approach for evaluating complex interventions and describes the entire process from development to implementation [2]. Cognitive stimulation therapy (CST) is an evidence-based psychological intervention for people with dementia, which consists of mentally stimulating activities usually performed in a group setting. Previous research has shown that it can lead to improvements in cognition and quality of life (QoL) [3]. Individual cognitive stimulation therapy (iCST) is an extension of CST and is usually delivered at home by a carer. Its development using the MRC framework enabled it to be relevant and suitable for people with dementia and their carers, and iCST showed improvements in the quality of the relationship within the dyad [4,5].

The need for more complex interventions has also led to the development of a wide range of technologies, which consist of assistive devices (eg, tracking or reminder tools), touchscreen apps (eg, games, health, and fitness apps), and more [6], to better support people with dementia. However, there is a lack in the availability of apps for mental stimulation and communication targeted toward people with dementia [7,8]. Therefore, considering the evidence base behind CST and iCST, a computerized version of iCST is needed to offer iCST on a more novel and interactive platform and to increase its accessibility. For the development of novel technology, in particular, van Gemert-Pijnen et al [9] developed the Centre for eHealth Research (CeHRes) roadmap, which includes distinct development phases from contextual inquiry to operationalization. Together with the MRC framework, this enables a highly systematic approach toward the development of a computerized version of iCST to ensure that the intervention is both usable and useful for people with dementia.

Aims and Objectives

The aim of this study is to develop an iCST app that can be used by people with dementia and carers on touchscreen tablets.

Objective 1

The primary objective of this study is to develop a first prototype based on an understanding of the theoretical mechanisms behind CST, iCST, and use of technology; the attitudes of people with dementia toward paper-based iCST and the iCST app; and a selection of iCST activities suitable for a touchscreen app.

Objective 2

The secondary objective of this study is to evaluate the first prototype in terms of clarity, suitability, and ease of use and to expand on the selection of activities for the second prototype.

Objective 3

The third objective of this study is to bench test the second prototype with people with dementia and carers to refine and modify the prototype and improve its usability and to develop a full list of 21 activities for the third prototype based on the findings.

Methods

Approach to Development

In the development of the iCST app, a research team at the University of Nottingham worked collaboratively with a software development company (Eumedianet) in Maastricht, the Netherlands. The teams adopted an agile approach during which development takes place in an iterative and dynamic manner while collaborating with all relevant stakeholders [10]. This approach is especially helpful because it encourages meaningful involvement of end users throughout development.

There are different types of agile development approaches (eg, Scrum, Extreme Programming, and Crystal methodologies), but they share common key principles and characteristics [10]. These include individuals and interactions over processes and tools, working software over comprehensive documentation, customer collaboration over contract negotiation, and responding to change over following a plan [11]. Scrum was chosen as the agile development method for the iCST app. This method is best suited because it focuses on efficient project management, iterative development, and feedback loops [11]. This allowed the research and software development teams, in collaboration with end users, to monitor the development of the iCST app on a regular basis and ensure that it met the necessary requirements. In Scrum, each iterative stage of development is labeled as a sprint. This led to the development of 3 prototypes over 3 sprints within the development phase of the MRC framework and the contextual inquiry, value specification, and design phases of the CeHRes roadmap (Figure 1).

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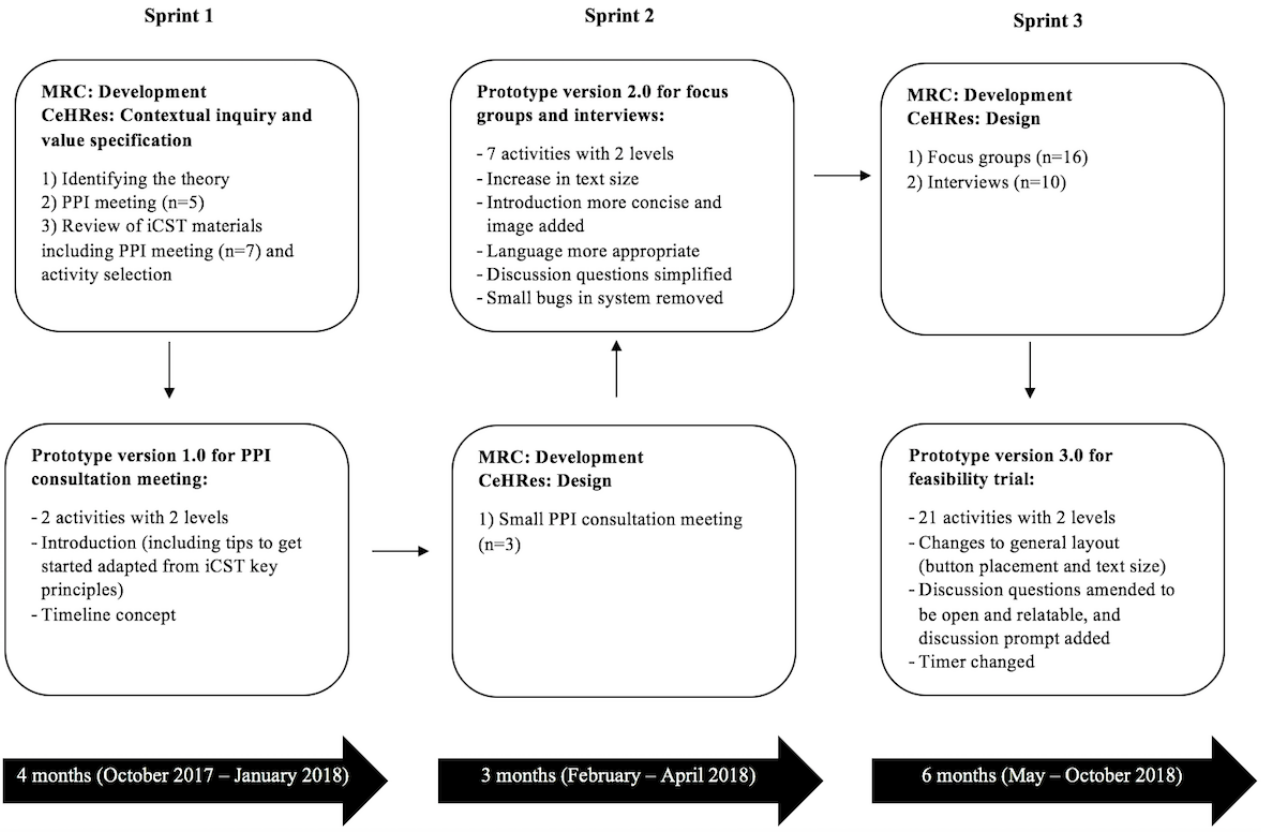
Figure 1. Agile development of the individual cognitive stimulation therapy app according to the Medical Research Council framework and Centre for eHealth Research roadmap. CeHRes: Centre for eHealth Research; iCST: individual cognitive stimulation therapy; MRC: Medical Research Council; PPI: patient and public involvement.



The development of the iCST app also adopted elements from an action research–oriented approach. Action research seeks to use action or intervention in a cyclical research process, including the development, implementation, and evaluation of plans for practice improvement [12]. Agile development focuses on building software, whereas action research allows for a better understanding of the problem to be solved together with active participation from relevant stakeholders, including the population group. For this study, these action research elements were incorporated in the sprints to explore barriers and facilitators toward the usability and feasibility of the iCST app and identify possible solutions.

Sprint 1: Development of Prototype Version 1.0

The first sprint consisted of 3 research activities to develop the first prototype of the iCST app: identification of the evidence base and theory behind CST and technology, a patient and public involvement (PPI) consultation meeting, and the review of existing iCST materials (including a PPI consultation meeting and activity selection). These activities reflect the recommendations of both the MRC framework and the CeHRes roadmap.

Within the development phase, the MRC framework recommends exploring the evidence base and identifying the theoretical mechanisms to better understand how an intervention can bring about change before any development work takes place [2]. Therefore, the research team reviewed the current literature on the effectiveness of CST, iCST, and the use of technology for people with dementia to better understand the mechanisms behind each component of the iCST app [13-15].

First PPI Consultation Meeting

To better understand the context, following the CeHRes roadmap, a PPI consultation meeting was organized with people with dementia and carers (n=5). We wanted to explore their attitudes toward a potential iCST app and to identify facilitators and barriers toward using (touchscreen) technology in general. A brief presentation was given about CST and the aims of the research project, followed by a short discussion. Topics included willingness to use an iCST app, potential benefits and limitations, and practicalities such as time investment. Notes from the meeting were communicated with the software development company.

Review of Paper-Based iCST Materials

The CeHRes roadmap indicates that contextual inquiry is followed by value specification, which helps to determine the most favorable solutions and features based on the values of the intended users and other stakeholders [9]. The iCST manual consists of 75 activities spread over 21 themes, leading to approximately 3 or 4 activities per theme. To better understand which features and activities should be included in the iCST app, a second PPI consultation meeting with people with dementia and carers (n=7) was organized at the Institute of Mental Health (IMH). A researcher (HR) presented a short video clip from the iCST DVD of different caregiving dyads using paper-based iCST materials. Participants were given iCST manuals and, in pairs, were asked to review the materials and

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discuss the qualities they liked or disliked. Participants were also asked to discuss how the iCST manual could best be adapted into a touchscreen version. A group discussion followed, and key topics included the design, content, and feasibility of a potential iCST app. The notes and contributions from the PPI meeting were fed back to the software development company.

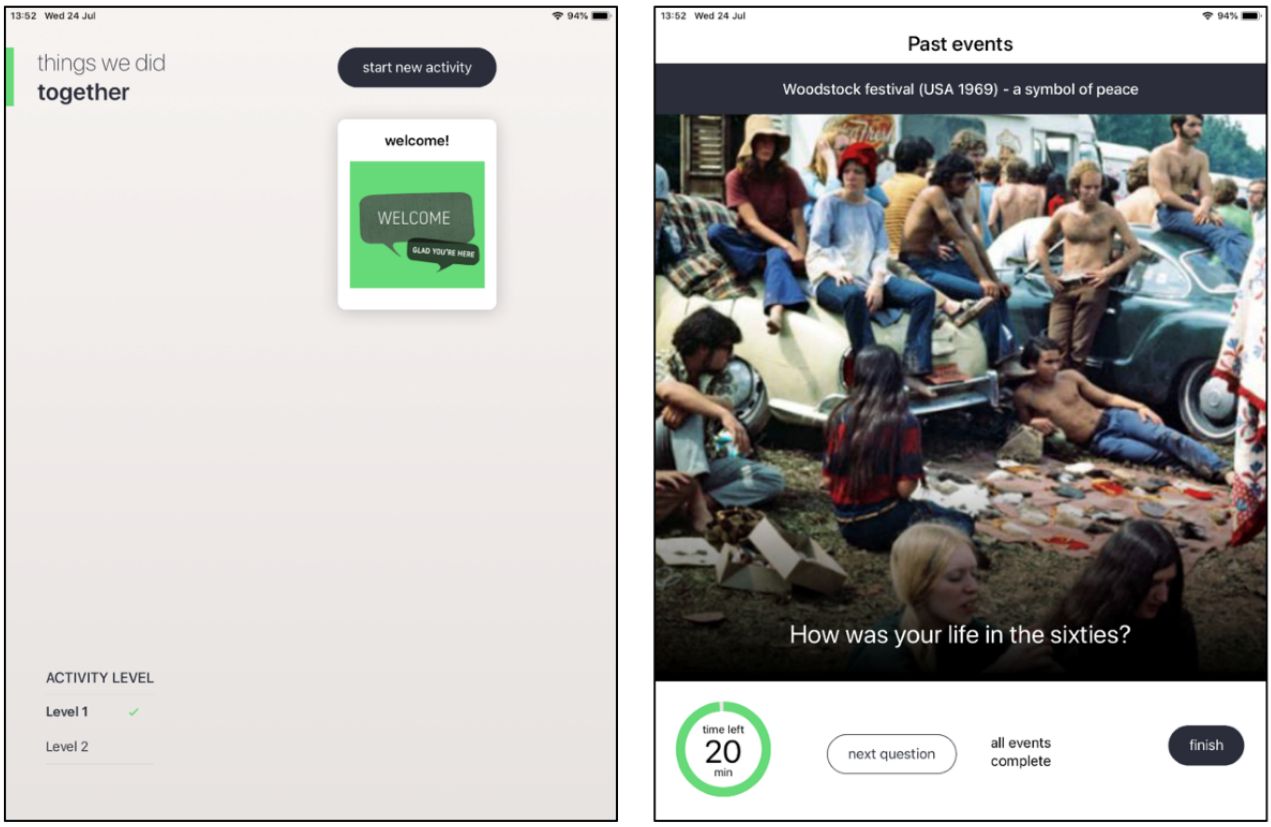
Value specification should involve all stakeholders; therefore, both the research and software development teams also evaluated the iCST materials. Each activity was evaluated for its potential to be adapted to a touchscreen platform. Considerations included the added level of interactivity and novelty, promoting mental stimulation or the sharing of ideas and opinions, and overall enjoyment. On the basis of these considerations, all activities were first categorized per the iCST theme and the type of activity (eg, a quiz, picture game, and audio) and then ranked according to priority for development separately by the research and software development teams. After reaching a consensus in terms of priority, a small selection of activities was made, and these were developed for the iCST app prototype version 1.0.

Prototype Version 1.0

Following the principles of an agile approach toward development, there was a need to develop a working prototype rather than paper wireframes. This allows end users to operate a device that resembles the final product and hence to obtain more accurate feedback. In terms of design, Castilla et al [16] recommend a linear navigation over a hypertextual structure. In a linear structure, the user makes his or her way through the intervention in the order that is intended by the developer. He or she does not make decisions that reorganize the content. In a hypertextual structure, the content is rearranged based on the user's choices, leading to nonlinear pathways [16]. The researchers assert that a linear navigation resembles an analog format of books and magazines, for instance, which are more familiar to older adults. Familiarity then further supports the learning process with the technological intervention.

The first prototype consisted of several key features: a home screen, welcome or introduction, 2 activities with 2 levels of difficulty (Sounds and Past Events), and a timeline. When opening the app, users were first presented with the home screen (Figure 2). It included a welcome icon, which took the user to an introduction section. This section explained the purpose of the app and provided a few tips and aims derived from the CST and iCST principles. Furthermore, users could select a new activity on the home screen. Prototype version 1.0 included a Sounds and Past Events activity (Figure 2). A short summary preceded the actual activity to provide some instructions. Within the activity itself, there was a timer, which counted down from 20 min to keep track of the amount of time spent, and some buttons to move through the activity or finish it. Finally, each completed activity was added to the timeline on the home screen. This enabled users to keep track of their journey through the app.

Figure 2. Screenshots of prototype version 1.0: home screen (left) and Past Events (right).



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Sprint 2: Evaluation of Prototype Version 1.0

Third PPI Consultation Meeting

Design is the third stage of the CeHRes roadmap and is used to build prototypes that fit the user requirements. End users are invited to give feedback and test prototypes to assess whether they match their expectations in terms of system, content, and service qualities [9]. The iCST app prototype version 1.0 was taken forward in a small PPI consultation meeting with 2 people with dementia and 1 carer at the IMH. The software development team supplied the research team with a list of questions relating to clarity and overall ease of use. The main topics included the design, navigation, and content of the prototype. After an introduction and general explanation about the prototype, each participant was given a touchscreen tablet to use the prototype for 15 to 20 min. A researcher (HR) provided support and guidance in case of any difficulties and answered questions throughout the trialing period. This was followed by a group discussion of approximately 1 hour. Another researcher (JS) made observations and took detailed notes during the meeting, which were communicated with the software development team through video conferencing. Feedback from the consultation meeting was used to further expand the prototype and build version 2.0 for bench testing.

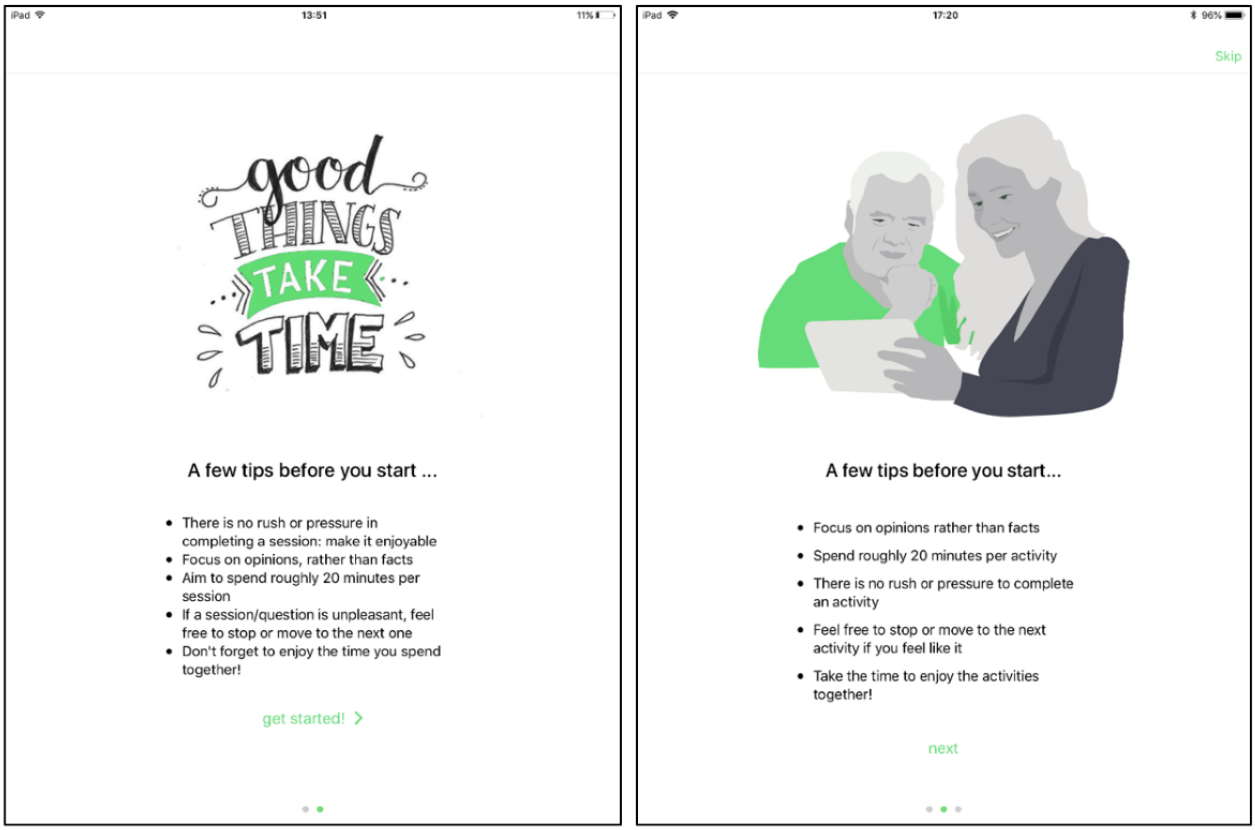
Prototype Version 2.0

Following the feedback from the PPI consultation meeting, the second prototype was expanded with an additional 5 activities, making it a total of 7 (Textbox 1). These 5 activities (Garland, Hangman, Odd One Out, The Price is Right, and Useful Tips) were chosen based on the initial selection of activities during sprint 1. The aim was to have a diverse selection and therefore included several types of activities, such as a number game, categorization activity, and a video. The introduction section was simplified, and an image displaying 2 people interacting with a tablet was added (Figure 3). Finally, some bugs in the system were removed, such as incomplete captions within activities.

Textbox 1. Overview of activities for each prototype version.

- Prototype version 1.0: Sounds and Past Events
- Prototype version 2.0: Sounds, Past Events, Garland, Hangman, Odd One Out, The Price is Right, and Useful Tips
- Prototype version 3.0: Sounds, Past Events, Being Creative, Spaceman, Odd One Out, The Price is Right, Useful Tips, iSpy, Trivia Quiz, Word Search, Sudoku, Globe Trotter, Sayings, My Life, Being Active, Food, Brainstorm, Arts, Old Wives' Tales, Toys Are Us, and In Pairs

Figure 3. Screenshots of the introduction section of prototype version 1.0 (left) and prototype version 2.0 (right).



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Sprint 3: Evaluation of Prototype Version 2.0

Design

The evaluation of the second prototype also comprised the design phase of the CeHRes roadmap. However, focus groups and semistructured interviews were included in this sprint, according to the recommendations of the MRC framework, which enabled the gathering of more in-depth and rich qualitative data. The second prototype was presented to people with dementia and family carers for them to bench test it and modify, refine, and improve its usability. Ethical approval for the involvement of vulnerable adults with dementia and their carers was obtained through the National Health Service (NHS) Health Research Authority—Yorkshire & The Humber—Bradford Leeds Research Ethics Committee (Reference number 17/YH/0405).

Sample

A total of 13 people with dementia and 13 family carers participated in the focus groups and interviews (N=26). Eligibility criteria were adapted from previous iCST research [4]. Recruitment took place in primary and secondary care settings, including memory clinics, voluntary sector organizations, and support groups through the Nottinghamshire Healthcare NHS Foundation Trust.

Methods

In total, 4 focus groups were organized: one with people with dementia (n=4), one with family carers (n=4), and 2 mixed groups with both (n=8). In addition, 10 individual interviews were conducted with people with dementia (n=5) and family carers (n=5) in the homes of the participants. All interview participants completed an additional usability questionnaire [16]. The aim of combining these methods was to gather more diverse data. Furthermore, where focus groups allow the sharing of thoughts with others and coming to different ideas, individual interviews are more useful to allow participants to voice their opinions without the potential group influences. Discussion guides were developed by the research team and included a range of topics, such as the layout and content of the prototype, using it as a dyad, and any practicalities and general points related to the prototype (Multimedia Appendix 1). Participants were asked to trial the app in pairs for 10 to 15 min before the discussion, while 2 researchers gathered observational data as per the recommendations of the software development team. Guidance from the researchers was kept at a minimum to investigate whether the app was intuitive. However, the researchers provided support when participants had any questions. The feedback and contributions from this qualitative study supported the development of the iCST prototype version 3.0.

Analysis

The data from the focus groups and interviews were audio recorded and transcribed by the research team. The data were coded by 2 researchers using inductive thematic analysis to identify the key themes within the data [17]. The findings were further supported by observational data.

Prototype Version 3.0

On the basis of these findings, the third prototype was expanded with a full range of 21 activities to be taken forward in a feasibility trial (Textbox 1). As participants were happy with the diversity of the activities in prototype version 2.0, the teams decided to continue building the remainder of the activities that were selected in sprint 1. Some suggestions for new activities given by the participants were incorporated into the prototype version 3.0, such as a word search and a quiz. The majority of the improvements were related to the design of the app and activities (Figure 4). For instance, some participants felt rushed while doing an activity because of the timer counting down the amount of minutes. Therefore, the timer was changed to count up to 20 min, with participants being able to spend more time on it if they wanted to (Figure 4). Furthermore, the level of the activity was added to the top-right corner. The activity Hangman was changed to Spaceman, as the initial icon image included a noose, which was too negative. The language was deemed appropriate and free of jargon; however, more changes to the discussion questions were necessary. Hence, the questions were written to be more open and relatable. In addition, some participants suggested adding a little prompt above the question saying *discuss* to clarify the purpose of the questions. Finally, some more context was provided to the Garland activity to clarify that it is an activity that can be done without the tablet.

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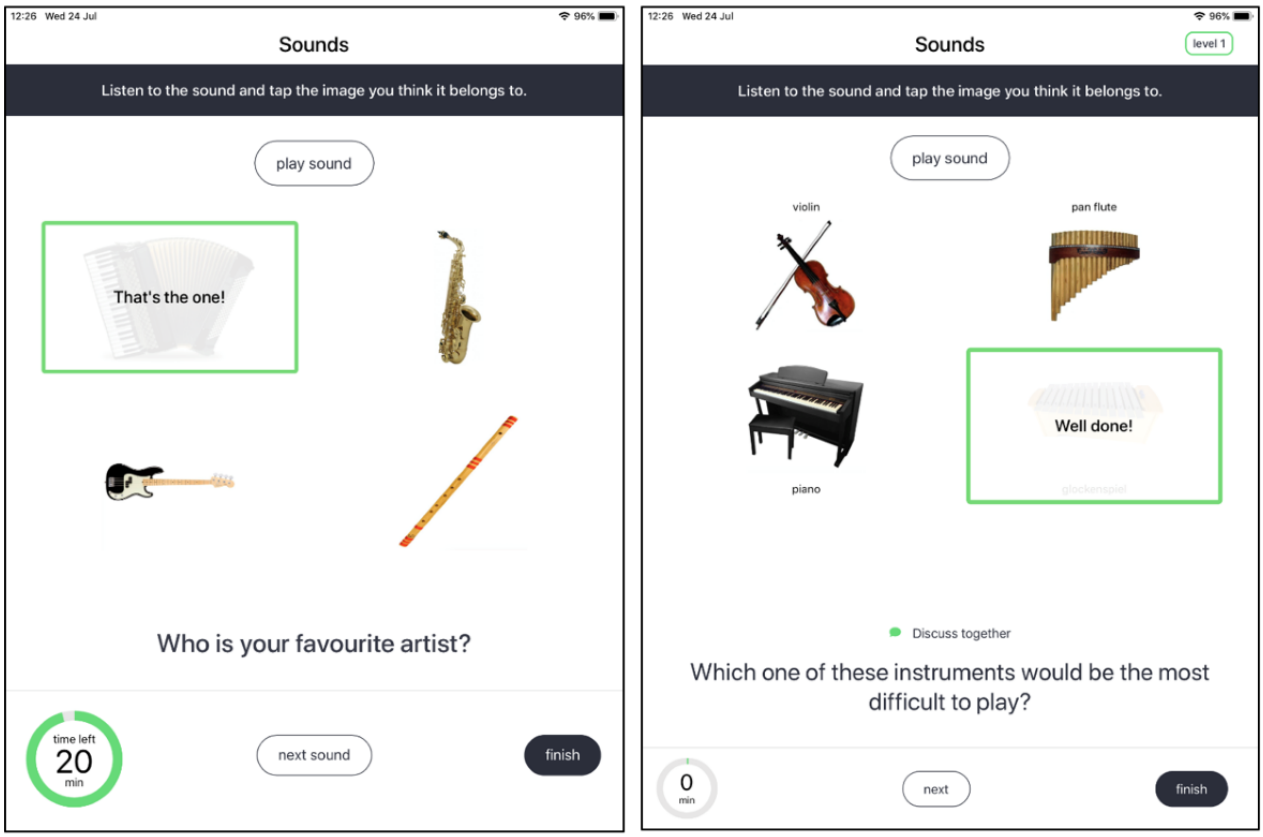
Figure 4. Screenshots of the Sounds activity in prototype version 2.0 (left) and prototype version 3.0 (right).



Results

Sprint 1: Development of Prototype Version 1.0

Identifying the Evidence Base and Theory Behind CST and Technology

A recent book published by CST research members served as the main resource for key evidence relating to CST and iCST. Both group CST and iCST were developed following the MRC framework, which helped to create a strong foundation for both interventions [18]. For group CST, a large-scale randomized controlled trial (RCT) demonstrated positive effects on the cognitive functioning and QoL of people with dementia, which were further supported by qualitative findings [3,19]. CST is multifaceted, and its key principles reinforcing mental stimulation, use of reminiscence, and enjoyment, contribute to its effectiveness. Evidence suggests that stimulating activities targeting certain neuropsychological domains, similar to those in CST, can improve cognition [20]. Furthermore, CST provides a social context for its participants, and previous research suggests that social interaction between 2 or more individuals can improve cognition [21]. The effects of CST on QoL may be explained through the mediating role of improvements in cognitive functioning [13].

The large-scale RCT with iCST did not have positive effects on cognition and QoL for people with dementia, which could perhaps be because of a low completion rate of the planned activities. Instead, researchers found improvements in the quality of the caregiving relationship between the person with dementia and the carer [4]. Although iCST is as multifaceted as group CST, the trial results may be the result of a lack of adherence to the intervention. Alternatively, the lack of a social setting in iCST may have contributed to the results. Researchers emphasize the need for more research, particularly with experimenting with computerized platforms for providing iCST. Novel cognitive stimulating activities that promote the learning of a new skill can benefit the cognitive functioning of older people [14]. For example, Chan et al [22] found that training healthy older adults to use iPads (Apple Inc) could lead to benefits in episodic memory and processing speeds. Increased processing speeds are especially beneficial, as they are associated with improved execution of various technological tasks [23].

Computerized cognitive interventions for people with dementia are becoming increasingly widespread. Garcia-Casal et al [15] concluded that computerized cognitive interventions led to significant improvements in cognition, depression, and anxiety among people with dementia. Therefore, computerized cognitive interventions may have even more of an impact on cognition than noncomputerized cognitive interventions such as group CST [15]. However, these interventions can vary greatly; therefore, there is a need for more research, with computerized cognitive stimulation in particular, to better understand the effects. The platform on which an intervention is offered is also important, for instance, a touchscreen device or a computer. There is considerable evidence suggesting that touchscreen tablets are highly intuitive for older people with dementia [24,25]. Moreover, Tyack and Camic [26] found that touchscreen interventions, which are simple, intuitive,

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aesthetically pleasant, and error free, can lead to several benefits for people with dementia, including mood, mental health, and social relationships. The intervention should include slightly challenging content so that the user is invited to apply more complex cognitive skills rather than simpler ones [26].

Despite the current evidence and available technological resources, there is still a need for more technologies that provide people with dementia with independent activities for mental stimulation, enjoyment, and a meaningful way to spend time [7,8]. An iCST app with appropriate content and design is well placed to contribute to the current lack of technologies for mental stimulation and enjoyment.

First PPI Consultation Meeting

Participants were particularly enthusiastic about CST and said they would welcome it in any format, whether this was computerized or paper based. They said that researchers would have to keep a few things in mind when developing a computerized version of CST, namely, that there would be a need for personalization according to the person's background and a diverse selection of activities. Some participants mentioned the need for a facilitator to provide support for the activities. This could be an informal or a paid carer. Being able to keep track of which activities were done and when was also considered to be a useful feature.

Attitudes toward technology were diverse, with some more willing to use technology than others. A person with dementia mentioned that she would not want to be pushed to use technology, which might happen through the involvement of a carer. However, there was consensus among the group that people with dementia need to be empowered and to be made aware of how to handle technology. An example was given on how some people with dementia with a lack of experience with technology may think a piece of technology could break easily by pressing the wrong button. People would need an explanation on how to use the actual technology before using any kind of app on it. Finally, for technology to be useful for people with dementia, it should be free of jargon and difficult terminology as much as possible.

Review of Paper-Based iCST Materials (PPI Consultation and Activity Selection)

All participants liked the iCST manual in terms of content and usefulness, and the comments for improvements were mostly related to practicalities and some layout issues for a potential iCST app. For instance, participants agreed that there was too much text on one page and that this would have to be minimized significantly for an app. Keeping with this, although the content was perceived to be useful, participants felt that there were too many activities and that researchers would need to consider which activities could be better for online adaptation onto an app than others.

In terms of feasibility, flexibility was considered to be one of the most important needs for an iCST app. The amount of time needed to complete one activity, and to make their way through the entire app would differ between people with dementia. Therefore, people should be able to use it according to their own pace and decide how much time they would like to spend on the app per day. One person with dementia was keen on using the app for any amount of recommended time as long as it could benefit her. Participants also emphasized some challenges. For example, it might be difficult for some users to maintain concentration for a certain period. In addition, their physical condition might prevent them from using the app (eg, pains).

After the PPI consultation meeting, the research and software development teams reviewed each iCST activity in detail. All 75 activities were ranked according to the type of activity and its potential for adaptation to a touchscreen platform. Following the advice from the PPI group members, the researchers decided to reduce the number of iCST activities from 75 to 21 for the initial iCST app. This encompasses one activity per theme.

Sprint 2: Evaluation of Prototype Version 1.0

The design was evaluated positively with a minor suggestion to increase the size of the text. The use of colors was deemed appropriate as well. One example came from a person with dementia who did not seem to have any problems with the color scheme despite being color blind. The navigation was intuitive, as participants were able to move through different parts of the prototype with little difficulty. However, the purpose of the timeline was not clear and needed additional explanation from the researcher.

In terms of content, the participants were positive about the type of activities and found them relevant and enjoyable. To encourage discussion based on the questions, it was suggested to simplify the questions by directing them to the person with dementia rather than a general question. Participants also looked at the introduction section and suggested adding an image of a person with dementia and a carer using the app together to clarify how it is meant to be used (Figure 3). Some changes were suggested to the language to make it more suitable. Suggestions included shortening the sentences and improving the overall sentence structure. Some words were discussed in more detail, for example, using *finish activity* rather than *stop activity*. Finally, participants were keen on seeing more levels included in the future.

All but few suggestions were included in the next iteration of the prototype. For instance, there was a need to add buttons on the screen to adjust for the sounds and brightness; however, there was a potential that this would have made the interface more crowded and therefore less intuitive. We decided to further investigate this in the next sprint.

Sprint 3: Evaluation of Prototype Version 2.0

In total, 13 people with dementia and 13 carers participated in the qualitative study. The majority of the people with dementia were male (n=8), and the majority of carers were female (n=9). The mean age of people with dementia was 74.23 (SD 6.06) years, and the mean age of the cares was 69.15 (SD 9.32) years. Most people with dementia (n=10) and all carers (n=13) had some experience with using technology. A total of 4 main themes emerged from the analysis: approaches to technology, quality of the iCST app, perceived benefits of the iCST app, and involvement of a relative or friend.

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The majority of the participants were enthusiastic about the app and found it to be useful. Some participants also appreciated the novelty of the intervention:

> *I think it's nice to have something different every so often. Yeah it's something different because it's not something that crept up before shall I say.* [Person with dementia, interview 5]

Observations indicated that the app was intuitive for most participants, which was confirmed through discussions and usability questionnaires. There were some cases where researchers needed to provide some assistance, and although the navigation was generally considered to be appropriate, there was a need for better signposting and clearer button placement:

> *For navigation purposes I found it difficult if I wanted to go back and start another one. [...] I thought that one [button] could be bigger...or more obvious.* [Carer, interview 2]

Participants noted that the images and text could both be slightly bigger, but overall they were rated well in terms of clarity:

> *I understand what each one is showing and that's all that's necessary for it to do. So long as the image is clear I don't see a problem, and generally speaking they are clear.* [Person with dementia, interview 7]

Finally, there was no general consensus on the color scheme, with some participants opting for the inclusion of more colors and others preferring the current scheme with fewer colors to avoid distractions.

Table 1 describes the usability and acceptability of the iCST app according to people with dementia (n=5) and carers (n=5) who participated in the individual interviews. Item 5 includes 1 missing response from a person with dementia. Overall, the iCST app was rated well in multiple areas, namely, its ease of use, usefulness, and suitability of the letter or button size for both people with dementia and carers, suggesting that the overall design was appropriate. Although most participants indicated that they knew what to do at any given time, carers felt more confident while using the app than people with dementia and were also more willing to use it frequently. This suggests that the navigation of the iCST app might not be as intuitive for people with dementia as it is for carers.

Table 1. Results from the usability questionnaire with the individual cognitive stimulation therapy app prototype version 2.0.

Questionnaire item	Person with dementia (n=5), individual responses, n (%)		Carer (n=5), individual responses, n (%)	
	Positive	Do not know or negative	Positive	Do not know or negative
Ease of use	5 (100)	0 (0)	5 (100)	0 (0)
Usefulness	5 (100)	0 (0)	5 (100)	0 (0)
Knew what to do at any time	4 (80)	1 (20)	5 (100)	0 (0)
Felt confident while using the app	3 (60)	2 (40)	5 (100)	0 (0)
Feeling while using the app	3 (60)	1 (20)	5 (100)	0 (0)
Suitability letter or button size	5 (100)	0 (0)	4 (80)	1 (20)
Willingness to use the app often	3 (60)	2 (40)	5 (100)	0 (0)

The majority of the suggestions for improvements and additions to the app were made, and these were taken forward in the next iteration for the feasibility trial, which has been registered on the Clinical Trials website (registration number NCT0328277).

Discussion

Principal Findings

This is the first study to create an interactive, touchscreen iCST app for people with dementia and carers based on the principles of CST and iCST. The systematic approach to development included an agile methodology, principles from action research, and guidance from the MRC framework and CeHRes roadmap [2,9]. To the best of our knowledge, this is also the first study to combine these elements in the development of a technology-based intervention for people with dementia and carers. Within this approach lie the strengths of this study. For instance, the agile methodology helped to create and regularly review prototypes of the app in an iterative manner. This was necessary not only to monitor the overall progress and direction of development but also to find and resolve any faults on a continuous basis. Both the MRC framework and the CeHRes roadmap helped to better define the development process and determine which research activities were necessary at each stage. In lieu of this, there were various diverse research activities ranging from PPI consultations to a qualitative study and questionnaires, leading to the collection of in-depth and rich data. Finally, the involvement of end users at each stage, as per the principles of action research, was beneficial as their consistent and useful feedback helped to refine the iCST app prototypes.

The MRC framework recommends using the best available evidence and appropriate theory in the development of a new intervention [2]. Sprint 1 supported this and pinpointed several mechanisms behind the use of CST and technology, such as mental stimulation of neuropsychological domains, providing a social context, and learning a new skill [14,20,21]. The combination of these elements might be able to demonstrate how an iCST app can benefit cognition compared with paper-based iCST, which did not find such benefits for the person with dementia. An iCST app would also allow for improved monitoring of adherence to the intervention through

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analytical data, which was a challenge in previous iCST research [4]. This would provide further insights into the potential benefits of an iCST-based approach. Furthermore, as part of contextual inquiry, researchers explored the attitudes of people with dementia and carers toward technology. Attitudes were varied, but most participants were willing to use technology as part of their daily lives. The most important conclusion was that people with dementia would need individually tailored support on how to use the technology. This is in accordance with previous research showing that technology can be helpful for people with dementia, but some might require continuous support and education to maximize the benefits [27]. This support could be provided through the involvement of skilled practitioners or informal carers. In 2018, it was estimated that 42% of people aged ≥65 years in the United Kingdom use a touchscreen tablet compared with any other device to access the internet, making it the most popular choice among the age group [28]. However, there is a need to increase education and awareness regarding the use of technology, such as touchscreen tablets to support the empowerment of people with dementia, which was another prerequisite mentioned in the first PPI consultation meeting. However, some people may be unable to access technology and thus the iCST app, and the availability of other CST resources such as group CST and paper-based iCST will help them access a form of CST.

Through value specification, people with dementia and carers were asked to identify their most important needs for an iCST app. The identification of needs is a common process in the development of technology, as it helps to define and prioritize user requirements. In PPI consultation meetings, people with dementia and carers stressed the need to minimize the current paper-based iCST content, flexibility in using the iCST app, and a diverse range of activities to appeal to personal interests. These requirements are supported by Tyack and Camic [26], who found that touchscreen interventions should be tailored where possible in terms of content but should also include a simple and intuitive interface. This can facilitate the uptake of the intervention. Minimizing the iCST content would make the interface less crowded and easier to use. Value specification was continued by both the research and the software development teams to assess which paper-based iCST activities should be taken forward in the iCST app. On the basis of priority ranking of each team, a small first prototype was developed.

In sprint 2, the development moved toward the design aspect of the CeHRes roadmap during which the first version of the digital health intervention is communicated with end users to collect feedback. It is recommended to initially present a prototype that does not fully resemble the final product but does include the essential features and then build on successive prototypes [9]. Therefore, the iCST app prototype version 1.0 only included 2 activities in addition to the main features (eg, the timeline). Participants in a PPI consultation meeting rated the format of the iCST app prototype version 1.0 positively, particularly the design was deemed appropriate. However, there was a need to simplify the content. For instance, the introduction contained some jargon, and the discussion questions needed to be clearer. This feedback informed the expansion of the next prototype, which better resembled the final product.

Sprint 3 was an extension of the design stage of the CeHRes roadmap and included more formal usability testing through focus groups, interviews, and questionnaires. These activities are also recommended by the MRC framework to assess the acceptability of the intervention [2]. The iCST app prototype version 2.0 was evaluated positively, and participants gave some suggestions for improving the design, including an increase in the size of the text and images.

Limitations

Working agile requires a quick turnaround for prototypes in terms of development and evaluation. The latter proved more challenging, as research activities with end users require a sufficient amount of time for recruitment and organization. For instance, the lack of time caused the evaluation of prototype version 1.0 in sprint 2 to be less in depth. An additional challenge in recruitment was that the PPI consultation meeting contained a small sample size, potentially leading to insufficient data and feedback. To better cope with these challenges and add more value to development, it is recommended to involve 1 or 2 people with dementia as co-researchers throughout the development process to receive consistent feedback.

Future Research

Future studies involving new technology-based interventions for people with dementia will need to establish a strong collaboration with researchers, software developers, and end users from the beginning stages of development. Furthermore, new interventions and their development will need to be supported by appropriate frameworks and methodologies. These recommendations will help to create an intervention, which is fit for purpose and has better potential to be successfully implemented in practice.

This study did not include the last development phases of piloting, evaluation, and implementation. Therefore, the next iCST app prototype (version 3.0) will now be taken forward in a feasibility trial to better understand its acceptability, usefulness, and any potential signs of the effectiveness of the iCST app in daily life. Additional future activities could support the promotion and dissemination of the iCST app. Some examples include collaborations with international Alzheimer associations, visits to local memory cafes and dementia support groups in the community, and media exposure through the newspaper or radio.

Conclusions

This study demonstrates that an agile approach toward technology development involving all relevant stakeholders can be effective in creating suitable technology for people with dementia. This process can be further supported by using appropriate frameworks to better understand the development process and determine the necessary research activities. Furthermore, this study demonstrated that there is an interest and willingness to use an iCST app among people with dementia and carers. Therefore, these results have been added to our previous knowledge of paper-based CST, and a commercial release of the iCST app will strengthen CST's current international impact by making it more accessible to users around the world.

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Acknowledgments

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Authors' Contributions

HR collaboratively developed the app with Eumedianet, conducted the 3 sprints, and drafted the paper. JS provided additional support in sprint 2, including the PPI consultation. MO and JS provided supervision and guidance throughout the development process of Thinkability and commented on drafts of the paper.

Conflicts of Interest

Royalties from the sales of Thinkability go to Eumedianet and the University of Nottingham for ongoing support and maintenance of the app, including future updates. Additional information can be found on the Thinkability website.

Multimedia Appendix 1
Interview discussion guide for sprint 3.
[DOCX File , 19 KB - aging_v3i2e17105_app1.docx]

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Abbreviations

CeHRes: Centre for eHealth Research
CST: cognitive stimulation therapy
iCST: individual cognitive stimulation therapy
IMH: Institute of Mental Health
MRC: Medical Research Council
NHS: National Health Service
PPI: patient and public involvement
QoL: quality of life
RCT: randomized controlled trial

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Original Paper

A Smart Health Platform for Measuring Health and Well-Being Improvement in People With Dementia and Their Informal Caregivers: Usability Study

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Abstract

Background: Dementia is a neurodegenerative chronic condition characterized by a progressive decline in a person's memory, thinking, learning skills, and the ability to perform activities of daily living. Previous research has indicated that there are many types of technology interventions available in the literature that have shown promising results in improving disease progression, disease management, and the well-being of people with dementia (PwD) and their informal caregiver, thus facilitating dementia care and living. Technology-driven home care interventions, such as Connected Health (CH), could offer a convenient and low-cost alternative to traditional home care, providing an informal caregiver with the support they may need at home while caring for a PwD, improving their physical and mental well-being.

Objective: This study aimed (1) to create a multidimensional profile for evaluating the well-being progression of the PwD–informal caregiver dyad for a year during their use of a CH platform, designed for monitoring PwD and supporting their informal caregivers at home, and (2) to conduct a long-term follow-up using the proposed well-being profile at different time-interval evaluations.

Methods: The PwD–informal caregiver well-being profile was created based on the World Health Organization International Classification of Functioning considering the following outcomes: functional status, cognitive status, and quality of life for the PwD and mental well-being, sleeping quality, and burden for the informal caregiver. Over a year, comprehensive assessments of these outcomes were conducted every 3 months to evaluate the well-being of PwD–informal caregivers, using international and standardized validated questionnaires. Participants' demographic information was analyzed using descriptive statistics and presented as means and SDs. A nonparametric Friedman test was used to analyze the outcome changes and the progression in the PwD-caregiver dyads and to determine if those changes were statistically significant.

Results: There were no significant changes in the well-being of PwD or their caregivers over the year of follow-up, with the majority of the PwD-caregiver dyads remaining stable. The only instances in which significant changes were observed were the functional status in the PwD and sleep quality in their caregivers. In each of these measures, post hoc pairwise comparisons did not indicate that the changes observed were related to the deployment of the CH platform.

Conclusions: The follow-up of this population of PwD and their informal caregivers has shown that disease progression and physical and mental well-being do not change significantly during the time, being a slow and gradual process. The well-being profile created to analyze the potential impact of the CH platform on the PwD–informal caregiver dyad well-being, once validated, could be used as a future tool to conduct the same analyses with other CH technologies for this population.

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KEYWORDS

Connected Health; dementia; informal caregiver; home care; home monitoring

Introduction

Background

Dementia is a neurodegenerative chronic condition characterized by a progressive decline in a person's memory, thinking, learning skills, and the ability to perform activities of daily living (ADLs) [1]. Currently, dementia affects 47 million people worldwide, and these numbers are expected to increase to 75 million by 2030 and 132 million by 2050 [2]. A diagnosis of dementia has a significant impact on family members of people with dementia (PwD), who often bear the responsibility of caring for them as they deteriorate [3]. These family members, usually a spouse or a child, are often referred to as *informal caregivers*, as they offer continuous unpaid assistance, in contrast to *formal caregivers*, who offer paid professional services [3]. Informal caregiving can help to maintain the PwD at home, avoiding institutionalization and providing the *Aging in Place* model of care; avoiding nursing home placement; and contributing to an increase in well-being, independence, social participation, and healthy aging [4].

Previous research has indicated that there are many types of technology interventions available in the literature that have shown promising results in improving disease progression, disease management, and the well-being of PwD and their informal caregivers, thus facilitating dementia care and living [5,6]. This is the case for Connected Health (CH), a model of chronic care delivery facilitated by technology where all the stakeholders involved in a person's care are *connected* through a health portal that provides a continuous and efficient flow of information between them [7]. The concept of CH has gained attention among dementia researchers, as it has shown positive results in helping informal caregivers in their delivery of home care for the elderly [8,9]. Using a wide variety of technologies such as body-worn and monitoring devices, CH can help the informal caregiver in their caring duties through the continuous monitoring of the health status of the PwD at home, alerting them to changes in the PwD and their environment (such as falls or any other emergency event), and facilitating communication with health care professionals (HCP) when needed. CH-driven interventions could offer a convenient and low-cost alternative to traditional home care, providing an informal caregiver with reliable information and social and emotional support as well as enhancing information exchange with other caregivers and HCPs, facilitating the informal caregiver the decision-making process for matters concerned with PwD care [10]. The literature also suggests that many of these types of technology-driven interventions are designed to provide well-being to informal caregivers, helping to ameliorate the levels of burden and stress they can feel derived from their caring process [11]. Similarly, technology applied for dementia home care might play a role in PwD monitoring and disease decline prevention through the detection of changes in the PwD ADLs performance or physical parameters, alerting the caregiver and the HCP to act in advance and prevent further complications (eg, falls prevention, disease relapse, or hospitalization) [11]. At the same time, these technologies aim to empower the informal caregiver and increase their confidence and self-efficacy in their care role, improving the quality of life (QoL) and well-being of PwD and their informal caregivers [10]. An excellent example of a combination of patient home monitoring and informal caregiver support is the ALADDIN project, conducted by Torkamani et al. in 2014 [12]. ALADDIN is a digital platform designed to offer support to the informal caregiver through the provision of information (*Television* and *Social Networking*), a communication tool with formal carers (*Contact us*), and a distant monitoring feature (*My tasks*) where the informal caregiver had to complete a questionnaire that gathered information about the PwD health. It was tested in a multisite randomized controlled pilot study with 30 community living informal caregivers of PwD. The intervention and control groups were assessed at baseline, at 3 months, and at 6 months in terms of burden depression and QoL for the caregiver and for cognitive and disease stage, functional disability, comorbidities, and QoL for the PwD. The authors reported a significant improvement in the QoL of the carers in the platform group, with some reduction in caregiver burden and distress, and that the platform was useful in monitoring the PwD and facilitating contact with other professionals. In addition, caregivers and clinicians rated the access to and use of the ALADDIN platform positively. The success of studies such as this supports further testing of the utility and the value of technology interventions in other dementia cohorts, but they need to be studied for more extended periods to investigate the true impact that it can have on the PwD care. Furthermore, the addition of technology devices and wearables to monitor the vital signs of PwD can be a facilitator in this remotely telemonitoring process.

On the basis of the literature knowledge, this study aimed to create a well-being profile of the PwD–informal caregiver dyads involved in *Connected HEalth Sustaining home Stay* (CHESS) in dementia project, a CH study, to help to report their progression during their year of involvement in the study to see if there was any impact on it because of the use of a CH platform for home care.

CHESS Project Overview

CHESS is a CH longitudinal cohort study that took place in the University College Dublin (UCD, Ireland) between the beginning of 2016 and the end of 2019. The project aimed to (1) evaluate the effectiveness of a CH platform in supporting informal caregivers of PwD at home, compared with usual care; (2) study the impact of CH on dementia home care, in terms of the potential improvement of the PwD and their informal

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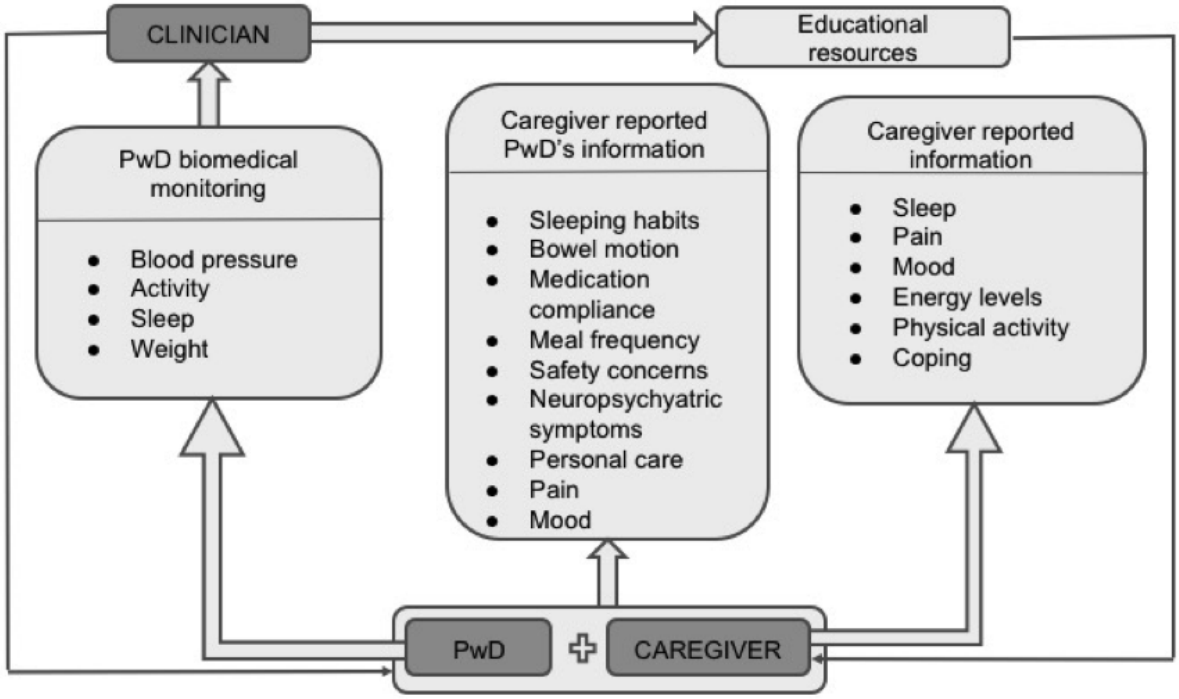
caregivers' physical and mental health and QoL; and (3) to determine the CH platform's usability and user experience from the informal caregivers' perspectives. The full CHESS project protocol has already been published [13]. The CH platform works on a tablet computer (Samsung Galaxy Tab A 10.1, 2016) and is connected to a series of PwD monitoring devices for home use, including a blood pressure (BP) monitor (Omron M6 by OMRON Healthcare Ltd), an electronic weighing scale (Withings, France), and an activity and sleeping tracker (Withings Go). The platform provides 4 features to the informal caregivers: an educational section with information and videos from dementia experts offering advice about daily care; an assessment module with daily questionnaires for the informal caregivers that collects health-related information about themselves and the PwD (in the case of PwD, data on their mood, nutrition, activity, bowel movements, and medication compliance are collected; for caregivers, surveys on their mood, energy levels, sleep quality, and anxiety levels are conducted); a diary for the caregivers to keep track of events, with summary reports of changes in the PwD care plan; and a dashboard with an overview of the PwD activity levels, sleep patterns, BP, and weight, recorded by the monitoring devices. The encrypted platform securely connects all the key stakeholders involved in PwD's care (ie, informal caregiver, general practitioner, public health nurse, and hospital geriatric services). As mentioned earlier, the generated data are presented on the platform and made available for the informal caregivers and HCPs as an objective measure of the PwD's health status. Figure 1 shows a representation of the CH platform components. Screenshots of the platform interface, sections, and devices can be found in Multimedia Appendix 1.

A preliminary subjective feedback study was conducted from a sample of our participants. This preliminary study showed that their initial impressions about what the CHESS platform could offer to them to improve their delivery of home care for the PwD did not correspond with what they found. In the beginning, they considered the platform as a tool to enhance their caring tasks and to improve their self-efficacy. After the deployment, they considered the platform to be more helpful for research than for themselves. This study has already been published, and more information about these informal caregivers' subjective experience can be found in the manuscript [14].

Figure 1. Representation of the Connected Health platform components.



Methods

Study Aims

In this study, we aimed (1) to create a multidimensional profile for evaluating the progression of the well-being of PwD–informal caregiver dyads during their use of the CH platform and their involvement in the CHESS study (1 year) and (2) to conduct a long-term follow-up using the proposed well-being profile, including different time-interval evaluations.

Study Design

This study reported a longitudinal quantitative analysis of the well-being of PwD-caregiver dyads that were involved in the *CHESS* project during a year's time, using a well-being profile created for the occasion.

Participants' Well-Being Profile Creation and Assessment

The PwD–informal caregiver well-being profile was created based on the World Health Organization (WHO) International Classification of Functioning (ICF) [15]. The ICF is a framework for describing and organizing an individual's

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information about functioning, health, and disability (Figure 2). In it is reflected how a disease or a health condition can make an impact on an individual in 3 main domains: body functions and structures, activities, and social participation. This impact may lead to a restriction in socialization and isolation and, therefore, affect well-being. These domains encompass all the physical, mental, and social aspects that define a person's well-being. As clinicians, we have to consider a person or a patient as a whole entity. Therefore, a person's well-being cannot be defined just by one of the following domains: their physical and mental functioning or social relationships. Our aim was to use this framework to create a PwD–informal caregiver well-being profile that comprehends all those aspects of a person's well-being and to use this as a tool for evaluating their well-being progression during the year they were involved in the study.

Applying this framework to the PwD, we created a well-being profile considering the PwD's following outcomes:

- The PwD functional status (body functions and structures domain): as a measure of disability
- The PwD cognitive status (activities domain): as a measure of their limitation in performing ADLs
- The PwD QoL (participation domain): as a measure of their social participation restriction.

For the informal caregiver, we created a well-being profile considering the following outcomes:

- The informal caregiver's mental health wellness, including anxiety, depression, and stress (body functions and structures domain): as a measure of the impact that their mental well-being can have on their body functions and how they respond to the daily caring demands
- The informal caregiver sleep quality (activity domain): as a measure of the impact that the lack of sleep can have in performing their daily caring tasks
- The informal caregiver burden (participation domain): as a measure of their social participation restriction.

These outcomes were evaluated using a series of validated international questionnaires:

- For the PwD:
  - PwD-related functional status was evaluated with the help of the Disability Assessment Dementia (DAD) scale [16]. The DAD scale was initially designed for community-based individuals with Alzheimer dementia, but it has been recently used in other types of dementia research. It is a tool used by the HCP to investigate the PwD levels of dependency and to guide the provision of tailored interventions for PwD. In addition, as a research tool, it can be used to describe the functional characteristics of PwD and the progression of the disease. A total score is converted out of 100, with the result of a percentage that provides an understanding of the PwD global function in ADLs. Higher scores indicate less disability in conducting ADLs, with lower scores indicating more dysfunction and more dependency on the caregiver [16].
  - PwD cognitive status was measured using the Mini-Mental State Examination (MMSE) [17,18]. The MMSE is composed of 11 questions that cover 5 areas of cognitive function: orientation, registration, attention and calculation, recall, and language. The maximum score was 30, with a score of 23 or less being indicative of cognitive impairment. This is a quick and easy tool to administer directly with the PwD and is very useful when conducting it repetitively [17,18].
  - PwD QoL was measured using the self-reported Dementia Quality of Life (DEMQoL) scale [19,20]. DEMQoL is designed to work across dementia subtypes and care arrangements and is suitable for all stages of the disease. It comprised 2 questionnaires: (1) DEMQoL: a 28-item questionnaire answered by the PwD (self-reported QoL), and (2) DEMQoL-Proxy: a 31-item questionnaire answered by the caregiver (PwD's caregiver-reported QoL). Scored items are summed to produce a total score, with higher scores indicating better health-related QoL [19,20].
- For the informal caregiver:
  - The Hospital Anxiety and Depression Scale (HADS) was used to measure anxiety and depression levels [21,22]. The HADS is a brief and straightforward self-report questionnaire. A total summary score classifies the respondent into 3 groups, depending on their levels of depression or anxiety: normal, borderline case, or abnormal. This questionnaire does not provide a diagnosis, as it was created for screening purposes only [21,22].
  - Caregivers' sleep quality was determined using the Pittsburgh Sleep Quality Index (PSQI) [23,24]. The PSQI is designed to evaluate the overall sleep quality for 1 month. It is a 19-item self-reported questionnaire with 7 subcategories: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction. This questionnaire was initially created to measure the sleep quality in psychiatric populations but has been widely used for clinical and research purposes [23,24].
  - Caregiver burden was evaluated using the Zarit Burden Interview (ZBI) scale [25,26]. It is comprised of 22 questions about the impact of the PwD's disabilities on caregivers' lives and has been designed to reveal the stress experienced by the caregiver. For each item, the caregivers must indicate how burdened they are (never, rarely, sometimes, quite frequently, or nearly always). A total score can be calculated from the summing of each answer, with higher scores indicating higher levels of burden and stress due to the caring process [25,26].

Table 1 provides details on the PwD–informal caregiver dyads well-being profile created based on the WHO ICF.

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Figure 2. World Health Organization International Classification of Functioning framework.

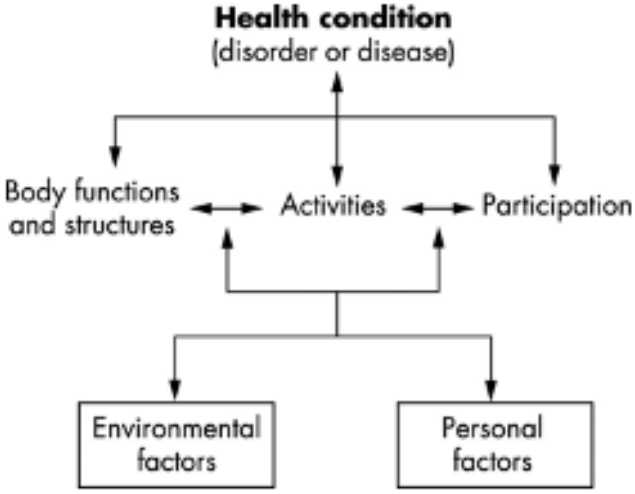

Table 1. People with dementia and informal caregiver well-being profile based on the World Health Organization International Classification of Functioning framework.

Domains	Person with dementia	Caregiver
Body structure and function	• Mini-Mental State Exam (cognitive function)	• Hospital Anxiety and Depression Scale (anxiety and depression) • Zarit Burden Interview (stress/distress)
Activity limitation	• Disability Assessment Dementia (functional status)	• Pittsburgh Sleep Quality Index (sleep quality)
Participation restriction	• Dementia Quality of Life and Dementia Quality of Life-proxy (quality of life)	• Zarit Burden Interview (participation)

Timing of Measurements

During the year of follow-up, comprehensive assessments to evaluate the well-being of PwD–informal caregivers were conducted every 3 months following the study protocol [13], at 0, 3, 6, 9, and 12 months, using the international and standardized validated questionnaires described earlier. They were completed electronically on the researchers' administrators' interface of the platform by the caregiver and the patient, with the help of the researcher (see Table 2 for the comprehensive list of the well-being questionnaires and their timing during the 12-month follow-up).

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Table 2. Quarterly comprehensive list of well-being evaluation questionnaires and timing with the informal caregiver and people with dementia during the year of follow-up.

Individuals	Month 0	Month 3	Month 6	Month	Month 12
People with dementia					
	• DEMQoL[a] • MMSE[b] • DAD[c] • DEMQoL-proxy	• DEMQoL • MMSE • DAD • DEMQoL-proxy	• DEMQoL • MMSE • DAD • DEMQoL-proxy	• DEMQoL • MMSE • DAD • DEMQoL-proxy	• DEMQoL • MMSE • DAD • DEMQoL-proxy
Caregiver					
	• HADS[d] • PSQI[e] • ZBI[f]	• HADS • PSQI • ZBI	• HADS • PSQI • ZBI	• HADS • PSQI • ZBI	• HADS • PSQI • ZBI

[a]DEMQoL: Dementia Quality of Life.

[b]MMSE: Mini-Mental State Examination.

[c]DAD: Disability Assessment Dementia.

[d]HADS: Hospital Anxiety and Depression Scale.

[e]PSQI: Pittsburgh Sleep Quality Index.

[f]ZBI: Zarit Burden Interview.

Study Participants

Our participants' sample was recruited from the already participating dyads in the CHESS project. We included participants from June 2017 and who had completed the year follow up by December 2018. Ethical approval for this study was obtained, as part of the CHESS project, from the research ethics committees from the collaborating hospitals (Mater Misericordiae University Hospital and Saint Vincent's University Hospital) and UCD Human Research Ethics Committee.

Statistical Analysis

Participants' demographic information was analyzed using descriptive statistics and presented as means and SDs. Owing to the small sample size, the nonparametric Friedman test was used to analyze the changes in the outcomes and progression during the year of follow-up in the PwD (MMSE, DAD, DEMQoL, and DEMQoL-proxy) and their respective informal caregivers (HADS, PSQI, and ZBI) and to determine if those changes were statistically significant. In case of finding significant changes in any of the outcomes, post hoc pairwise comparisons analysis was conducted using the nonparametric Wilcoxon test to help understand specific differences between the different time intervals. Only some scales could be classified by ranges (MMSE, HADS, PSQI, and ZBI). Table 3 provide details of each variable's scoring and classification. In the case of the scales in which scores were not classified by ranges (DAD, DEMQoL, and DEMQoL-proxy), only a description of the score changes was provided. Where data were missing, the analysis was based on the available data, without discarding any participant because of the small sample size recruited. All statistical data analyses were conducted using SPSS version 24 for Mac (IBM Corp, Released 2016; IBM SPSS Statistics for Macintosh, version 24.0).

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Table 3. Mini-Mental State Examination score and range classification.

Scales and classifications	Scoring
Mini-Mental State Examination	
Mild cognitive impairment	25-30
Mild dementia	21-24
Moderate dementia	13-20
Severe dementia	<12
Hospital Anxiety and Depression Scale	
Normal	0-7
Borderline	8-10
Abnormal (case)	11-21
Pittsburgh Sleep Quality Index	
Poor sleep	>5
Normal	<5
Zarit Burden Interview	
Little/no burden	0-21
Mild/moderate	21-40
Moderate/severe	41-60
Severe	61-88

Minimal Clinical Significance Analysis

To further explore the participants' changes and progression, their group and individual profiles were examined using minimum clinically significant changes in status. Minimal clinical significance has been established for several measures as follows:

- MMSE score at more than 3 points [27]
- DAD by 12 points [28]
- HADS by 1.5 points [29].

These cutoff points or thresholds were applied to identify clinically significant changes in our individuals during the year of follow-up. We did not find any cutoff points for DEMQoL, DEMQoL-proxy, PSQI, and ZBI scales in the literature. For these cases, we have just described the progression of our participants based on the score changes.

Results

Participant Characteristics

A total of 11 PwD–informal caregiver dyads were recruited. The informal caregivers had a reasonable balance between females and males (6/11, 54% female vs 5/11, 45% male), with an average age of 69.27 (SD 13.14) years. Most caregivers were spouses of the PwD (8/11, 72% cases), having been a dedicated caregiver for the PwD for an average of 3 (SD 2.69) years. Most of the informal caregivers were retired (8/11, 72% cases). In terms of the PwD they were caring for, there was a reasonable balance between genders (6/11, 54.5% female vs 5/11, 45.5% male), and the PwD had an average age of 75.09 (SD 10.13) years. The majority of the PwD had vascular dementia (4/11, 36%) or a nonspecified type of dementia (4/11, 36% cases). All the PwD were living at home with their informal caregivers. At enrollment time, the mean MMSE score was 24.10 (SD 3.66), indicating mild dementia, and the mean DAD score was 74.64 (SD 27.76). Tables 4 and 5 provide further details of the participants.

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Table 4. Demographic characteristics of the people with dementia involved in the year of follow-up (N=11).

People with dementia demographics	Values
Gender, n (%)	
Male	5 (45)
Female	6 (54)
Type of dementia, n (%)	
Vascular dementia	4 (36)
Not specified	4 (36)
Alzheimer disease	1 (9)
Other (Parkinson disease)	1 (9)
Lewy body	1 (9)
Education, n (%)	
Primary	3 (27.3)
Secondary	4 (36.4)
Tertiary	2 (18.2)
Postgraduate	2 (18.2)
Mini-Mental State Examination levels at enrollment, n (%)	
Mild cognitive impairment	4 (36.36)
Mild	4 (36.36)
Moderate	3 (27.27)
Severe	0 (0)
Disability Assessment Dementia score at enrollment, mean (SD)	74.64 (27.76)
Age, mean (SD)	75.09 (10.13)

Table 5. Demographic characteristics of the informal caregivers involved in the year of follow-up (N=11).

Caregiver's Demographics	Values
Gender, n (%)	
Male	5 (45)
Female	6 (54)
Caregiver- people with dementia relationship, n (%)	
Spouses	8 (72)
Children	3 (27)
Caregiver employment, n (%)	
Retired	8 (72)
Part time	2 (18)
Carers' allowance	1 (9)
Caregiver educational levels, n (%)	
Primary	2 (18)
Secondary	4 (36)
Tertiary	3 (27)
Postgraduate	2 (18)
Caregiver age, mean (SD)	69.27 (13.14)
Caregiver years in care, mean (SD)	3.0 (2.69)

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PwD–Informal Caregiver Dyad Well-Being Progression During the Year of Follow-Up

PwD Well-Being Progression

From all of the outcomes analyzed, we only found significant changes in 2: the PwD functional status (DAD scale) and in the informal caregiver sleep quality (PSQI scale). When individual cases were analyzed, we found considerable variation between participants, reflected in changes on an individual basis for both the PwD and their informal caregivers. A detailed description of each outcome progression is described in the following sections.

The global cognitive function in our PwD population sample showed a small decrease in the mean MMSE of 1.5 (SD 0.9) points from baseline to the year of follow-up period. However, this did not reach the threshold for statistical significance at the 0.5 level (P=.61) in the Friedman test. The overall mean MMSE score was 23.25 (SD 4.77), indicating a mild dementia stage (4/11, 36% of participants). When looking at individual cases, 18% (2/11) of PwD decreased more than 3 points their MMSE score during the year of follow-up, experiencing a clinically significant cognitive decline. The other 9 PwD (81%) remained stable (changed by 3 points or less). See Tables 6 and 7 below for further details.

In terms of the functional status of our sample of PwD, the overall mean DAD score was 65.47 (SD 28.80), with a progressive deterioration during the year of follow-up, shown by a diminution of 11.39 points in the total DAD score. There was a significant difference across the 5 time points measurement during the year of follow-up (Friedman test P=.02), with a mean score at month 0 of 71.53 (SD 27.95) and a mean score at month 12 of 60.14 (SD 30.12).

When looking at individual cases, the DAD scores of 63% (7/11) of PwD dropped by more than 12 points during the year of follow-up, experiencing a clinically significant functional decline, whereas the other 4 PwD (36.36%) remained the same (changed <12 points). See Table 8 for more details.

Table 6. People with dementia Mini-Mental State Examination score during the year progression.

Mini-Mental State Examination	Month 0	Month 3	Month 6	Month 9	Month 12	Friedman test (P value)
Minimum	19	18	11	15	12	.06
Quartile 1	21.5	19	19	19.2	20	N/A[a]
Median	23.5	23	23	23.5	23.5	N/A
Mean (SD)	24.1 (3.6)	24.0 (5.0)	22.6 (5.9)	22.6 (4.3)	22.8 (5.0)	N/A
Quartile 3	27.2	29	27.5	24.7	26	N/A
Maximum	30	30	30	29	30	N/A

[a]N/A: not applicable.

Table 7. Number of people with dementia in each Mini-Mental State Examination range group at months 0 and 12.

Mini-Mental State Examination ranges	Mini-Mental State Examination Score	Participants at month 0 (n=11), n	Participants at month 12 (n=10), n
Mild cognitive impairment	25-30	4	4
Mild-Moderate	21-24	4	2
Moderate	13-20	3	3
Severe	<12	0	1

Table 8. People with dementia Disability Assessment Dementia score during the year progression.

Disability Assessment Dementia	Month 0	Month 3	Month 6	Month 9	Month 12	Friedman test (P value)
Minimum	27.7	20.5	15	12.5	12.5	.02
Quartile 1	49.7	50.5	39.4	27.5	38.1	N/A[a]
Median	80.2	80	71.7	60.5	65.1	N/A
Quartile 3	96.0	94.7	88.6	80	79.3	N/A
Maximum	97.4	100	100	100	100	N/A
Mean (SD)	71.5 (27.9)	72.1 (27.6)	65.1 (29.6)	58.4 (31.3)	60.1 (30.1)	N/A

[a]N/A: not applicable.

Post hoc pairwise comparisons analysis was conducted using a nonparametric Wilcoxon test to help understand specific differences between the different time intervals within the DAD results, to find where the significance difference relies on

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between the 5 time point measurements. The Wilcoxon test results revealed a statistically significant reduction in PwD DAD score from months 3 to 6, from months 6 to 9, from months 0 to 6, from months 0 to 9, from months 3 to 9, and from months 3 to 12. The median score for the PwD DAD decreased from platform preimplementation at month 3 (median 80.26) to platform postimplementation at month 9 (median 60.53). Please see Table A1 in the Multimedia Appendix 2 for further details.

In terms of the PwD QoL, it was quite stable during the year of follow-up, with no statistically significant change over the year of follow-up time for DEMQoL and DEMQoL-proxy (Friedman test *P*=.78 and *P*=.06, respectively). The overall mean of the DEMQoL-proxy score was 102.26 (SD 10.92), and the overall mean of DEMQoL was 95.21 (SD 7.57), indicating a very good reported QoL from both, the PwD and the caregiver. DEMQoL-proxy scores were, on average, higher than the DEMQoL scores at each time measurement. See Tables 9 and 10 and Figures 3 and 4 for details.

Table 9. Dementia Quality of Life score during the year follow-up.

DEMQoL[a]	Month 0	Month 3	Month 6	Month 9	Month 12	Friedman test (*P* value)
Minimum	76	83	82	84	87	.78
Quartile 1	90	91	89	91	91.75	N/A[b]
Median	96	97	96	97	97	N/A
Mean (SD)	93.0 (8.4)	95.7 (7.7)	94.6 (8.2)	95.4 (6.2)	97.4 (7.6)	N/A
Quartile 3	98	103	100	99.7	104.7	N/A
Maximum	102	105	107	105	106	N/A

[a]DEMQoL: Dementia Quality of Life.
[b]N/A: not applicable.

Table 10. Dementia Quality of Life-proxy score during the year follow-up.

DEMQoL[a]-proxy	Month 0	Month 3	Month 6	Month 9	Month 12	Friedman test (*P* value)
Minimum	88	92	71	81	70	.06
Quartile 1	99	100.50	101.50	92.50	95.25	N/A[b]
Median	102	106	105	102	107	N/A
Mean (SD)	101.6 (7.4)	106.1 (7.8)	103.5 (12.9)	99.5 (10.9)	100.2 (14.7)	N/A
Quartile 3	104.50	112.50	112.50	105.50	110.50	N/A
Maximum	117	117	117	115	113	N/A

[a]DEMQoL: Dementia Quality of Life.
[b]N/A: not applicable.

Figure 3. People with dementia self-reported Quality of Life during the year observation period (minimum, quartile 1, median, quartile 3, maximum).

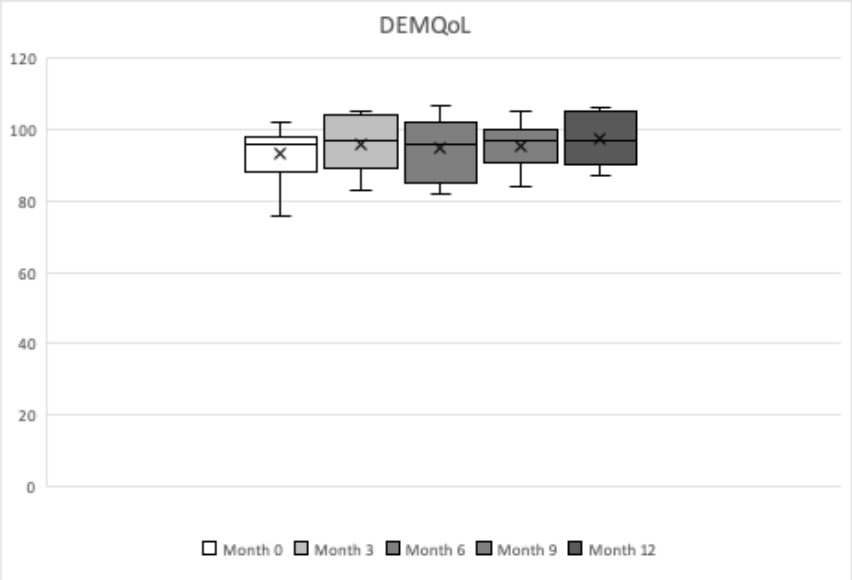

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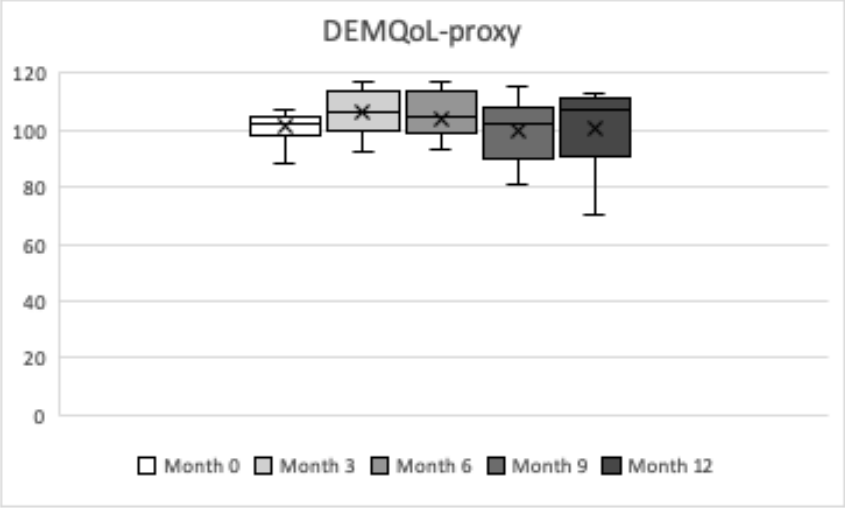
Figure 4. People with dementia informal caregiver reported Quality of Life during the year observation period (minimum, quartile 1, median, quartile 3, maximum).



Informal Caregiver Well-Being Progression

Anxiety and depression scoring did not follow a linear progression, with fluctuations in the scoring along the observation period for both of them. This means that, depending on the assessment month, their anxiety or depression symptoms underwent an improvement or worsening (see individual progression in Multimedia Appendix 3). The overall anxiety mean score (HADS-A) for our informal caregivers was 5.59 (SD 3.91); the global depression mean score (HADS-D) was 2.43 (SD 1.75), with no statistically significant differences between anxiety or depression scores during the year of follow-up (Friedman test P=.97 and P=.69, respectively). When looking at individual case analysis, 27% (3/11) of caregivers increased their HADS-A score by more than 1.5 points during the year of follow-up, experiencing a worsening of their anxiety, and only 9% (1/11) of caregivers dropped their scores by more than 1.5 points, experiencing an improvement in the anxiety levels. For the HADS-D, 9% (1/11) of caregivers increased their score by more than 1.5 points during the year of follow-up, experiencing a worsening of their depression symptoms, and only 9% (1/11) of caregivers decreased their scores by more than 1.5 points, experiencing an improvement in the depression symptoms. See Tables 11-14 and Figures 5 and 6 for further details.

Table 11. Informal caregivers' anxiety and depression scores during the year observation period.

Hospital Anxiety and Depression Scale-Anxiety	Month 0	Month 3	Month 6	Month 9	Month 12	Friedman test (P value)
Minimum	0	0	1	0	1	.97
Quartile 1	3	3	4	3	3.5	N/A[a]
Median	5	4	5	6	6	N/A
Mean (SD)	5.7 (5.4)	5.6 (4.2)	5.2 (2.5)	5.8 (4.0)	5.5 (3.3)	N/A
Quartile 3	6	8.5	7	8	6.7	N/A
Maximum	21	14	10	12	13	N/A

[a]N/A: not applicable.

Table 12. Informal caregivers' anxiety and depression scores during the year observation period.

Hospital Anxiety and Depression Scale-Depression	Month 0	Month 3	Month 6	Month 9	Month 12	Friedman test (P value)
Minimum	0	0	1	0	0	.69
Quartile 1	1	1.5	1	1	1	N/A[a]
Median	2	2	2	2	1.50	N/A
Mean (SD)	2.2 (1.6)	2.2 (1.6)	2.3 (1.5)	2.6 (1.9)	2.6 (2.2)	N/A
Quartile 3	4	2.5	3	4	4.50	N/A
Maximum	5	6	5	6	6	N/A

[a]N/A: not applicable.

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Table 13. Number of caregivers in each Hospital Anxiety and Depression Scale-Anxiety range group at months 0 and 12.

Hospital Anxiety and Depression Scale-Anxiety ranges	Score	Month 0 (n=11), n	Month 12 (n=10), n
Normal	0-7	10	9
Borderline	8-10	0	0
Abnormal (case)	11-21	1	1

Table 14. Number of caregivers in each Hospital Anxiety and Depression Scale-Depression range group at months 0 and 12.

Hospital Anxiety and Depression Scale-Depression ranges	Score	Month 0 (n=11), n	Month 12 (n=10), n
Normal	0-7	11	10
Borderline	8-10	0	0
Abnormal (case)	11-21	0	0

Figure 5. Informal caregivers' Hospital Anxiety and Depression Scale-A during the year observation period (minimum, quartile 1, median, quartile 3, maximum).

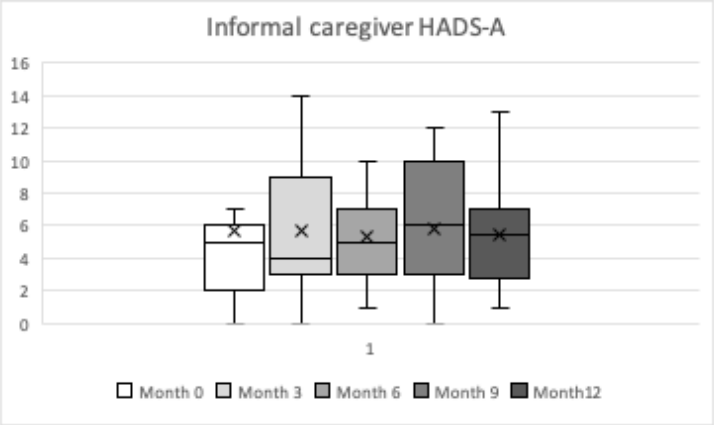
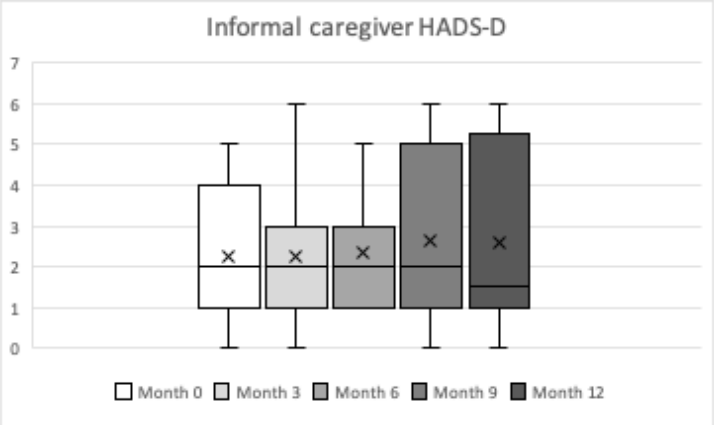


Figure 6. Informal caregivers' Hospital Anxiety and Depression Scale-D during the year observation period (minimum, quartile 1, median, quartile 3, maximum).



In terms of sleep quality, our informal caregivers' overall mean PSQI score was 7.87 (SD 4.01) points. Caregivers' sleep quality followed a slight progressive decrease in the PSQI of 1.66 points during the year. This means that from the 10 of 11 informal caregivers who had poor sleep quality at month 0, only 5 of 11 had poor sleep quality at month 12. Friedman test indicated that there was a statistically significant difference in caregivers' sleep quality between each time measurement during the year of follow-up (P=.04). When looking at individual cases, it was quite varied and not homogeneous in our participants. See Tables 15-16 and Figure 7 for further details.

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Table 15. Informal caregivers' Pittsburgh Sleep Quality Index score during the year progression.

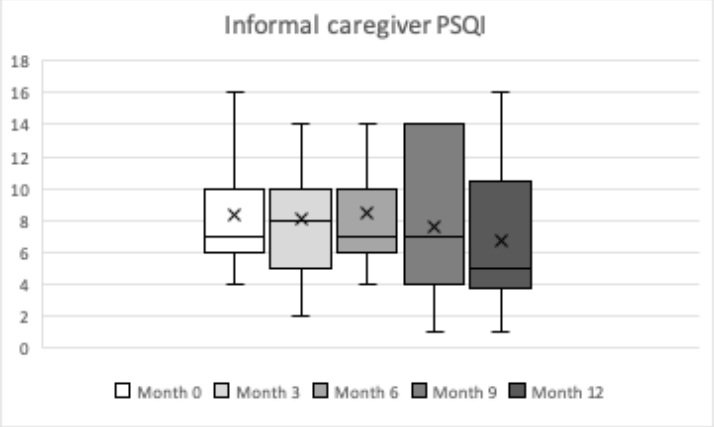
Pittsburgh Sleep Quality Index	Month 0	Month 3	Month 6	Month 9	Month 12	Friedman test (*P* value)
Minimum	4	2	4	1	1	.04
Quartile 1	6.50	5.50	6.50	4.50	4	N/A[a]
Median (SD)	7 (3.4)	8 (3.6)	7 (3.9)	7 (4.8)	5 (4.6)	N/A
Mean	8.36	8.09	8.45	7.64	6.70	N/A
Quartile 3	9.50	10	9.50	12	9.25	N/A
Maximum	16	14	17	14	16	N/A

[a]N/A: not applicable.

Table 16. Number of caregivers in each Pittsburgh Sleep Quality Index range group at months 0 and 12.

Pittsburgh Sleep Quality Index ranges	Score	Month 0 (n=11), n	Month 12 (n=10), n
Poor sleep quality	>5	10	5
Normal	<5	1	5

Figure 7. Informal caregivers' Pittsburgh Sleep Quality Index year progression (minimum, quartile 1, median, quartile 3, maximum).



Post hoc pairwise comparisons analysis was conducted using a nonparametric Wilcoxon test to help understand specific differences between the different time intervals within the overall PSQI results, to find where the significance difference relies on between the 5 time point measurements. The Wilcoxon test results revealed a statistical significance in caregivers' PSQI score from months 3 to 12 and from months 6 to 12. See Table A2 in the Multimedia Appendix 2 for further details.

Overall, informal caregivers' burden fluctuated during the year observation period. The ZBI mean score over the year was 24.94 (SD 12.55), corresponding to mild-to-moderate levels of burden in our informal caregivers. There was an increase in the proportion of caregivers' expression of mild-to-moderate levels of burden from an initial 27% (3/11) to 50% (5/11) at the end of the year of follow-up. Friedman test indicated that there was no statistically significant difference in the mean burden score between each time measurement during the year of follow-up (P=.13). See Tables 17 and 18 and Figure 8 for further details.

To summarize, we can say that although the global mean for MMSE, DEMQoL, DEMQoL-proxy, HADS-A, HADS-D, and ZBI did not change over time in our PwD and caregiver participants, in some of them, when looking on an individual basis, there were noticeable changes. When individual dyads were analyzed in a case series, we observed a heterogeneous pattern of changes over the year of follow-up. We found 4 cases (Dyad 1, Dyad 3, Dyad 4, and Dyad 10) where there were minimal changes across the full range of measures for the PwD, yet there were changes observed for the caregiver in the cases of D1 and D4. The most common observation was that of a variable pattern of changes where some outcome measures remained stable, and others fluctuated throughout the year, with variation across the PwD and caregiver in each dyad. Detailed individual case analysis descriptions can be found in Multimedia Appendix 1.

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Table 17. Informal caregivers' Zarit Burden Interview score during the year progression.

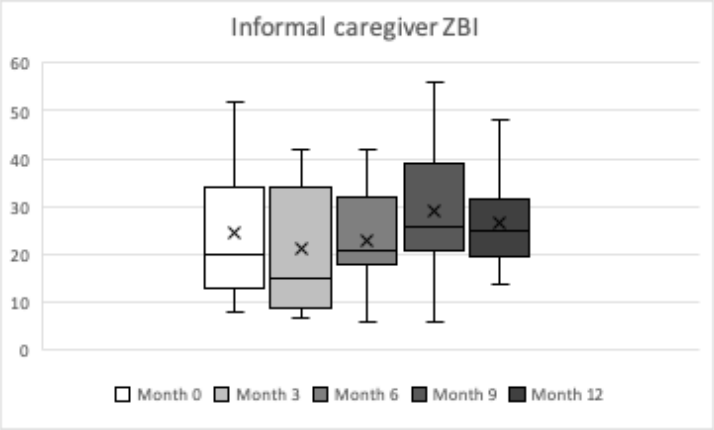
Zarit Burden Interview	Month 0	Month 3	Month 6	Month 9	Month 12	Friedman test (*P* value)
Minimum	8	7	6	6	14	.13
Quartile 1	15	10.5	18.5	21.5	20.2	N/A[a]
Median	20	15	21	26	25	N/A
Mean (SD)	24.5 (14.3)	21.36 (13.0)	23 (10.6)	29.2 (14.4)	26.7 (10.1)	N/A
Quartile 3	29.5	33.5	32	38	28.7	N/A
Maximum	52	42	42	56	48	N/A

[a]N/A: not applicable.

Table 18. Number of caregivers in each Zarit Burden Interview range group at months 0 and 12.

Zarit Burden Interview ranges	Score	Month 0 (n=11), n	Month 12 (n=10), n
Little/no burden	0-21	6	4
Mild/moderate	21-40	3	5
Moderate/severe	41-60	2	1
Severe	61-88	0	0

Figure 8. Informal caregivers' Zarit Burden Interview year progression (minimum, quartile 1, median, quartile 3, maximum).



Discussion

Principal Findings

The findings from our study suggest that in the majority of measurement outcomes analyzed, there were no significant changes in the PwD or their caregivers' well-being over the year of follow-up when analyzed as a group. The only instances in which statistically significant changes were observed were a worsening in the functional status of the PwD (using the DAD scale) and a slight improvement in sleep quality for their caregivers (using the PSQI scale). However, in each of these 2 measures, post hoc pairwise comparisons did not indicate any evidence of statistically significant scoring change between the 3 monthly time intervals. This is not unexpected because the small number of participants and the accompanying lack of statistical power limit the statistical inference in this study design. Furthermore, given the observational nature of the study, we cannot attribute that the changes observed were related to the deployment of the platform. However, this lack of statistical significance does not automatically mean that the CHESS platform and its continuous monitoring could offer some advantages in disease progression and disease pattern detection in the long term. When we looked across the individual cases, the results were very varied for each dyad, with no common pattern, but these results support the potential value of individual-level monitoring. As with the group results, we lack evidence to conclude that any of these changes were because of the introduction of the CHESS platform.

The novelty of our work relies on how we approached the PwD and their informal caregivers' well-being. On the basis of the WHO ICF framework, we have built up a multidimensional profile of the PwD and their informal caregiver to analyze the impact that the health platform could have on their well-being. This could be validated in the future and used as a standard tool to conduct the same analysis with other different s-Health technologies for PwD and their informal caregivers. Furthermore, it is the first time, to our knowledge, that the PwD-caregiver dyad well-being is measured through different outcomes, as usually follow-up studies focus on one single variable measured at different time points [30,31].

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Furthermore, as cognition deteriorates, it is more challenging to assess PwD well-being; however, in our study, we used both self-reported and proxy-reported assessments to evaluate how the same situation can be perceived discordantly by the PwD and the caregiver, giving more strength to it. Another strength of our study relies on the time-interval analysis conducted. Measuring the same outcomes, with the same tools, and at a higher frequency during an extended observation period allows us to build up a better outline of a population or an individual and its fluctuation over time. This could provide an opportunity to study some external factors that may influence these variations in time.

Comparison With Prior Work

Our findings for our PwD–informal caregiver dyads' well-being progression are in line with similar previous studies in the field, which found that their PwD population did not suffer a significant QoL change during the time they were followed up [30,32]. This is consistent with the literature, which reports that PwD have a progressive adaptation to their cognitive and functional decline, assimilating their limitations and continuing to have positive experiences [33]. The same adaptation is described in the literature for informal caregivers, who do not increase their levels of burden or strain despite the progressive decline of the PwD [34].

Many reviews and meta-analyses have investigated the potential benefits that different types of nonpharmacological interventions can have in the well-being of PwD and their informal caregivers, reducing their levels of burden and depression and improving their QoL, positive affect, physical activity, and self-efficacy, thus having a positive impact on the care recipient [35]. Despite this, they all have something in common: their results do not provide enough evidence to support their use [36]. One of the main reasons that these works argue for that lack of evidence is that there are many different types of studies, including psychoeducational interventions, cognitive behavioral therapy, counseling, support and management, respite, training for the caregiver, or physical health promotion, to name a few. This wide variety of interventions leads to difficulties in comparing the different types of studies [36]. In addition, most of these studies have been found to lack a proper scientific methodology, with different scopes, content, and outcome measures, which decreases their quality and leads them to a lack of evidence [35]. The same issue is noted in the case of technology interventions aimed at improving the PwD's and their informal caregivers' QoL. Despite recommending the use of these newly developed technology interventions for improving the well-being of PwD-caregivers at home, the reviews conducted do not provide strong support and claim a lack of evidence in the studies included, arguing having found the same methodology and consistency issues in them [10,37]. Authors in the field claim that there is a need for improvement in the quality of these interventions and that more longitudinal studies need to be conducted to provide evidence of the effect that these interventions can have in the long term [36].

Limitations

There are some limitations to our study. Despite conducting nonparametric tests, the results cannot be extrapolated to the population because of the small number of participants included. In addition, our PwD sample was quite heterogeneous in terms of the dementia diagnoses and participants' characteristics. Therefore, our results must be considered in the context of this particular PwD group, their informal caregivers, and their personal living conditions and environment. Our study could also have benefited from a longer follow-up study, as some other studies in the literature indicate.

Another thing to consider is not including the informal caregiver QoL outcome in our study variables when it is considered in the literature as an important factor for assessing the caregiver burden related to continuous care for chronic patients.

We did not differentiate between caregivers who are spouses and those who are children of the PwD. Along the same line, we have not considered the potential impact of the PwD comorbidities in the caregiver, having described only the impact that dementia may have on them.

Conclusions

The follow-up of this population of PwD and their informal caregivers has shown us that disease progression and their physical and mental well-being do not undergo a significant change during the time, being a more slow and gradual process. The well-being profile created to analyze the potential impact of the CH platform on the PwD–informal caregiver dyad well-being, once validated, could be used as a future tool to conduct the same analyses with other CH technologies for this population.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
CHESS platform and components.
[DOCX File , 1068 KB - aging_v3i2e15600_app1.docx]

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Multimedia Appendix 2
Descriptive tables.
[DOCX File , 83 KB - aging_v3i2e15600_app2.docx]

Multimedia Appendix 3
Individual dyads description.
[DOCX File , 81 KB - aging_v3i2e15600_app3.docx]

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Abbreviations

ADL: activities of daily living
BP: blood pressure
CH: Connected Health
CHESS: Connected HEalth Sustaining home Stay
DAD: Disability Assessment Dementia
DEMQoL: Dementia Quality of Life
HADS: Hospital Anxiety and Depression Scale
HCP: health care professional
ICF: International Classification of Functioning
MMSE: Mini-Mental State Examination
PSQI: Pittsburgh Sleep Quality Index

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QoL: quality of life
UCD: University College Dublin
WHO: World Health Organization
ZBI: Zarit Burden Interview

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Review

Challenges and Recommendations for the Deployment of Information and Communication Technology Solutions for Informal Caregivers: Scoping Review

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Abstract

Background: Information and communication technology (ICT)–based solutions have the potential to support informal caregivers in home care delivery. However, there are many challenges to the deployment of these solutions.

Objective: The aim of this study was to review literature to explore the challenges of the deployment of ICT-based support solutions for informal caregivers and provide relevant recommendations on how to overcome these challenges.

Methods: A scoping review methodology was used following the Arksey and O'Malley methodological framework to map the relevant literature. A search was conducted using PubMed, IEEE library, and Scopus. Publication screening and scrutiny were conducted following inclusion criteria based on inductive thematic analysis to gain insight into patterns of challenges rising from deploying ICT-based support solutions for informal caregivers. The analysis took place through an iterative process of combining, categorizing, summarizing, and comparing information across studies. Through this iterative process, relevant information was identified and coded under emergent broader themes as they pertain to each of the research questions.

Results: The analysis identified 18 common challenges using a coding scheme grouping them under four thematic categories: technology-related, organizational, socioeconomic, and ethical challenges. These range from specific challenges related to the technological component of the ICT-based service such as design and usability of technology, to organizational challenges such as fragmentation of support solutions to socioeconomic challenges such as funding of technology and sustainability of solutions to ethical challenges around autonomy and privacy of data. For each identified challenge, recommendations were created on how to overcome it. The recommendations from this study can provide guidance for the deployment of ICT-based support solutions for informal caregivers.

Conclusions: Despite a growing interest in the potential offered by ICT solutions for informal caregiving, diverse and overlapping challenges to their deployment still remain. Designers for ICTs for informal caregivers should follow participatory design and involve older informal caregivers in the design process as much as possible. A collaboration between designers and academic researchers is also needed to ensure ICT solutions are designed with the current empirical evidence in mind. Taking actions to build the digital skills of informal caregivers early in the caregiving process is crucial for optimal use of available ICT solutions. Moreover, the lack of awareness of the potential added-value and trust toward ICT-based support solutions requires strategies to raise awareness among all stakeholders—including policy makers, health care professionals, informal caregivers, and care recipients—about support opportunities offered by ICT. On the macro-level, policies to fund ICT solutions that have been shown to be effective at supporting and improving informal caregiver health outcomes via subsidies or other incentives should be considered.

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KEYWORDS

informal caregivers; ICT; digital health; eHealth; health economics; internet; health technology; ageing; home care; digital solutions

Introduction

The United Nations estimates that by 2050, 1 in 6 people in the world will be aged over 65 years, up from 1 in 11 in 2019 [1]. It is estimated that 1 in 3 older adults lives with more than a single chronic condition (eg, heart disease, diabetes, cancer, and dementia) [2,3], and this figure is closer to 3 out of 4 in older adults living in developed countries where it is predicted to rise significantly [4].

To manage chronic conditions more effectively, policy makers are supporting the idea of family-centered home-based care for older people rather than institutional care [5]. Older people are depending more on their families and friends for support with daily activities due to this shift from institutional to home care [6]. Informal caregivers are relatives, friends, and neighbors who care for older adults but are not trained or paid to provide care in contrast to formal caregivers, who offer paid professional services [7]. In 2013, the estimated economic value of unpaid informal care in the United States was $470 billion [8]. In Europe, 80% of all care is provided by informal caregivers, and estimates on the economic value of unpaid informal care in European Union member states range from 50% to 90% of the overall costs of formal long-term care provision [9]. Informal caregivers who care for old people save Canada's health care system between $24 to $31 billion annually [10].

Lamura et al [11,12] pointed to the importance of novel technology solutions as a promising approach for empowering and supporting informal caregivers. Information and communication technology (ICT) consists of digital and analog technologies, including hardware, software, networks, and media, that facilitate collecting, capturing, storing, processing, transmitting, exchanging, and presenting information, and/or communication [13]. Barbabella et al [14] define ICT-based support solutions for informal caregivers as a service provided by any private or public organization that addresses caregiver and/or care recipient needs through technological devices that are integrated or not in a wider intervention program.

ICTs provide informal caregivers with remote access to information and training about caring-related issues though websites and online training materials [15]. They provide informal caregivers with personal support and social integration providing social, emotional, and peer support; social networking systems for peer support; and volunteer call networks [16]. Research showed that ICT solutions can improve psychological outcomes in informal caregivers [14-17]. ICT solutions may reduce caregiver depression, anxiety, stress, and burden as these solutions increase positive aspects of caregiving, caregiver self-efficacy, and confidence [14-17]. ICT solutions have also macro-level benefits as these solutions may help in the integration of informal and formal care through the reduction of inappropriate hospitalizations and lengths of stay. Consequently, the deployment of these solutions may generate savings contributing to the sustainability of the care systems [15-17].

Although ICT solutions can facilitate the delivery of home care and support informal caregivers of old people, there are many challenges to the deployment of these solutions [17]. Challenges are diverse and range from usability of technology solutions, sustainability, data security, digital literacy levels of informal caregivers, and other key issues [15-17]. Consequently, there is a need for mapping these different challenges and developing relevant recommendations on how to overcome them to inform the successful research and development of ICT solutions for informal caregivers. Although some reviews [18-21] have begun to synthesize the literature on ICT solutions for informal caregivers, they have focused solely on evaluating the effectiveness of these solutions and their impact on the informal caregivers, and the focus was mainly on informal caregivers of people with dementia. The aim of this scoping study is to provide an overview of the challenges of deployment of ICT-based support solutions delivered over the internet for informal caregivers of older people, which is, to the best of my knowledge, an unexplored field within the literature. Hence, this scoping review narrows the gap in the literature with respect to the ICT solutions designed for informal caregivers and the most frequently reported challenges for the deployment of these solutions. Moreover, by synthesizing the literature across the challenges of the deployment of ICT solutions delivered over the internet for informal caregivers of older people, this scoping review aims to provide relevant recommendations on how to overcome these challenges in order to guide future development of ICT solutions for informal caregivers.

Methods

Study Design

To carry out this scoping review, Arksey and O'Malley's methodological framework [22,23] for conducting scoping reviews was followed. The five stages outlined by Arskey and O'Malley's framework are as follows:

- Identification of the research question
- Identification of relevant studies
- Selection of relevant studies
- Charting the data from the selected literature
- Collating, summarizing, and reporting the results

The identified research topic includes a wide range of study designs addressing contexts in many countries as well as different technology solutions and a population of caregivers caring for older people with different chronic conditions. In order to comprehensively synthesize evidence to map this broad, complex, and emerging field of study, this framework has been selected as it is an appropriate approach to map a complex research topic and explore studies that use various methodologies, which is expected to be the case in this research topic [22,23]. Khalil et al [24] suggested using this inclusive

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approach in conducting scoping reviews to avoid potential exclusion of important information. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines have been followed (as far as relevant for a scoping review according to the PRISMA extension for scoping reviews) to verify the structure and content of this scoping review [25]. The checklist for the reported items according to the PRISMA extension for scoping reviews can be found in Multimedia Appendix 1.

Stage 1: Identifying the Research Question

The research question for this scoping review was identified from a preliminary scan of the literature and meetings with different stakeholders representing national level caregiver organizations, researchers, and experts from the European Association Working for Carers (Eurocarers) also involving research centers working in these areas, the Centre for Socio-Economic Research on Ageing of the Italian National Institute of Health and Science on Ageing (IRCCS-INRCA), University Medical Center Groningen, and the Department of Economics and Social Sciences of Marche Polytechnic University. Due to the rapid technological change in recent years, there is a lack of consensus in the academic literature on the challenges faced by informal caregivers—and specifically those who care for dependent older adults living at home with chronic conditions—in using ICT-based support solutions. Hence, the following research questions have been developed for this scoping review: What are the challenges of the deployment of ICT-based support solutions delivered over the internet for informal caregivers of older people? What are the recommendations for overcoming these challenges?

Stage 2: Identification of Relevant Studies

In order to capture the most relevant research studies in different domains (medical, engineering, social, economic, etc) on the challenges faced by informal caregivers of older people in using ICT solutions, the following databases were used to locate the relevant literature, as they contain relevant works in different domains: PubMed, IEEE library, and Scopus. Due to the rapid technological change in recent years, date restrictions were set in the period from January 1, 2015, to December 31, 2019, to capture recent and up-to-date relevant literature on ICT solutions. In order to address the components of the research questions, keywords and search terms were classified into four main groups:

- Keywords representing variations of the term informal caregiver (eg, informal carer, family caregiver)
- Keywords representing variations of the term older people (eg, old, aged)
- Keywords representing variations of the term challenges (eg, problems, barriers)
- Keywords of relevant ICT (eg, web, internet)

An overview of the different groups of keywords is presented in Table 1. Keywords were searched using Boolean operators. The search strategy can be found in Multimedia Appendix 2.

Table 1. Keywords and search terms.

Keywords	Search terms
Group 1	Family carers, informal caregivers, informal carers, family caregivers
Group 2	Old, elderly, aged, senior, older people
Group 3	Barriers, obstacles, challenges, problems, difficulties, complications, concerns
Group 4	Web, internet, online platform, information technology, mobile application, information and communications technology, ICT[a]

[a]ICT: information and communications technology.

Stage 3: Selection of Relevant Studies for the Review

In order to best address the indicated research questions, inclusion and exclusion criteria have been identified.

The inclusion criteria were as follows:

- Publications in English language
- Studies with research aimed at investigating the use of ICT-based support solutions delivered over the internet, such as web platforms and mobile apps, for informal caregivers
- Literature focused on informal caregivers of dependent older individuals. The main focus of this scoping review is studies dealing with ICT solutions that address caregiver needs, relieve pressure on caregivers, and give remote access to information and training about caring-related issues
- Research studies using different methodologies (qualitative, quantitative, and systematic reviews) as well as theoretical papers

The following exclusion criteria were applied:

- Studies focused on informal caregivers of pediatric patients and disabled adults
- Studies focused on professional or paid caregivers
- Studies on other assistive technologies that are not delivered mainly over the internet (eg, assistive robots)
- Studies that took place in nursing homes or care facilities, as the main focus of this scoping study is the informal caregivers of older adults living at home

The database searches retrieved 454 studies for consideration. After reviewing further publications suggested by researchers and experts from Eurocarers, INRCA-IRCCS, University Medical Center Groningen, and the Department of Economics and Social Sciences of Marche Polytechnic University and reviewing the studies' reference lists, an additional 6 studies were identified through these external sources. After removing duplicates, 359 studies remained.

Thereafter, a 2-stage process was followed. During the first one, the retrieved studies were screened by title and abstract to

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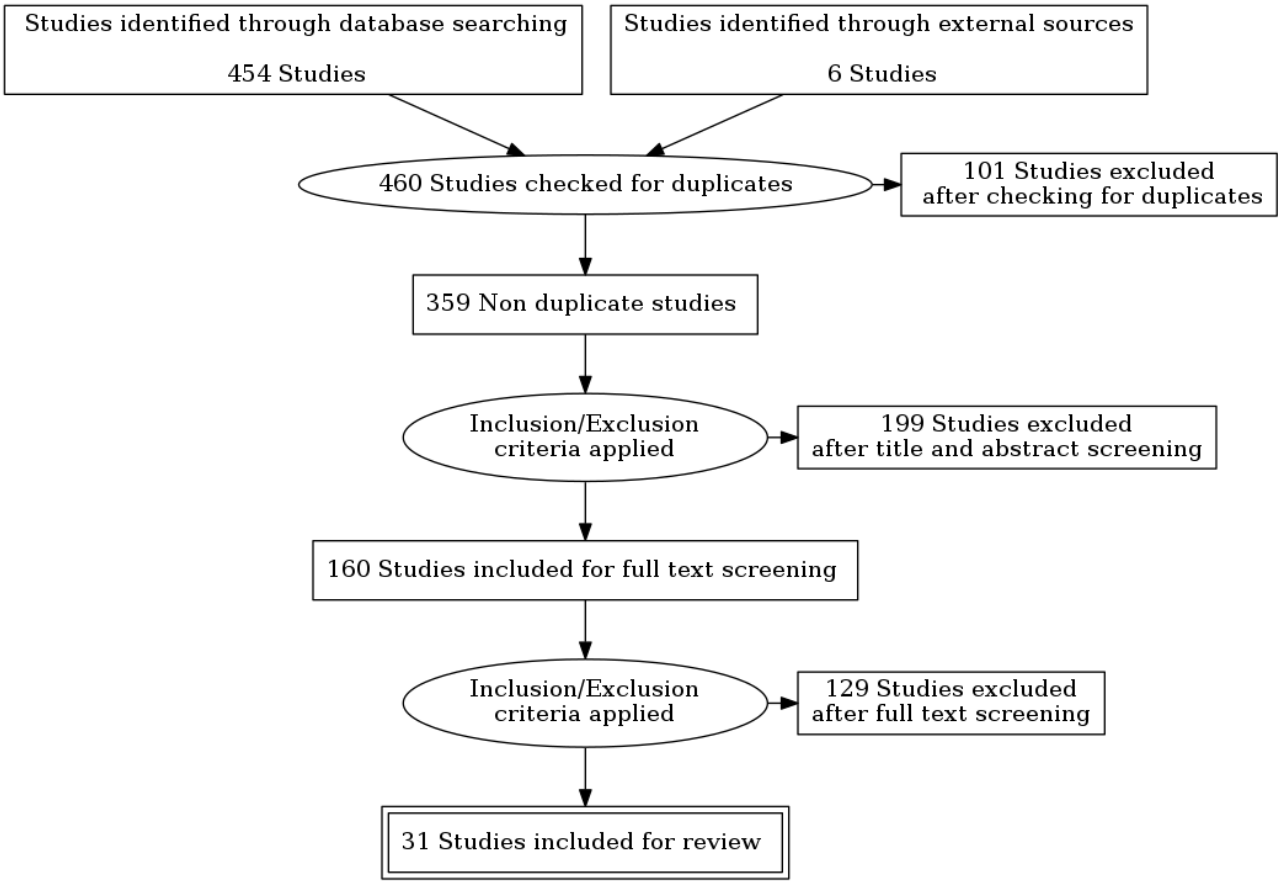
determine whether they met the selection criteria. In this first stage, 199 studies were excluded after title and abstract screening, and 160 publications identified for full text reading. In the second stage, 31 articles met the selection criteria and were included for the scoping analysis. In order to effectively manage the process of literature identification, citations obtained from the searches were imported into EndNote software (Clarivate Analytics) and Zotero software (Center for History and New Media at George Mason University) for reference management. Consequently, a master citation database was constructed to collate all the citations from various sources. Built-in functions of the software allowed duplicates to be easily detected. As consistent with the scoping review approach [22,23], the methodological quality of the published articles was not a selection criterion. This enabled the inclusion of a range of development, implementation, and evaluation studies using different methodologies. The overall study selection workflow is illustrated in Figure 1.

Figure 1. Study selection workflow.



Stage 4: Charting the Data

Data charts were created to organize information from the included studies. In line with Arksey and O'Malley's methodological framework, data entered for each study included authors and publication year, study type and methodology, study location, study aim, condition of cared-for family member, caregiver sample, and relationship of the caregiver to the care recipient.

Out of the 31 studies included in this scoping review, 17 were qualitative studies, 4 were quantitative studies, 1 was a systematic literature review, 1 was an integrative literature review, and 8 used mixed methods. Of these 31 studies, 10 studies were conducted in the United States, 4 studies in Canada, 3 studies in the United Kingdom, 3 studies in the Netherlands, 3 studies in Sweden, 3 studies were international, 2 studies in Germany, and 1 each in Spain, Italy, Poland, Denmark, France, and Australia. A summary of the information for each included publication is shown in Table 2.

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Table 2. Summary of the information for the included publications.

Authors	Year	Study type and methodology	Study location	Study aim	Condition of cared-for family member	Caregiver sample	Relationship of the caregiver to the care recipient[a]
Allemann et al [26]	2019	Qualitative study with focus groups	Sweden	Explore the perceptions of ICT[b] solutions as supportive solutions among informal caregivers of persons with heart failure	Heart failure	23	Spouse/partner: 22; Child: 1
Andersson et al [27]	2017	Qualitative exploratory descriptive study based on semistructured in-depth interviews	Sweden	Describe working informal caregiver experiences of having access to the web-based family care support network	Different conditions	9	Spouse: 1; child: 7; in-law: 3; niece:1
Austrom et al [28]	2015	Qualitative longitudinal study with focus groups	US[c]	Assess the feasibility and acceptability of a web-based video support group offered in real time for informal caregivers of persons with dementia	Dementia	5	Spouse: 4; parent: 1; friend: 1
Barbabella et al [29]	2018	Mixed-methods sequential explanatory study with structured questionnaires and focus groups	Germany, Italy, and Sweden	Assess the use and usability of a psychosocial web-based program for informal caregivers	Different conditions	118	Spouse/partner: 34; child/child-in-law: 67; other: 17
Bergström and Hanson [30]	2018	Integrative literature review	International	Explore studies concerning ICT support of adult carers of older people	N/A[d]	N/A	N/A
Boessen et al [31]	2017	Mixed-methods study with semistructured interviews and questionnaire	The Netherlands	Test the usability and perceived value of an online platform that aims to support the communication and collaboration between informal and professional caregivers of patients with dementia	Dementia	7	Spouse/partner: 1; child: 6
Boots et al [32]	2016	Exploratory mixed-methods study with focus groups, interviews, and questionnaire	The Netherlands	Development and initial evaluation of a web-based support solution for informal caregivers	Early-stage dementia	28	Spouse: 22; child: 2; child-in-law: 2; sibling: 1; friend: 1
Coffey et al [33]	2017	Qualitative study with semistructured interviews	US	Identify preferred sources of health information for informal caregivers	Traumatic brain injury, spinal cord injury, or burn injury	32	Not reported
Cristancho et al [34]	2015	Mixed-methods unblinded monocentric pilot RCT[e]	France	Evaluate the efficacy and acceptability of a web-based psychoeducational program for informal caregivers of persons with Alzheimer disease	Alzheimer disease	49	Not reported
Dam et al [35]	2017	Qualitative study with semistructured interviews	The Netherlands	Test the development and feasibility of an online social support intervention for informal caregivers of people with dementia	Dementia	23	Not reported
Duggleby et al [36]	2019	Mixed-methods secondary analysis study	Canada	Compare users and nonusers of a web-based intervention for informal caregivers of older people	Alzheimer Disease	92	Not reported
Gaugler et al [37]	2016	Mixed-methods study with survey and semistructured interview	US	Test the feasibility of an online resource for dementia caregivers	Dementia	30	Not reported
Gibson et al [38]	2015	Qualitative study with semistructured interviews	UK[f]	Explore the everyday use of ICT by people with dementia and their families	Dementia	26	Not reported

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Authors	Year	Study type and methodology	Study location	Study aim	Condition of cared-for family member	Caregiver sample	Relationship of the caregiver to the care recipient[a]
Grossman et al [39]	2018	Quantitative content analysis study	International	Identify mobile apps geared toward caregivers of older adults, catalog features, and suggest best practices for adoption	N/A	N/A	Not reported
Heynsbergh et al [40]	2018	Qualitative study with focus groups and semistructured interviews	Australia	Understand how digital technology may be used to address informal caregiver needs	Cancer	45	Spouse: 29; parent: 13; other (relative/friend): 3
Holden et al [41]	2018	Qualitative study with semistructured interviews	US	Understand the current personal health information management practices in informal caregiving for adults with and without dementia	Dementia	10	Not Reported
Kales et al [42]	2017	Qualitative study with focus groups	US	Develop a caregiver-focused, web-based program to assess and manage behavioral and psychological symptoms of dementia	Dementia	26	Adult child: 15; spouse: 6; other relative: 5
Kim [43]	2015	Quantitative cross-sectional and descriptive correlational design study using a secondary analysis	US	Understand internet use among dementia informal caregivers	Dementia	450	Spouse: 29; parent: 15; child or grandchild: 335; other type of relative: 38; friend/nonrelative/neighbor: 29; missing data :4
Núñez et al [44]	2016	Pilot randomized controlled pre-post	Denmark, Poland, and Spain	Assess the satisfaction of the informal caregivers with an ICT platform	Dementia	61	Not reported
O'Connor et al [45]	2016	Qualitative exploratory study with focus groups and interviews	UK	Explore barriers experienced by participants during the co-design of mobile app for informal caregivers	Dementia	16	Not reported
Phongtankuel et al [46]	2018	Qualitative study with semistructured interviews	US	Explore informal caregiver receptivity and concerns in using mHealth apps	Different conditions	80	Child: 46; spouse:10; other relative: 19; friend: 5
Ploeg et al [47]	2018	Qualitative study with semistructured interviews	Canada	Understand how web-based support help informal caregivers	Multiple chronic conditions	56	Spouse/partner: 31; son/daughter :22; daughter-in-law: 2; grand-daughter: 1
Schaller et al [48]	2016	Mixed-method design with questionnaires and interviews	Germany	Assess the usefulness and impact of the eHealth Monitor Dementia Portal service in the dementia care	Dementia	25	Spouse:11; child: 9; relative: 5; grand-daughter: 1
Schulz et al [49]	2016	Quantitative study with online survey	US	Assess whether and how much informal caregivers are willing to pay for technologies designed to help monitor and support care recipients	Different conditions	512	Not reported
Sriram et al [50]	2019	Systematic review	International	Explore the positive and negative aspects, knowledge, acceptance, and ethical issues in the use of assistive technology by caregivers of persons with dementia	N/A	N/A	N/A
Tonsaker et al [51]	2016	Qualitative study with focus groups	Canada	Investigate how caregivers access and use information on the internet about caregiving and their perspectives on the design and features of a new personal health experiences website	Different conditions	16	Not reported

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Authors	Year	Study type and methodology	Study location	Study aim	Condition of cared-for family member	Caregiver sample	Relationship of the caregiver to the care recipient[a]
Turk et al [52]	2019	Qualitative study with focus groups and semistructured interviews	UK	Explore the perceived usefulness and ease of use of a personalized web-based resource for informal caregivers	Different conditions	50	Not reported
Vaughan et al [53]	2018	Mixed-methods study with survey, focus groups and semistructured interview	US	Examine use and perceptions of a web-based social support intervention for informal caregivers	Different conditions	211	Spouse/partner: 186; other: 31
Walker et al [54]	2016	Qualitative study with focus groups	US	Gain insights into how older people and their families manage health information and communication	Different conditions	23	Not reported
Werner et al [55]	2017	Qualitative study with focus groups	US	Identify barriers to information needs of informal caregivers to manage dementia-related behavioral symptoms	Dementia	26	Not reported

[a]Some participants in some studies cared for multiple family members. Therefore, counts do not add up to the sample size.

[b]ICT: information and communication technology.

[c]US: United States.

[d]N/A: not applicable.

[e]RCT: randomized controlled trial.

[f]UK: United Kingdom.

Stage 5: Collating, Summarizing, and Reporting the Results

NVivo software version 12 (QSR International) was used to collect and organize study data. Full articles were imported as pdf files into NVivo software program for data extraction, analysis, and coding. The analysis took place through an iterative process of combining, categorizing, summarizing, and comparing information across studies. Through this iterative process, relevant information was identified and coded under emergent broader themes as it pertained to each of the research questions. Inductive thematic analysis was conducted as described by Braun and Clarke [56] to analyze the texts from the included studies. Patterns of challenges of the deployment of ICT solutions delivered over the internet for informal caregivers of older people were filtered out from an initial literature search and the previous meetings with experts in the field to develop an optimal category system. If challenges were found that did not fit into any previously known pattern, categories were iteratively added [23,57]. For each identified challenge, a list of recommendations on how to overcome it was created based on the findings of this scoping analysis and the suggestions provided by the reviewed studies as a guide for future development, research, and innovation in the area of ICT solutions for informal caregivers.

Results

Emerging Themes

This section provides a detailed description of the emerging themes around the challenges influencing the deployment of ICT solutions for informal caregivers that rose from the analysis of the included studies. According to the analyzed studies, four major categories of challenges could be identified:

- Technology-related challenges
- Organizational challenges
- Socioeconomic challenges
- Ethical challenges

Table 3 provides an overview of the identified challenges, showing the prevailing theme and the possible co-themes for each challenge. The categories were used to organize identified challenges as commonly presented in the studies reviewed. Under each individual theme, the challenges were ordered from the least overlapping (ie, most specific to the relevant theme) to the most overlapping (ie, least specific to the relevant theme). Due to the complexity of ICT and the interconnectedness of the identified challenges, a nonoverlapping categorization of individual identified challenges was not possible. In order to optimize the classification system, the categories were refined through several reiterations of the revision process. Each of the identified challenges was assigned to the most prevailing theme and additional possible co-themes. For instance, the challenge privacy came under the prevailing theme ethical challenges, as the abuse of data leads to violation of ethical principles, but it also fell into the additional possible co-theme technology-related challenges, as ICT solutions need security authentication measures and strong encryption mechanisms.

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Table 3. Overview of the identified challenges with the prevailing theme and the possible co-themes for each challenge.

Challenge	Type of challenge			
	Technology-related	Organizational	Socioeconomic	Ethical
Design and usability of technology	x[a]			
ICT[b] solutions are time-consuming	x			
ICT solutions lack specificity	x			
ICT solutions are not integrated in different devices	x			
ICT solutions don't provide diverse content	x			
Distrust in technology	x	y[c]		
Digital illiteracy	x	y	y	y
ICT may replace other support measures for informal caregivers		x		
Lack of awareness		x		
Lack of Interoperability and fragmentation of support solutions	y	x		
Gap between research and ICT-based support solutions providers	y	x		
Funding and cost of technology		y	x	
Sustainability and lack of business models		y	x	
ICT may create inequality			x	y
Poor ICT infrastructure	y	y	x	
Autonomy				x
Privacy	y			x
Technophobia and dehumanization of care	y	y		x

[a]x: prevailing type of challenge.

[b]ICT: information and communication technology.

[c]y: overlapping with additional possible co-themes.

In the following, a brief description is provided for each of the subdimensions identified for each macro-challenge.

Theme 1: Technology-Related Challenges

The progress that has been taking place in developing ICT solutions for informal caregivers has been widely recognized [15-21]. However, many informal caregivers find it challenging to incorporate such technologies into their daily work routines because of the struggles experienced with the technological component of the ICT-based solutions (eg, the difficulty in using technology solutions developed for informal caregivers and their poor design). This theme provides an overview of the identified challenges related to this issue.

Design and Usability of Technology

In the literature reviewed, informal caregivers reported technical troubles related to the design and usability of the solutions [31,35,39,44]. With regard to the former, the design process plays an important role in ICT use, acting as a barrier or a facilitator [39]. Many informal caregivers experience difficulties in navigating ICT solutions, due to the complexity of the design of technology [58]. This is partly due to the fact that informal caregivers are not included in the design of ICT-based support solutions even though these solutions should be co-designed with end users [58]. Gélinas-Bronsard et al [58] reported that this type of design may constrain informal caregiver behavior accordingly and inadequately reflect their needs as users of ICT solutions.

As for the second issue, many informal caregivers report challenges related to the usability of the solutions. They include aspects such as navigation through the menus [44], help and search options [44], high battery consumption of some apps on smartphones [31], insufficient instructions to participants regarding the use of the different functionalities of the solutions [31], and complex log-in procedures [35]. The inefficiency deriving from the difficulties experienced by caregivers due to either design- or usability-related issues decreases the overall ease of using ICT solutions [35].

Information and Communication Technology Solutions Are Time-Consuming

In the reviewed literature, informal caregivers find ICT-based supporting solutions to be time-consuming [33,39,43,44]. This time consumption may overload the caregiving daily routines instead of supporting them and thus increases the burden [36]. Furthermore, informal caregivers are a group of people for whom time is typically strained, hence they prefer simple and easy-to-operate technologies [39]. When caregivers spend longer times providing direct caregiving tasks, they do not have the time or energy to search for information and seek support via the internet [33,39,43,44].

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Coffey et al [33] mentioned that informal caregivers have very little extra time to participate in online activities such as calls and webinars and they avoid spending too much time using complicated technologies. This is in line with the findings of another reviewed study by Nunez et al [44] where informal caregivers found the supporting solution in the study to be time-consuming given the solution could not be integrated with their existing medical records, which was perceived as a complication by them.

Information and Communication Technology Solutions Lack Specificity

Technology solutions are not optimized to specific informal caregiver needs as it could be hard to recognize themselves in the information provided through ICT [26]. The content delivered via ICT solutions is often static and not specific to caregiving needs [34,41]. The literature reported that the experience of seeking information about caregiving situations using ICT solutions appeared to be a chaotic and confusing process, as informal caregivers need to access multiple information routes to get the information they need [34,37,38,55]. In many studies, informal caregivers reported difficulties in finding specific and up-to-date information related to their caregiving situation which adapts to changing needs over time [41,48,55].

Information and Communication Technology Solutions Are Not Integrated in Different Devices

Some ICT services are only available via single channel (eg, web) although informal caregivers might use other devices (eg, tablets, smartphones) [35,52]. Turk et al [52] reported that many informal caregivers use devices other than computers to access online services such as tablets and smartphones to overcome some of the extrinsic hardware barriers to accessing the service.

Information and Communication Technology Solutions Do Not Provide Diverse Content

The content delivered on many ICT solutions is basic (eg, only textual content rather than video content) [26,52]. ICT-based support solutions lack visual graphics such as video content, which is necessary to mitigate verbose text and help informal caregivers with language barriers to access the content [52].

Distrust in Technology

Some informal caregivers don't feel confident about the information provided via ICT solutions [41,55]. Informal caregivers reported their concerns about the quality of the content presented via ICT solution [33,34,51]. The content is almost superficial, and finding credible concrete information for informal caregivers still proved to be a challenging task [33,34]. Some studies report that some informal caregivers avoided networking via ICTs and sharing experiences with other informal caregivers who were previously unknown to them as they prefer to have previous knowledge of potential peer contacts [27,41].

Digital Illiteracy

Digital literacy is a set of skills associated with the use of ICT that every individual should develop to be able to perform in a computerized society [59]. Many informal caregivers are middle-aged to older people with a low to middle educational level [16], and these sociodemographic characteristics are often associated with a low level of digital skills, which could prevent them from benefiting from ICT [39].

The literature identifies digital illiteracy as a major challenge for informal caregivers as it increases the need for additional time and effort to adopt a new technology [26-29,36,44,52,58]. Lack of digital skills is found to be a main barrier for informal caregivers in using ICT solutions in many studies analyzed in this review [26,28,29,31,37,48]. For example, as reported in a study by Barbabella et al [29], informal caregivers in their study sometimes avoid chatting and networking due to experiencing the ICT-based support solutions as technically challenging for them as they have insufficient digital skills. Boessen et al [31] reported that the limited use of ICT solution in their study was due to a mismatch between informal caregiver digital competence and technology requirements of the solution.

Theme 2: Organizational Challenges

There is a common concern in the literature [26,27,31,43,52,54,58] that there are many organizational gaps in terms of the fragmentation of ICT-based support solutions for informal caregivers, lack of coordination between statutory support solutions for informal caregivers, and lack of awareness of the availability of these solutions. This theme highlights some of these organizational challenges that fall between the micro- and macro-level.

Information and Communication Technology May Replace Other Support Measures for Informal Caregivers

Informal caregivers fear that ICT support solutions might substitute other statutory forms of support that they are already receiving, thus ending up reducing the overall support at their disposal [52]. It was noted that informal caregivers may be hesitant to adopt ICT-based support solutions unless they are assured that these solutions will not affect their rights in other statutory support as respite care, access to training, and recognition of skills and work-life balance measures [43,52].

Lack of Awareness

Informal caregivers perceive a lack of relevant information on the available ICT-based support solutions and their benefits. Policy makers, health care professionals, and other stakeholders lack awareness and/or are unconvinced of the opportunities that ICTs bring to all the actors involved in home care provision [38,52,58]. Lack of awareness of ICT solutions available to informal caregivers means that informal caregivers are unlikely to access these solutions, and this could have an impact on the number or severity of unmet support needs [40]. The issue of the lack of awareness of ICTs may be particularly pertinent to older informal caregivers [52]. This imbalance suggests that greater efforts need to be made to reach this population and show them the value of this technology for their specific needs [39].

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Lack of Interoperability and Fragmentation of Support Solutions

Interoperability is the ability of different information systems, devices, and apps (systems) to access, exchange, integrate, and cooperatively use data in a coordinated manner, within and across organizational, regional, and national boundaries to provide timely and seamless portability of information and optimize the health of individuals and populations globally [60]. Some countries lack standards and regulations regarding the deployment of ICT in health care which leads to fragmentation of services, and many ICT solutions for informal caregivers lack the ability to exchange and make use of information among systems and software [31,54,58]. The lack of interoperability between the digital health information systems in many countries and the ICT-based support solutions is a challenge for the deployment of ICT solutions, as the inability to integrate different support solutions for informal caregivers entails double recording of information which limits the use of these solutions [31,54,58].

Gap Between Research and Information and Communication Technology Solutions Providers

The reviewed literature acknowledges that research that assesses the use of technology for informal caregivers is still based mainly on pilot programs, and further assessment of these programs is needed to understand the main findings and possibly enlarge their scope of application [26,27,29,39,51]. Moreover, most of the informal caregiving ICT solutions currently on the market do not seem to have been developed with the guidance of caregiving researchers [39]. Therefore, there may be gaps between ICT solution features and empirical findings regarding informal caregiver effective means of intervention [39].

There is also a knowledge gap with regard to how informal caregivers perceive ICT in their everyday life in relation to these needs [26]. The insight into how ICT is perceived by informal caregivers is important knowledge that could be used in developing interventions to support informal caregivers as well as supporting the implementation of ICT [26,39]. Andersson et al [27] argued that the paucity of research exploring informal caregiver experiences increases the risk of implementing ICT solutions that do not address the actual support preferences, concerns, and perceptions of the informal caregiver. This gap may discourage informal caregivers from using ICT solutions [26,27].

Theme 3: Socioeconomic Challenges

The literature identifies a series of socioeconomic issues that might have a negative influence on the deployment of ICT-based support solutions delivered over the internet for informal caregivers of older people. Questions such as who should fund ICT solutions for informal caregivers and whether a successful business model can be demonstrated for these solutions are common in the literature [26,36,38,42,44,49,52,58]. In the following, some of the challenges related to this category of issues are highlighted.

Funding and Cost of Technology

Lack of financial availability to invest in the acquisition of technologies is perceived as a barrier by informal caregivers. They tend to believe that governments should pay for the delivery and deployment of technology solutions [49]. Informal caregivers also indicate that waiting lists for publicly funded programs significantly delay the access and procurement of ICT solutions [38,58].

Sustainability and Lack of Business Models

The lack of business models and evidence on the long-term impact and sustainability of ICT solutions beyond trials and pilots leads to considerable variations in the perceived role and importance of such technologies from the point of view of users and health care providers as well as policy makers [30,42,49,58].

Gélinas-Bronsard et al [58] argued that sustainability is a main challenge to the deployment of the ICT solutions, and that this depends on technological, organizational, and political factors. Hence, obtaining government support for caregiving technologies will likely require strong evidence of successful and sustainable business cases [49]. On the other hand, few ICT solutions have been translated into a deliverable and sustainable service [42]. Further studies operating at a macro-level are therefore essential to develop more rigorous proofs about the sustainability of ICT solutions [30].

Information and Communication Technologies May Create Inequality

Informal caregivers from lower socioeconomic backgrounds may be less able to use ICT-based support solutions, which might lead to health inequality [58]. Moreover, the literature identifies a potential social justice issue if governments do not value these support solutions and a “user-pays” implementation—a pricing approach based on the idea that the most efficient allocation of resources occurs when consumers pay the full cost of the goods that they consume—must be used for ICT solutions. This would then limit the accessibility of the solutions to only those who can afford to pay [26,44,52,58].

Poor Information and Communication Technology Infrastructure

The lack of adequate ICT infrastructure in some countries acts as a barrier to the deployment of ICT for informal caregivers. Poor connectivity to the internet, particularly for informal caregivers in rural areas, is a barrier to the use of any ICT solutions delivered over the internet [36,58]. Poor ICT infrastructure and underperforming internet connection is also a concern for research with ICT solutions and possibly an exclusion criterion for participants in efficacy and effectiveness trials [36].

Theme 4: Ethical Challenges

The use of ICT solutions raises ethical concerns as issues of privacy and autonomy, among other moral issues, can be present. Questions about how ICT solutions are dehumanizing the care process, how the privacy of informal caregivers and their care recipients is protected, or the confidentiality of the information provided are raised throughout the literature [29,32,34,35,39,41,46,53].

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Autonomy

Ethical issues around who held the power of choice of use and discontinuance of ICT solutions arise from some studies [41,50,54]. Informal caregivers have concerns on controlling care recipients via ICT and on who has the power of choice of use and discontinuance of ICT [50]. This concern is related to the fear that constant monitoring of care recipients via ICT solutions is restricting their freedom [50]. There is a consensus among informal caregivers that care recipients must be involved as much as possible in the selection and use of ICTs [41].

Privacy

Informal caregivers have concerns on data ownership and privacy of the data [27]. Grossmann et al [39] point out that privacy concerns may be especially relevant to older informal caregivers, who voice the most concerns over the privacy and security of their information online. Literature shows that informal caregivers are concerned that if they have uploaded personal information this would compromise their safety and there might be the possibility of other people reading and accessing their private notes [27,52]. Concerns about online privacy and confidentiality are reported in many studies [42,46,48,49,52,58], showing that informal caregivers are often afraid that their personal data may be misused and manipulated.

Technophobia and Dehumanization of Care

Many informal caregivers are described as having technophobia, which is partially explained by the human contact that usually characterizes caregiving tasks and the fear that technology introduction could disrupt the caregiving nature [16]. Some informal caregivers are concerned that ICT solutions would replace the personal component of caring [50]. ICTs are perceived by informal caregivers as being too impersonal and entailing limited personal interaction and individualization, which could cause mistrust of information and cause a feeling of ICT solutions being less usable [26]. For some informal caregivers, it is considered important to have personal contact with the health care personnel to obtain individualized information [26,58]. The literature notes that informal caregivers view ICT solutions as beneficial in terms of helping with care, but less preferable to care provided by a real person [28,36,38,40]. Many studies reported the lack of desire of the informal caregiver to engage with ICT solutions because of the impersonal nature and their preference to access support using methods such as face-to-face settings [40,47,53].

Recommendations for Overcoming Challenges of the Deployment of Information and Communication Technology Solutions for Informal Caregivers

The emerging themes obtained during this scoping analysis allowed the extraction of insights that were grouped to create a series of recommendations for overcoming the challenges of deployment of ICT solutions based on the suggestions from the reviewed studies. Table 4 presents, for each identified challenge, recommendations to overcome this challenge based on the findings of this scoping analysis.

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Table 4. Recommendations to overcome each of the identified challenges.

Challenge	Recommendations to address or overcome the related challenge
Design and usability of technology	• Implement user-centered and participatory design strategies to improve usability [55] • Implement features that only add value for informal caregivers and avoid designing extra services of which not all are necessary [31] • Designers should involve older informal caregivers in the design process as much as possible as opposed to simply testing with younger demographics [39,50] • Designers should follow a design process that integrates feedback loops and adaptations based on specific needs of informal caregivers that may change over time [26,47,55]
ICT[a] solutions are time-consuming	• Combine as many useful features as possible into easy-to-use solutions in order to reduce informal caregiver load to help their productivity rather than hinder it [39] • Design care coordination tools in solutions to allow better coordination between multiple informal caregivers in providing care [37]
ICT solutions lack specificity	• Content introduced on ICT solutions for informal caregivers should be personalized, tailored, and specific to informal caregiver individual situations. Feedback loops should be integrated in the different solutions to improve tailoring and allow the content to be adaptive to changing needs over time [26,38,42,48,55] • Health and social care professionals should be consulted by ICT solutions designers when introducing content for informal caregivers to change the focus of these tools from providing general information to providing more specific information [27] • ICT solutions should provide dynamic, flexible, and more customizable content based on a structure that favors interaction with professionals and peers, such as online community support. They should facilitate creating new templates for information specific to the diagnosis and caregiving needs of the care recipient. This includes the ability to select or filter situationally pertinent information [26,34,41] • Informal caregivers should be able to compile information incrementally through the disease progression so as to not become overwhelmed [41] • ICT solutions for informal caregivers should match the needs of the informal caregivers, rather than informal caregivers being molded to match what ICT-based support solutions are available for them [50] • Dedicated virtual desks or online appointments through ICT solutions with informal caregivers would be helpful for getting more tailored health information, personalized advice, and counseling on clinical aspects of the care recipient [29]
ICT solutions are not integrated in different devices	• ICT solutions should be integrated in different devices, not only web-based. Web platforms should be optimized for use on devices other than computers such as tablets and smartphones [31,52]
ICT solutions don't provide diverse content	• Content delivered via ICT solutions should be diverse and not only textual. Video content including more visual graphics is important to mitigate verbose text and associated language barriers [26,52] • ICT solutions should provide content at accessible levels, reducing the use of complicated medical language and adjusting literacy levels by providing content at different knowledge levels [26,47,55]
Distrust in technology	• Solutions should use trusted information sources with evidence-based materials and provide citations for sources of information [55] • Training informal caregivers on how to evaluate ICT solutions is important to improve informal caregiver confidence in accessing quality information via support solutions [33] • Features that combine the utility of the internet with the expertise of medical professionals, including care-support hotlines, have been shown to improve informal caregiver trust in technology solutions [33]
Digital illiteracy	• Actions that build informal caregiver technical and computer skills early in the caregiving process are important for optimal use of available ICT-based support solutions [27,28] • Assessment of informal caregiver needs and digital skills is essential to educate and support informal caregivers on how to operate ICT solutions [26,44,52] • Training and technical support would need to be an ongoing activity and not a one-off task [29,58] • ICT solutions should also include educational programs to increase computer literacy with illustrated features embedded into the solutions to assist informal caregivers who have low computer literacy [36] • ICT solutions should be easy to use by accommodating a range of informal caregiver skills and abilities [41,42,53]
ICT may replace other support measures for informal caregivers	• ICT-based support solutions should be tailored in a coordinated way with other existing services such as respite care, access to training, and recognition of skills and work-life balance measures [9,43,52]
Lack of awareness	• Strategies are needed to raise awareness among all stakeholders, including policymakers, health care professionals, and informal caregivers and care recipients, about all support opportunities afforded by ICT [29,51] • Health professionals should consider providing informal caregivers with information on ICT solutions available to them as a means of additional support and guide them in terms of selecting solutions with evidence-based content [39]

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Challenge	Recommendations to address or overcome the related challenge
Lack of interoperability and fragmentation of support solutions	• Defining standards and regulations on interoperability of information and devices and enhancing integration with existing ICT systems in health and social care is necessary [41,54] • Integrating disparate systems rather than adding content to the multiple solutions one already uses (eg, calendar, personal health record, educational materials) [41] • Designing services for informal caregivers and care recipients that improve interoperability through interfaces that connect and communicate across institution-specific portals. Improving interoperability allows connecting informal caregivers and care recipients with multiple providers in the most care recipient–centered manner [54]
Gap between research and ICT solutions providers	• Future developers should collaborate with academic researchers to ensure that their solutions are designed with the current empirical evidence in mind [39] • User experience studies are needed to customize ICT solutions to the needs, desires, and abilities of the informal caregivers [39,40] • Future development of ICT solutions should consider a theory-based approach and how to best meet the complex transition-related needs of informal caregivers [45,47] • Research is needed to better understand the impact of ICT solutions for informal caregivers when used in combination with other forms of support, including professional and peer support [47]
Funding and cost of technology	• Policy makers and insurance providers should consider policies promoting the use of ICT solutions that have been shown to be effective at supporting and improving informal caregiver health outcomes via subsidies or other incentives [39]
Sustainability and lack of business models	• ICT solutions must be offered early in the caregiving process, and its support functions need to be adaptable over the course of the caring trajectory [27] • Identification of sustainable business models, exchange of good practices, collection of evidence, and transferability of optimal solutions among localities, regions, and countries are all important to continue allocating public funding for initiatives [49]
ICT may create inequality	• Promote digital inclusion policies, providing access and promoting the use of ICT solutions for informal caregivers [26,44,52] • Foster continuous development of digital competencies in informal caregivers [29,58]
Poor ICT infrastructure	• Governments and policy makers should allocate funding for improving ICT and digital infrastructures [39,43,49]
Autonomy	• Informal caregivers should be given the choice to accept or refuse access to ICT solutions. Access to all ICT solutions should be regulated by the primary informal caregiver and the care recipient [41] • Care recipients should be involved as much as possible in the selection and use of ICT solutions [50]
Privacy	• Involving municipal family care advisors known to the users of ICT solutions in the administration of the tools enhances experiencing ICT as safe and secure [27] • ICT solutions need to focus on standard development guidelines and security authentication measures such as passwords, strong encryption mechanisms, and informative privacy policies [39,46]
Technophobia and dehumanization of care	• Blending online support with regular face-to-face support can increase the acceptance of ICT solutions [32] • Involving different health care professionals in the provision of professional support leads to overcoming possible skepticism and lack of knowledge about ICT solutions [29,32,34] • Guidance by professional moderators or volunteers might provide practical hands-on advice to informal caregivers and increase their engagement with ICT solutions [35]

[a]ICT: information and communication technology.

Table 5 provides an overview of the prevailing perspective and additional possible perspectives for intervention for each challenge. This overview aims to identify at which level possible solutions to each specific challenge might take place. Solutions may take place at the following levels: system (macro), provider (meso), and user (micro). For instance, possible intervention perspectives for the challenge "lack of awareness" may be at the user level, as informal caregivers are unlikely to access these solutions without awareness and information on the available ICT solutions and their benefits, but they could also be at the system and provider levels, also needed to raise awareness among stakeholders, including policy makers and health care professionals, about support opportunities afforded by ICT.

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Table 5. Overview of the prevailing and possible additional levels of interventions recommended to address the identified challenges.

Challenge	Level of intervention		
	System (macro)	Provider (meso)	User (micro)
Design and usability of technology	y[a]	x[b]	y
ICT[c] solutions are time-consuming		y	x
ICT solutions lack specificity		x	
ICT solutions are not integrated in different devices		x	
ICT solutions don't provide diverse content		x	
Distrust in technology			x
Digital illiteracy			x
ICT may replace other support measures for informal caregivers	y	y	x
Lack of awareness	y	y	x
Lack of interoperability and fragmentation of support solutions	x	y	
Gap between research and ICT solutions providers	x	y	
Funding and cost of technology	x	y	
Sustainability and lack of business models	y	x	
ICT may create inequality	y	y	x
Poor ICT infrastructure	x		
Autonomy		y	x
Privacy		y	x
Technophobia and dehumanization of care	y	y	x

[a]y: additional possible perspectives for intervention.

[b]x: prevailing perspective for intervention.

[c]ICT: information and communication technology.

Discussion

Principal Findings

The purpose of this scoping review was to identify challenges related to deployment of ICT solutions delivered over the internet for informal caregivers of older people. Emerging themes for these challenges were divided and classified for better understanding. These insights were used to produce a series of recommendations for overcoming the challenges of deployment of ICT solutions delivered over the internet for informal caregivers of older people. The recommendations will contribute richly to future ICT developments for informal caregivers and for this rapidly growing technological context.

Challenges of Deployment of Information and Communication Technology Solutions for Informal Caregivers

The findings highlighted in this review demonstrate that deployment of ICT solutions delivered over the internet for informal caregivers of older people is coming with a variety of challenges. These range from specific challenges related to the technological component of the ICT-based service regarding design and usability of technology to organizational challenges such as fragmentation of support solutions to socioeconomic challenges such as funding of technology and sustainability of solutions to ethical challenges around autonomy and privacy of data. These findings confirm previous studies performed in the field and integrate them with a conceptually grounded classification system for organizing the different challenges into four specific thematic categories. Other studies have also highlighted the challenges of deployment of ICTs for informal caregivers [11,12,15,16]. Kluzer et al [15] mentioned that older informal caregivers with low or no digital skills have difficulties using ICT solutions and lack of a sustainable business model in ICTs is one of the major challenges of their deployment. Cucculelli et al [61] raised the importance of sustainability models in ICTs and digital innovation. The lack of successful business models in the case of ICT solutions for informal caregivers was one of the major challenges to the deployment of ICTs for informal caregivers in the European Commission's policy report on technology-based services support and long-term care challenges in home care [16]. One explanation for that could be the economic value of ICTs as support service for informal caregivers is not always a direct translation of the value found in other areas of activity where a sustainable business model could be identified [17].

The analysis reveals that challenges to deployment of ICT solutions delivered over the internet for informal caregivers of older people are diverse and overlap at the same time. The challenges of deployment of these solutions, although reported as separate issues in the literature, appear to be at least partially

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interrelated. For instance, the digital illiteracy of many informal caregivers means it takes more time to use ICTs so that, with caregiving demands, less time is available. Moreover, ICT-based support solutions are perceived by informal caregivers as being too impersonal causing distrust in these solutions, which leads in turn to a feeling that ICT solutions might be less usable.

Recommendations and Implications

Based on the categories of challenges and the overlap existing between the elements of challenges in each theme, recommendations were extrapolated. As shown in Table 4, each challenge on its own can suggest a series of relevant recommendations. The recommendations relevant to each specific challenge might take place at different levels of intervention.

With regard to the challenges related to the technological component of the ICT-based service, the main recommendations were to follow participatory design and involve older informal caregivers in the design process as much as possible as opposed to testing with younger users. Technology solutions that are user-friendly for younger adults may not be user-friendly for older users. This is in line with other studies demonstrating that participatory design increases the adoption of technology solutions and their use by the intended users [62]. Designers need to identify how technologies are incorporated into the everyday lives of informal caregivers and care recipients [30]. Designing care coordination tools in solutions is important to allow better coordination between multiple informal caregivers in providing care, which may introduce ICT-based support solutions as time-saving solutions rather than time-consuming tools [37]. Contents introduced in ICT solutions for informal caregivers should be personalized, tailored, and specific to individual situations of informal caregivers. In this context, feedback loops should be integrated in the different solutions to improve tailoring and allow the content to be adaptive to changing needs over time. Additionally, information delivered through ICT could cause added stress if not carefully worded. Therefore, when producing content via ICT solutions, questions such as whom it will reach and how the information could affect those reading it need to be properly addressed. Adapting information to the relationship the informal caregiver has to the care recipient is important, too [26].

An example of an ICT solution that responds to the challenges mentioned is a solution such as a web platform or mobile app that offers interactive tools allowing specific information to be provided to informal caregivers. The design of the solution should be interactive with feedback loops allowing immediate response to the needs of the informal caregivers, aiding in the decision process and selection of the most relevant information [63]. Content should be developed with a focus on the basic needs of daily life and supported by demonstration videos of procedures and audio documents [63]. The design must be intuitively based and should not require prior knowledge [64]. As many informal caregivers are middle-aged to older people, the text view should have a font size compatible with the characteristic limitations of old age and allow the user to adjust it depending on the device and the viewing distance [65]. The information should be clear and simple providing alternative text information with animation, video, and audio. Decreasing the number of pages informal caregivers must access is recommended in a solution, and consequently the workload, probability of errors, and time needed for using the solution will be reduced. Validation processes in accessing accounts that involve issues such as asking the user about a significant date should be avoided as that may be confusing and demotivating for older informal caregivers.

Another important recommendation in this theme addresses the suggestion to undertake actions on a large scale to equip informal caregivers with the needed digital skills. Lamura et al [12] highlighted the importance of improving older informal caregiver digital literacy based on an early assessment of their needs and digital skills. Research showed that older adults are capable of learning and acquiring digital literacy skills as long as they know the functional benefits related to ICT [59]. Thus, this is in line with another recommendation in this theme to combine the utility of the internet with the expertise of medical professionals, including care-support hotlines, to improve informal caregiver trust in technology solutions and their functional benefits.

This issue is also connected with the recommendations formulated to address and overcome organizational challenges. Health care professionals should consider providing informal caregivers with information on ICT-based support solutions available to them and guide them in terms of selecting the most appropriate solutions. In a study analyzing 12 of the most relevant ICT-based initiatives in Europe to support informal caregivers of older people living in the community [16], raising awareness of the opportunities provided by ICT-based services for informal caregivers among all stakeholders has been identified as one of the main policy recommendations. Public information campaigns are needed to increase knowledge about support opportunities afforded by ICT for informal caregivers. At the macro-level, defining standards and regulations regarding the deployment of ICT in health care is important to overcome the fragmentation of ICT solutions [41,54].

Furthermore, health information systems should start addressing how best to get information from care recipients and their informal caregivers into the systems. It is important to support bidirectional conversations instead of focusing only on getting information from health care systems out to care recipients and their informal caregivers. The cooperation of informal caregivers with information about their care recipients is required for health care professionals to be successful in their roles and impart appropriate professional advice [66]. The interaction of health care professionals and all parties with an interest in supporting informal caregivers such as caregiver advocacy organizations with informal caregivers becomes an integral part of the value chain that supports both communication and coordination. Hence, these parties should all be more engaged with developing ICT solutions to link them with informal caregivers.

Among the topics emerging in the socioeconomic challenges theme, one of the most frequently reported difficulties in the reviewed studies is the availability of adequate funding of ICT solutions and their sustainability over time. Governments should consider policies to fund ICT solutions that have been shown

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to be effective at supporting and improving informal caregiver health outcomes via subsidies or other incentives. In this context, it is crucial to promote an exchange of effective practices, collection of evidence, and transferability of optimal solutions among localities, regions, and countries, and across different bodies and organizations in order to optimize the deployment of ICT solutions [17]. Furthermore, ICT solutions must be offered early in the caregiving process, and its support functions need to be adaptable over the course of the caring trajectory [27]. Governments and policy makers should allocate funding for improving ICT and digital infrastructures. On the other hand, even though ICT-based support services have the potential to play a role in supporting caregivers, they are not likely, by themselves, to be a complete solution. To alleviate the burden and isolation that many informal caregivers experience, governments and policy makers should consider that other social support systems are needed for informal caregivers. ICT solutions should be tailored in a coordinated way with other existing services as respite care, access to training, and recognition of skills and work-life balance measures.

Finally, with regard to the ethical challenges associated with the deployment of ICT solutions, this review recommends that ICT solutions should be sensitive to informal caregiver privacy concerns and the extent to which a technology might undermine their autonomy, control, and dignity. In this context, blending online support with involving health care professionals in the provision of professional support leads to overcoming possible skepticism. Previous studies related to ICT solutions for informal caregivers have shown that caregivers embrace the connection with health care professionals to support them in their caregiving, and this connection also enhances experiencing ICTs as safe and secure solutions [67,68].

Limitations

Some limitations concerning this review need to be considered. First, a quality assessment of the methodology adopted by the selected papers was not used to exclude publications, and results from studies using a variety of study designs and author opinions were incorporated into the findings of this review. However, this is in line with the principles usually applied by the scoping review methodology, and all the publications included in this review are peer reviewed. Another limitation is that only one researcher conducted the data extraction and the analysis for this review. Hence, there is a potential that some data were not extracted. Also, a systematization of all the challenges of the deployment of ICT solutions for informal caregivers without any overlaps was not possible due to the complexity of ICTs. Although the highest possible quality standards for classification were followed in an iterative process, possible limitations in the analytical approach should be taken into account when interpreting the results. Moreover, considering recent developments in technology solutions, the classification of challenges may not cover all contexts where technology solutions (eg, assistive robots) are used on a minute-by-minute basis, and this may pose a different set of challenges. Furthermore, although a strict scoping review framework was followed, there is a chance that relevant research may have been omitted, especially when searching a large body of evidence produced in the form of non-English publications and grey literature.

Conclusions

Despite a growing interest in the potential offered by ICT solutions for informal caregiving, diverse and overlapping challenges to their deployment still remain. The deployment of ICT solutions for informal caregivers is accompanied by technology-related challenges such as the complexity of technology solutions and their poor design, which decrease the overall ease of using ICT solutions. Designers for ICTs for informal caregivers should follow participatory design and involve older informal caregivers in the design process as much as possible. A collaboration between designers and academic researchers is also needed to ensure ICT solutions are designed with the current empirical evidence in mind. In many studies analyzed in this review, a lack of digital skills has been found to be a main challenge for informal caregivers in using ICTs. The study concluded that taking actions to build informal caregiver digital skills early in the caregiving process is crucial for optimal use of available ICT solutions. Moreover, the lack of awareness of the potential added value and trust toward ICT-based support solutions requires strategies to raise awareness among all stakeholders—including policy makers, health care professionals, informal caregivers, and care recipients—about all support opportunities offered by ICT. Another frequently repeated challenge in the reviewed studies is the funding of ICT solutions and sustainability. On the macro-level, policies to fund ICT solutions that have been shown to be effective at supporting and improving informal caregiver health outcomes via subsidies or other incentives should be considered. Ethical issues such as dehumanization of the care process by ICT solutions and privacy protection of informal caregivers and their care recipients are also often reported throughout the literature. Informal caregivers should be given the choice to accept or refuse access to ICT solutions. In this regard, there is a necessity to involve health care professionals and municipal family care advisors known to the users of ICT in the administration of these tools in order to enhance the experience of ICT as a set of safe and secure tools.

The recommendations from this study can provide guidance and assistance for the deployment of ICT-based support solutions for informal caregivers, filling a gap in the currently available knowledge. Nevertheless, due to rapid technological innovation, more research needs to be conducted and guidelines for designing and developing ICT solutions should be made adaptable to continuous change, as new tools become available and health care delivery systems experience a technologically supported transition toward home care. More research is needed to measure the prevalence of using ICT as a source of care-related information among informal caregivers. Moreover, it is important to determine whether certain characteristics of informal caregivers such as their gender, relationship to the care recipient (eg, spouse/partner, child, friend), health status, or socioeconomic status appear to make a difference in their use of ICT to obtain care-related information. Understanding the sociodemographic and socioeconomic profiles of informal caregivers could help improve the quality of ICT solutions and tools by producing age- or gender-specific online information

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platforms. On the macro-level, further studies are necessary to ascertain the availability, efficiency, and sustainability of ICT-based support solutions. Research on impacts at these levels should be collected to complement those at user level and to convince policy makers to promote policy frameworks for the creation of ICT-based support solutions for informal caregivers.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews checklist.
[DOCX File , 106 KB - aging_v3i2e20310_app1.docx]

Multimedia Appendix 2
Search strategy.
[DOCX File , 12 KB - aging_v3i2e20310_app2.docx]

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Abbreviations

ICT: information and communication technology
IRCCS-INRCA: Centre for Socio-Economic Research on Ageing of the Italian National Institute of Health and Science on Ageing
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analysis

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Original Paper

Barriers and Facilitators to Implementing Web-Based Dementia Caregiver Education From the Clinician's Perspective: Qualitative Study

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Abstract

Background: Internet-based dementia caregiver interventions have been shown to be effective for a range of caregiver outcomes; however, little is known about how to best implement them. We developed iGeriCare, an evidence-based, multimedia, web-based educational resource for family caregivers of people living with dementia.

Objective: This study aims to obtain feedback and opinions from experts and clinicians involved in dementia care and caregiver education about 1 iGeriCare and 2 barriers and facilitators to implementing a web-based caregiver program.

Methods: We carried out semistructured interviews with individuals who had a role in dementia care and/or caregiver education in several key stakeholder settings in Southern Ontario, Canada. We queried participants' perceptions of iGeriCare, caregiver education, the implementation process, and their experience with facilitators and barriers. Transcripts were coded and analyzed using a grounded theory approach. The themes that emerged were organized using the Consolidated Framework for Implementation Research.

Results: A total of 12 participants from a range of disciplines described their perceptions of iGeriCare and identified barriers and facilitators to the implementation of the intervention. The intervention was generally perceived as a high-quality resource for caregiver education and support, with many stakeholders highlighting the relative advantage of a web-based format. The intervention was seen to meet dementia caregiver needs, partially because of its flexibility, accessibility, and compatibility within existing clinical workflows. In addition, the intervention helps to overcome time constraints for both caregivers and clinicians.

Conclusions: Study findings indicate a generally positive response to the use of internet-based interventions for dementia caregiver education. Results suggest that iGeriCare may be a useful clinical resource to complement traditional face-to-face and print material–based caregiver education. More comprehensive studies are required to identify the effectiveness and longevity of web-based caregiver education interventions and to better understand barriers and facilitators with regard to the implementation of technology-enhanced caregiver educational interventions in various health care settings.

(JMIR Aging 2020;3(2):e21264) doi:10.2196/21264

KEYWORDS

dementia; caregiver; online education; implementation science; internet; eHealth

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Introduction

Background

The prevalence of dementia is increasing, and more family caregivers are involved in caring for people living with dementia. Despite their key role, many caregivers may have little knowledge of the disorder, community resources, or the caregiving role. As a result of the impact of dementia on caregivers, the Canadian National Dementia Strategy, Ontario Dementia Strategy, Health Quality Ontario Quality Standards for Dementia, and other clinical guidelines highlight dementia caregiver education as an important component of quality care [1-6]. Most caregiver education is provided face-to-face during a clinical visit. Providing caregiver education in a clinical setting can be extremely challenging because of time constraints. The most common forms of caregiver education include referrals to community organizations (such as the Alzheimer Society), commercially available materials, or customized clinical handouts and pamphlets. Caregivers in rural communities may have no access to dementia specialists, and therefore, no opportunities for face-to-face education.

Internet-based caregiver intervention has emerged as a potential solution to address some of these challenges. A recent needs assessment outlined that caregivers were actively seeking trustworthy sources of information about dementia on the internet [7]. Various systematic reviews suggest that web-based interventions may result in a range of improved health outcomes for caregivers, including reductions in depression, stress, distress, and anxiety [8-11]. Other studies have identified that greater public education is needed for caregivers, and improved mechanisms are needed for busy clinicians to provide caregiver education [12].

We developed iGeriCare (Division of e-Learning Innovation, McMaster University), a multimodal e-learning intervention, to help educate family caregivers of people with dementia. It was developed by experts in dementia and web-based learning as well as family caregivers to help meet the needs of caregivers by improving their knowledge and skills as well as by raising awareness of strategies and services to improve their quality of life and that of the person with dementia. iGeriCare consists of 10 multimedia e-learning lessons, curated resources, a series of weekly *microlearning* emails with small segments of content to reinforce material from the lessons and monthly web-streamed live events that allow participants to post questions to subject matter experts. iGeriCare has been designed to assist health care providers in providing high-quality education efficiently and effectively to caregivers of people living with dementia. We applied best practices in e-learning instructional design, such as the use of instructional graphics, audio narration, and personalization, which have been shown to be more effective than e-learning methods that do not conform to best-evidence instructional design [13,14].

Objectives

Although web-based education may be an effective intervention, little is known about how best to implement it in various family caregiver education settings [15]. In this study, we performed a qualitative examination to identify recurrent themes, including facilitators and barriers, that might inform other organizations' planning and implementation efforts with regard to web-based dementia caregiver education. We report on factors affecting the implementation of caregiver education from the perspective of those involved in the clinical care of people with dementia and caregiver education.

Methods

Study Design

We conducted a qualitative study consisting of semistructured interviews with 12 individuals involved in dementia care and caregiver education and used a grounded theory approach [16-19]. We chose to use semistructured interviews as opposed to close-ended survey questions to allow participants the freedom to express their views in their own terms. We used the Consolidated Framework for Implementation Research (CFIR) to evaluate factors that could influence implementation effectiveness. It provides a pragmatic structure for approaching real-world issues and themes by bringing together key constructs from published implementation theories [20].

Setting and Timing

The study was conducted in several key stakeholder health care settings in Southern Ontario, Canada, including family medicine clinics, geriatrics and/or dementia clinics, geriatric psychiatry, and others. The interviews were conducted from October 31, 2018, to March 25, 2019.

Participants

A total of 12 participants were interviewed, each with a key role in dementia care and/or caregiver education in their organization. Participants provided written informed consent, and the protocol was approved by the Hamilton Integrated Research Ethics Board at McMaster University.

We targeted opinion leaders who actively work with caregivers from a range of disciplines, including geriatrics, neurology, psychiatry, family medicine, and community care. We targeted a wide range of practice settings, including hospitals, outpatient clinics, and advocacy organizations. An internet search was conducted to identify potential participants from a range of disciplines. For convenience, we stayed within Southern Ontario as we wanted to conduct the interviews in person. None of the participants were involved in the development of iGeriCare.

Data Collection

The interviews took place in or near the participants' own offices and were conducted by 2 female research team members: a research assistant (SA) and a research coordinator (LB). Both interviewers had extensive experience in conducting interviews. The principal investigator (AL) participated in 2 interviews. Participants were asked to review the iGeriCare website before their interview. If they were unable to review the website before their interview, they were given the opportunity to review it before beginning the interview. The interviewers used semistructured interview questions and asked clarifying questions as needed (Multimedia Appendix 1). A practice interview was conducted during the design of the interview guide. Participants' perceptions of iGeriCare and collateral

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implementation tools were explored in particular and web-based dementia caregiver interventions and approaches to caregiver education in general. The interviewers debriefed with the broader research team after each interview to identify the emerging themes and potential areas of exploration and focus for subsequent interviews. The interviews were between 30 min and 45 min in length and were audiotaped and transcribed verbatim. Only 2 research staff members (SA and LB) had access to the file linking transcripts with participants' identities.

Data Analysis

Transcripts were analyzed using a grounded theory approach [16-19]. The members of the research team reviewed an initial transcript to generate a list of concepts and domains to determine a preliminary inductive coding scheme [21]. To test the preliminary inductive coding scheme, the research team applied codes to an initial transcript and revised the codes, themes, and subthemes as necessary to yield a final coding scheme by consensus (Multimedia Appendix 2). Overall, 2 research team members then independently reviewed the transcripts and applied the codes to each transcript by labeling phrases on the hard copies. Coding differences between the primary coders were resolved by weekly discussions with the members of the larger research team until a consensus was reached. The coded transcripts were entered into the QSR International NVivo 12 qualitative data analysis software to facilitate coding and analysis of transcripts. The research team members compared the codes within and across interviews to align and map them with the domains and constructs in the CFIR. CFIR has been applied to a variety of other contexts (eg, health care delivery and process redesign, quality improvement, health promotion, and disease management) and health outcomes (eg, mental health, obesity, and blood pressure). It is most commonly applied to gain an in-depth understanding of participant experiences (eg, implementation processes, barriers, and facilitators to implementation) in innovation implementation [22].

Results

Participant Characteristics

A total of 14 individuals were initially invited to participate; 1 was unavailable for the interview and 1 did not respond to correspondence (Table 1). Of the 12 individuals that participated, 8 provided a substantial review of the iGeriCare intervention before being interviewed, whereas 4 individuals provided little to no review. The participants had the following disciplines or specialty roles: family medicine (n=3), geriatrics (n=3), nursing (n=2), neurology (n=1), geriatric psychiatry (n=1), general internal medicine (n=1), and social science (n=1). A total of 9 participants were physicians. We tried to engage regional opinion leaders; overall, 9 participants were affiliated with the host institution, McMaster University, whereas 3 participants were from other institutions or organizations. Saturation of themes was seen after 12 interviews.

We present the key findings within each of the 5 CFIR domains and the relevant constructs within each domain.

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Table 1. Participants' demographic information.

ID	Gender/sex	Reviewed website before interview	Workplace						
			Division	Role	Setting	Practice location	Dementia or memory clinic	Organization	McMaster affiliation
001	Male	Substantial review	Family medicine	Physician	Outpatient and/or community	Urban	Yes	Health care organization and university	Yes
002	Male	Substantial review	Family medicine	Physician	Outpatient and/or community	Urban	Yes	Health care organization and university	Yes
003	Male	Minimal or no review	Geriatrics	Physician	Outpatient and/or community	Urban	Yes	Health care organization and university	No
004	Female	Substantial review	Geriatric psychiatry	Physician	Outpatient and/or community and inpatient	Urban	No	Health care organization and university	Yes
005	Female	Substantial review	Nursing	Researcher	Outpatient and/or community	Urban and rural	No	University	Yes
006	Male	Minimal or no review	Neurology	Physician	Outpatient and/or community and inpatient	Urban	No	Health care organization and university	Yes
007	Female	Minimal or no review	Family medicine	Physician	Outpatient and/or community	Urban and rural	Yes	Health care organization and university	Yes
008	Female	Substantial review	Geriatrics	Physician	Outpatient and/or community and inpatient	Urban	Yes	Health care organization and university	Yes
009	Female	Minimal or no review	Geriatrics	Physician	Inpatient	Urban	No	Health care organization and university	No
010	Female	Substantial review	Nursing	Researcher	Outpatient and/or community	Urban and rural	No	University	Yes
011	Female	Substantial review	Social science	Coordinator	Outpatient and/or community and inpatient	Urban and rural	No	Nonprofit organization	No
012	Male	Substantial review	General internal medicine	Physician	Outpatient and/or community and inpatient	Urban	No	Health care organization and university	Yes

Intervention Characteristics

Intervention characteristics refer to the specific characteristics of iGeriCare [20].

Theme 1

Theme 1 is as follows: iGeriCare was generally perceived as a high-quality, trusted intervention for caregiver education, with many participants highlighting the relative advantage of a web-based format.

The *design, quality, and packaging* of iGeriCare was perceived by many participants as being expertly bundled, presented, and assembled, noting that it was a resource that was *trusted* and *valuable* [20]:

> *I really like this, partly because it's knowledge that has been vetted, so it's not the same as googling dementia and you really can't control what comes up and what doesn't. So, I like the fact that it's summarized it's at a level where it is easily digestible, and it's not something that is difficult for family members.* [Participant 001]

> *It's a very nice-looking website...from what I've seen it's very comprehensive. I mean like, you're hitting caregiver wellness, you're hitting apathy, you're hitting driving—you know, you're hitting promotion of brain health. I mean, it seems like, I don't see any gaps just from a superficial look at it. It looks like its gone through multiple passes and stuff. It looks very polished. It seems to me that a lot of work has gone into it.* [Participant 006]

Relative advantage refers to the participants' perception of the advantage of implementing iGeriCare versus an alternative solution [20]. Most participants perceived the web-based format and increased ease of access to facilitate dementia education for a wider caregiver audience as a *relative advantage* when compared with traditional current practice or formats:

> *I think with the videos and that sort of thing [iGeriCare] is a much better alternative. It's*

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> *something that allows them to sit and watch and say, 'oh that's a digestible portion of information that I can take.* [Participant 001]
>
> *I think it is important. We can't possibly educate everybody about all of this in the context of clinic nor does it always feel like the right place for it. People just sometimes need to learn on their own at home, and then come back with questions once they've had a chance to be exposed to it.* [Participant 002]
>
> *The hundreds of people that I've heard say in an education series, 'I wish my brothers were here', or 'I wish my father would have joined me.' And they're not coming through our door, and they're not going to their local chapter, or if they live in another part of the province—that they can access [iGeriCare].* [Participant 011]

A few participants did, however, voice concerns about the format, noting that much of their current caregiver education was delivered with more traditional approaches such as face-to-face delivery or printed pamphlets. In addition, there remains a perception that older adults do not use the internet or search the web for information:

> *Many of the older persons that we deal with are either not really that computer-savvy, maybe they spend a little bit of time on the internet and might play some games on their computer, but many of them don't use it to search for information. I think that's a younger generation kind of thing.* [Participant 007]

Theme 2

Theme 2 is as follows: iGeriCare is perceived as being readily usable, with minimal disruption to existing workflows, and it can be customized or revised as needed.

The iGeriCare intervention was seen to have minimal barriers to immediate implementation, aligning with the CFIR construct of *trialability*:

> *It will be helpful...I can see us having it up during our memory clinic.* [Participant 002]
>
> *I am thrilled, this is really phenomenal; I'm going to immediately start using this.* [Participant 006]
>
> *We're already using it. We have the [iGeriCare educational prescription pad], and I give it to families as I'm talking about supports.* [Participant 008]

The overall construct of *intervention characteristics* was perceived positively by most participants.

Outer Setting

The outer setting is the economic, political, and social context within which an organization resides [20]. The outer setting influences implementation and is often affected by changes in the inner setting.

Theme 1 is as follows: iGeriCare was seen to meet patient needs because of its alternative format and because the flexibility of *on-demand* web-based learning helps overcome the barrier of time constraint for both clinicians and caregivers.

The *patient needs and resources* construct identifies the extent to which organizations understand the barriers and facilitators of meeting patient needs as well as their ability to prioritize those needs [20]. Patient needs were identified as an important outer-setting construct that could drive demand for services and facilitate participant support for implementing the intervention:

> *[Education] is a lot of "here are some pamphlets," and a lot of relying on the caregiver or on the person who may have a Mild Cognitive Impairment diagnosis to go on and sort of read for themselves. So, it can be a little overwhelming...it's a lot of text and sometimes you can get overwhelmed...by the end of that hour and a half, both of them are tired right, and so something like this [iGeriCare] is great to say, "Here, you don't need to try to remember everything I said, I really think you should read this and this, and when I see you again in 6 months, we can answer any questions."* [Participant 001]
>
> *I definitely think that there's obviously a need. Some people don't like to go to a [location] to be with other caregivers, that's not how they learn.* [Participant 008]

As noted above, patient and/or caregiver needs were seen to be met through the increased ease of access for a wider audience than traditional education practices currently in place. Health care provider participants highlighted the importance of having alternative resources available for delivery to patients and families.

Inner Setting

The inner setting refers to the provider's specific practice setting and includes features of structural, political, and cultural contexts through which the implementation process will proceed [20]. Our participants were selected specifically because they were leaders and decision makers in their health care settings and could provide insight into existing workflows.

Theme 1 is as follows: Most participants saw the iGeriCare intervention as a good fit with their existing workflows. Conversely, a few participants expressed concerns about its implementation within their practice settings and existing workflows.

Many participants stated that iGeriCare was presently being used or could easily be implemented because of its *compatibility* and *relative priority*. *Relative priority* refers to the individual's perception of the importance of implementation within an organization [20]:

> *I think that it would definitely streamline my practice. Because I know that it's one resource that I can trust, and I don't need to be looking for.* [Participant 001]
>
> *If I have a patient with dementia and I meet with the family I would say, "there's a nice program [iGeriCare] that you could look at, go look at it and then when you come back to see me, later on, we can go over things that you don't understand."* [Participant 012]

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Implementation climate identifies the stage of change an organization is in, how receptive individuals are to an intervention, and the extent to which it will be supported in the organization [20]. Within this construct, some participants identified barriers to the implementation of web-based education because of their current practices or concerns regarding caregiver demographics:

> *I give my overall framework for the patient, I then give them this Alzheimer's Society pack, with lots of information...and I give them a referral sheet.* [Participant 003]

> *I think we do a lot of that already via other ways, and I think that for the right person, I could see perhaps if it were a younger caregiver who was looking for more detailed information, perhaps that might be something we might include—but I don't think I would.* [Participant 007]

Characteristics of Individuals

Characteristics of individuals includes aspects that impact the individuals involved in the intervention and/or implementation process [20].

Theme 1

Theme 1 was as follows: Many participants were familiar with the intervention and felt confident of their ability to implement iGeriCare.

Knowledge and beliefs about the intervention refers to the participant attitudes toward and value placed on the intervention as well as familiarity with facts, truths, and principles related to it [20]. Our findings showed that individuals who had taken the time to review iGeriCare were more positively predisposed toward it and placed a higher value on the intervention than those who were less familiar with it:

> *I thought it was high quality, overall very useful.* [Participant 004; substantial review of the intervention]

> *It would certainly fit with the National Dementia Strategy.* [Participant 010; substantial review of the intervention]

> *I think it's great that people can go on, listen again to a session that they might have already done, share it with family and friends so there's consistency in messaging. We want to get everyone within a family network or small community on the same page if you will.* [Participant 011; substantial review of the intervention]

Theme 2

Theme 2 was as follows: The relationship of the participants to the iGeriCare developers' institution affected their degree of commitment to the intervention.

Participants did not specifically reference *individual identification with the organization*, a broad construct related to how individuals perceived the organization and their degree of commitment to it [20]. Rather, this was expressed as a sense of pride in their organization's current educational practices. Individuals who were more clearly identified with the organizations of the developers of the intervention were more positively predisposed to the intervention and its implementation. Individuals who did not clearly identify with the organizations of the developers were less predisposed to the intervention and its implementation.

Process

A successful *implementation process* typically requires an active change process aimed at achieving individual- and organization-level use of the intervention as designed [20].

Theme 1

Theme 1 was as follows: Most participants felt that they could implement iGeriCare using collateral promotional materials or by sharing the website's URL.

Most participants were confident of their ability to implement iGeriCare according to plan; this aligns with the CFIR construct of *executing* [20]. Participants commented on the need to give something to the families to go home with and praised the preexisting iGeriCare promotional materials that were available:

> *I think the only way that I can easily pass this information on to patients and their families is if I had something in my hand that I could give them to go away with. Whether it's a card or a link to a website something that can say, "I can vouch for this, this is a good resource, I need you to look at this."* [Participant 002]

> *This is great [iGeriCare educational prescription pad], this is so easy you know it's something that can be ready to pull out for every patient.* [Participant 004]

Although most participants felt that they could easily implement iGeriCare, one barrier identified was the need for a constant reminder about the resource and keep it front of mind to the organizations and individuals:

> *In primary care there are barriers to any new resource or any new community program and the biggest one is just the "noise"—the sheer number and volume of programs and tools and resources that are coming at us.* [Participant 002]

Theme 2

Theme 2 was as follows: Participants suggested several strategies to continue engaging stakeholders, including finding champions, engaging others in the circle of care, presenting at medical conferences, and incorporating the resource into various health professions' curricula.

Participants commented on the importance of attracting and involving appropriate individuals in the implementation and use of the intervention through a combination strategy of social marketing, education, role modeling, training, and other similar activities, which align with the CFIR construct of *engaging* [20]:

> *I do think it requires someone that is a champion that can bring it in and talk to the benefits of it. And I think*

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when people kind of see how this can match their learning gaps or their knowledge gaps, then that's when you are going to get it to pick up for that. [Participant 001]

That might be something good to send back to the family doctor to say, "look, I've recommended these things for your families and I think that they many actually come to talk about. Just so you know these are the resources," and to have that, so the family doctors are aware of, "maybe I should take a quick look at what's gone on," and things like that. [Participant 001]

It might help with Alzheimer Society's or First Links navigators, where a lot of this one-to-one peer education may be saved by helping people go through this, but I think it could certainly augment the care that's being provided, and it might help provide again support that actually might save some of the [the time of] allied health staff. [Participant 003]

What about the family docs, are you going to be explaining it to them? That's where the patients really are... [Participant 012]

In addition to the above-mentioned barriers and facilitators related to the implementation of iGeriCare within existing clinical workflows, we also discovered broader insights into the implementation of web-based education. Participant-identified barriers and facilitators related to the implementation of web-based educational interventions for caregivers related to CFIR constructs are summarized in Textbox 1.

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Textbox 1. Participant-identified barriers and facilitators related to implementation of web-based educational interventions for caregivers.

Intervention characteristics

- Facilitator
  - The design quality of the intervention, in part because of its simplistic layout, large icons, minimal effort
  - The intervention is easily implemented in everyday workflows and allows health care providers to trial with users before committing
- Barrier
  - Skepticism about the relative advantage of the web-based nature of the intervention
  - The intervention source being seen as externally developed

Outer setting

- Both facilitator and barrier
  - The format of the intervention being web-based is variably perceived as both a facilitator and a barrier. There is tension between health care providers as some have a positive opinion of the web-based format and others will not recommend because of concerns that the format might not be useful for some caregivers
- Facilitator
  - The content and format are perceived to be aligned with caregiver needs
  - Some networking with other external organizations (ie, Alzheimer Society, hospitals, memory clinics, family health teams)
- Barrier
  - The lack of language options, cultural adaptations, and alternative formats (ie, print)
  - The lack of external policy and incentives to encourage adoption

Inner setting

- Facilitator
  - The intervention easily fits into and is compatible with existing workflows
  - Some settings have a higher relative priority than others for implementation
  - Access to knowledge and information
- Barrier
  - Health care provider concerns over the amount of time it would take to review materials before recommending to patients and families. Lack of integration with electronic medical records
  - Lack of tension for change
  - Lack of organizational incentives and rewards

Characteristics of individuals

- Both facilitator and barrier
  - Level of knowledge about the intervention
- Facilitator
  - Identification with the developer organization
  - Tech-savviness
- Barrier
  - Identification with an external organization
  - Technophobe and/or assumes older adults do not use the internet

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Process

- Facilitator
  - Ease and enthusiasm to execute
  - Existing promotional materials
  - Existing champions and opinion leaders
- Barrier
  - Needs ongoing campaigns to maintain awareness of resource
  - Needs constant reminders
  - Costs of promotional materials
  - Costs of attending conferences and/or identifying and promoting resource to new champions

Discussion

Principal Findings

In this study, experts in dementia care provided detailed feedback about iGeriCare as well as on barriers and facilitators to implementing a web-based dementia education program for caregivers in general. iGeriCare aligns with the paradigm of shared decision making and the health care triad (the term *health care triad*, with regard to iGeriCare, refers to the person living with dementia, the informal caregiver, and the clinician educator and/or health professional). It can be a meaningful resource to complement face-to-face or print-based educational methods. Participants who reviewed iGeriCare in more depth and identified more with the organization that developed the intervention were more positive about the intervention and enthusiastic about its adoption and/or implementation. In addition to the design quality and credibility of the intervention, participants felt that a web-based intervention could be easily introduced and integrated into existing clinical workflows. Some participants strongly believed that older caregivers do not use the internet and were generally more skeptical about the value of web-based interventions compared with that of more traditional methods and formats. There were a variety of suggestions regarding the process of implementation and ongoing dissemination.

This study adds to the growing body of literature on web-based interventions for caregivers of people with dementia; in particular, it is one of the few studies to examine implementation. Despite the increase in research in this area—it has been estimated that the number of publications in this field increases by 13% each year, including several systematic reviews—we could find very little research published regarding the implementation of web-based caregiver interventions [9-11,23-26]. Moreover, many of the interventions described in the literature do not appear to be more widely accessible outside of their research context. To our knowledge, no previous research has used the CFIR framework to study web-based caregiver interventions.

Barriers and Facilitators to Web-Based Caregiver Education

We found several potential barriers and facilitators for the implementation of web-based caregiver education tools in clinical practice.

Intervention Characteristics

Participants appreciated the instructional design and high-quality web design of iGeriCare, features that are rarely described in the published literature. Web-based caregiver interventions could be quite heterogeneous and could include different components such as health information, education, peer support, professional support, web-based monitoring, or combinations of these components [11]. In the literature, educational interventions rarely describe their instructional design or report whether they conform to the best practices in multimedia learning. Of the available web-based interventions for caregivers of people with dementia, many focus on peer support, contact with a health or social care provider, decision support, and psychological support [26]. Few interventions focus solely on the provision of education or information to caregivers. Of the interventions that focus solely on the provision of education, most are no longer accessible to the public, which makes it challenging to assess the quality of the web-based educational resource.

We found that participants were more favorably predisposed to the intervention and its implementation if they identified with the organizational developers of iGeriCare. This aligns with the CFIR construct of *intervention source*, for example, the perception of key stakeholders about the source of the intervention—whether the intervention is externally or internally developed [27-29]. For some *external* participants, the intervention adaptability, design quality, and relative advantages outweighed the potential barrier of being an externally developed intervention. In other instances, organizations may be hesitant to recommend an intervention from an external source for a variety of reasons, including lack of trust, technical concerns, cultural factors, peer pressure to develop their own version, or fear of directing users to an external site and losing donations.

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Outer Setting

Most participants felt that providing caregiver education in a web-based format could reduce the gap for family caregiver support and help meet their needs, consistent with the literature [26]. Caregivers of people with dementia may favor reliable web-based education because of the lack of time for face-to-face education, concerns with privacy and stigma, or challenges with travel and arranging care for their care recipient [25]. Several studies have looked at caregiver experiences with web-based educational resources and reported that caregivers value the convenience and flexibility that web-based education provides [30-34]. The concept of clinicians *prescribing* iGeriCare resonated with the participants. This concept of *educational prescription* may also resonate with caregivers who perceive their health care providers as the foundational source of health information and are more likely to engage with high quality, provider-vetted web-based resources [12,35].

However, there were some more ambivalent opinions about whether the web-based format was optimal to meet the needs of caregivers; in particular, a couple of participants felt that older adult caregivers did not use the internet for health information. Despite encouragement from various provincial, national, and global guidelines and quality standards encouraging and referring to the use of web-based education for older-adult caregivers, it is challenging to change the attitudes of potential intervention agents about educational methods and formats. Internet usage of Canadians aged 65 years and above doubled from 32% to 68% between 2007 and 2016, a trend that is expected to continue given the high rates of internet usage by those aged between 45 and 64 years [35,36]. Recent studies support the fact that family caregivers are avid health information seekers [37]. However, an analysis of US caregiver survey data found that dementia caregivers reported somewhat lower levels of health-related internet usage compared with the general public [38]. Caregiver age, education level, and/or income as well as stress caused by caregiving were all shown to influence internet usage in that study. Raising awareness among clinicians with regard to the older caregivers' use of the internet may also increase their adoption and/or incorporation of web-based resource provision into their practice.

One finding of interest relates to the fact that none of our participants mentioned any external policies or incentives that might drive decisions about adoption. This is interesting given the recent dementia quality standards that promote caregiver education. More incentives might be an external force to help influence and encourage the implementation of effective web-based caregiver educational interventions [28,39].

Inner Setting

Our findings that most participants saw iGeriCare as a good fit with their clinical workflows and were keen to implement the intervention are aligned with the research around the constructs of compatibility of the implementation climate, the relative priority for caregiver education, and readiness for implementation. Participants represented a range of different clinical practice settings and disciplines with different structural characteristics. This did not seem to impact their perceptions of the intervention or desire to implement. Many of the participants were affiliated with the same organization—McMaster University—an organization with a relatively flexible culture that embraces innovation. Culture has been shown to have a significant influence on the implementation effectiveness and may help explain the enthusiasm for the intervention among participants from within this organization [40,41].

Most participants enthusiastically voiced their readiness for implementation. This is consistent with the elements of iGeriCare, such as ease of access to digestible information, knowledge about the intervention and how to incorporate it into work tasks, and the level of resources required to implement the intervention [27,42-44]. Very few resources are required for implementation, and most participants felt that they could implement iGeriCare by using the available collateral promotional materials (eg, poster, educational prescription pads) or just by sharing the website URL with the caregivers. Participants from primary care acknowledged that they were inundated with recommended resources; however, strategies to better integrate resources into workflows were identified as essential. Some participants were also enthusiastic about less reliance on print-based promotional materials and voiced an interest in electronic *educational prescriptions*, as long as the process was at least as efficient as traditional methods.

The amount of time an organization has to spend reviewing and approving a new web-based resource and the current culture of the organization are potential barriers to the implementation of web-based caregiver interventions. However, web-based educational interventions can align with existing workflows and can in turn help overcome barriers such as time constraints. Our finding of readiness to implement may also reflect the fact that our participants were predominantly leaders with decision-making power and/or self-efficacy to implement the intervention. Leadership engagement with the support of clinic administration and physicians is critical for the successful implementation of caregiver education delivered on the web [42,43,45-48].

Characteristics of Individuals

Our findings reflected the importance of 2 constructs related to the characteristics of individuals: (1) individual identification with the organization and (2) knowledge and beliefs about the intervention. Individual identification is a broad construct related to how individuals perceive the organization and their relationship and degree of commitment to that organization. These attributes may affect the willingness of staff to fully engage in implementation efforts or use the intervention [49,50]. We found that participants who identified more with the organization that developed the intervention were more enthusiastic about implementation, although some of this may also reflect the construct of *intervention source* (as noted above), where they felt that the intervention was *internally developed*.

The construct of knowledge and beliefs about the intervention was particularly relevant. We found that participants' knowledge about the intervention itself and opinions about older adults' usage of web-based health resources were important factors in their perception of the intervention and its implementation.

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Participants with little familiarity with iGeriCare or those who did not think that older adults used the internet were much less likely to consider the implementation. Individual clinician attitudes about web-based caregiver education may not be based on evidence but rather on personal opinions of preference for the format of delivery.

Many participants were physicians. The characteristics of individuals and their knowledge and beliefs about interventions may be particularly important constructs in contexts where physicians are the primary implementation agents, as they tend to have a lot of autonomy with regard to implementing interventions, especially within certain practice settings (such as ambulatory clinics or more *private practice* type of settings). Many physicians in independent practice might not strongly identify with their affiliated health care organizations (eg, hospitals), highlighting the added importance of individual characteristics as a construct in an organization's potential implementation that may rely on physicians.

Process

With regard to the CFIR domain of *process*, participants spoke predominantly of the constructs of *executing* and *engaging*. The quality of execution relates to several factors, including fidelity of implementation, intensity, timeliness of task completion, and engagement of key stakeholders in the implementation process [51,52]. Our finding that most participants felt that they could implement iGeriCare immediately by using collateral promotional materials that had been developed or simply by sharing the website URL with caregivers suggests that the simplicity of our intervention's implementation was another major facilitator of adoption. Very little additional planning was needed to implement the intervention. This lack of complexity as a facilitator of implementation is consistent with recommendations of other health technology implementation frameworks [53-55].

One of the most challenging elements of process relates to the construct of *engaging*, "attracting and involving appropriate individuals in the implementation and use of the intervention through a combined strategy of social marketing, education, role modeling, training, and other similar activities" [28]. Implementation of a resource is heavily dependent on the enthusiasm of users and adopters. It is almost never a *one-and-done* process but is more of an ongoing campaign that requires constant reminders to existing champions and opinion leaders. This is particularly the case with web-based caregiver education that is not organizationally mandated. Participants had many suggestions regarding how to continue to engage health professionals; these were mostly through continuing professional development conferences or integration into health professional learners' curricula. Most likely, a multimodal engagement strategy is required, targeting organizations, clinicians, trainees, and family caregivers. The costs associated with ongoing promotion and engagement (whether they be marketing costs, personnel, or the true costs of time for champions) are not trivial and may prove to be an important barrier with regard to the implementation of web-based caregiver education that is not embedded within some type of centralized strategy.

Limitations

Some limitations should be considered when interpreting the results. First, the recruitment of professionals to the project was limited to those residing in Southern Ontario, which might have led to an underrepresentation of key stakeholders in the discussion. Second, it might also be a limitation that several stakeholders were directly affiliated with the same organization as the developers of the intervention. However, local and regional implementation of iGeriCare was a key goal of the project; therefore, understanding the attitudes of local opinion leaders was important. We also tried to recruit from a range of different disciplines. Challenges for coding consensus have been identified as a limitation of the CFIR because of the large overlap of constructs within and between domains [56]. Another limitation in the application of the CFIR model to web-based interventions identified is the unidirectional (traditional face-to-face) process of implementation [56]. The implementation of iGeriCare needs to be investigated longitudinally to analyze its long-term effects on organizations, professional roles, ways of working, and ultimately on caregiver and patient-related outcomes.

Conclusions

In summary, we found that opinion leaders in dementia care were generally enthusiastic about implementing high-quality web-based dementia caregiver education. Key facilitators included the quality of the design of the intervention, ease of implementation, and value added for both the health care system and caregivers. Key barriers included the perception that the intervention came from an external source or organization; lack of policy incentives; current normative professional behaviors around health teaching and/or caregiver education; individuals' knowledge of the intervention and opinions about older caregivers' usage of the internet; and the costs and challenges with regard to ongoing engagement, awareness raising, and promotion of the intervention. Despite an increase in the number of interventions and research on web-based caregiver interventions, there is very little work to date describing their implementation. Frameworks such as CFIR and others are helpful in delineating the various domains related to implementation of web-based caregiver interventions. Further research with regard to the specific implementation of caregiver education interventions would be beneficial, given the increasing development of these interventions.

Our results have led us to increase the dissemination of collateral promotional materials, continue engagement with various champions and intervention agents, and continue ongoing multimodal strategies for implementation. A new educational prescription web application for clinicians is being field-tested. This innovation may help determine the reach of the intervention, in addition to providing other measures of whether the educational prescription gets *filled* by the caregiver as well as some data related to the *dose* of the educational intervention.

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Authors' Contributions

AL and RS led the conception and design of the study. SA and LB conducted all participant interviews. SA transcribed the audio recordings of interviews. AL, SA, and LB developed and applied the coding scheme. AL and SA reviewed the coding, identified themes, and drafted the manuscript. RS, AP, and SM provided revisions for the manuscript. All authors have read and approved the final manuscript.

Conflicts of Interest

AL and RS are co-owners of the iGeriCare intervention with McMaster University.

Multimedia Appendix 1
Qualitative interview guide.
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Multimedia Appendix 2
NVivo coding tree export.
[DOCX File , 567 KB - aging_v3i2e21264_app2.docx]

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Abbreviations

CFIR: Consolidated Framework for Implementation Research

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Original Paper

Video Narratives Intervention Among Stroke Survivors: Feasibility and Acceptability Study of a Randomized Controlled Trial

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Abstract

Background: A large number of stroke survivors worldwide suffer from moderate to severe disability. In Malaysia, long-term uncontrolled stroke risk factors lead to unforeseen rates of recurrent stroke and a growing incidence of stroke occurrence across ages, predominantly among the elderly population. This situation has motivated research efforts focused on tapping into patient education, especially related to patient self-efficacy of understanding and taking medication appropriately. Video narratives integrated with health belief model constructs have demonstrated potential impacts as an aide to patient education efforts.

Objective: The aim of this study was to investigate the feasibility and acceptability of study procedures based on a randomized controlled trial protocol of a video narratives intervention among poststroke patients. We also aimed to obtain preliminary findings of video narratives related to medication understanding and use self-efficacy (MUSE) and blood pressure control.

Methods: A parallel group randomized controlled trial including a control group (without video viewing) and an intervention group (with video viewing) was conducted by researchers at a neurology outpatient clinic on poststroke patients (N=54). Baseline data included patients' sociodemographic characteristics, medical information, and all outcome measures. Measurements of MUSE and blood pressure following the trial were taken during a 3-month follow-up period. Feasibility of the trial was assessed based on recruitment and study completion rates along with patients' feedback on the burden of the study procedures and outcome measures. Acceptability of the trial was analyzed qualitatively. Statistical analysis was applied to ascertain the preliminary results of video narratives.

Results: The recruitment rate was 60 out of 117 patients (51.3%). Nevertheless, the dropout rate of 10% was within the acceptable range. Patients were aged between 21 and 74 years. Nearly 50 of the patients (>85%) had adequate health literacy and exposure to stroke education. Most of the patients (>80%) were diagnosed with ischemic stroke, whereby the majority had primary hypertension. The technicalities of randomization and patient approach were carried out with minimal challenge and adequate patient satisfaction. The video contents received good responses with respect to comprehension and simplicity. Moreover, an in-depth phone interview with 8 patients indicated that the video narratives were considered to be useful and inspiring. These findings paralleled the preliminary findings of significant improvement within groups in MUSE (P=.001) and systolic blood pressure control (P=.04).

Conclusions: The queries and feedback from each phase in this study have been acknowledged and will be taken forward in the full trial.

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Trial Registration: Australian New Zealand Clinical Trials Registry ACTRN 12618000174280; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=373554

(JMIR Aging 2020;3(2):e17182) doi:10.2196/17182

KEYWORDS

feasibility and acceptability; medication understanding; use self-efficacy; stroke; video narratives

Introduction

Background

Establishing a patient narrative is a common method for analyzing how individuals with illnesses express themselves to best recognize and reflect the values and teachings that are most important to them and how they react toward their actions [1]. Personal and interpersonal factors such as coping strength and family or social support form the basis of these narratives [2]. Thus, a narrative can influence changes in health behaviors toward achieving appropriate health outcomes [3,4]. Narratives incorporated in multimedia format can effectively deliver patients' stories to viewers who can then become "carried away" by their peers' experiences and help them to learn from others [5]. A high percentage of the delivered information in patient education offers engagement via the visual and hearing senses. Therefore, the use of video narratives offers a great chance of proper comprehension and reflection among patients [6].

Video narratives have long been explored and developed for various patient education purposes in chronic disease management [7-9]. However, there are limited studies on video narrative-based interventions in poststroke patients, and their outcome measures varied in terms of the severity of the disease and psychosocial challenges [10,11]. In Malaysia, the ischemic stroke incidence has shown an increase of approximately 30% annually, with an increase of approximately 19% for hemorrhagic stroke, which is a more prominent condition among the aging community [12,13]. The majority of poststroke patients experience physical disability, learning, and speech impairment, which also lead to emotional problems [14,15]. Hence, an individual who experienced stroke will benefit from resilience, which requires self-efficacy [16,17]. Medication nonadherence had been associated with a lack of self-efficacy in poststroke patients, especially with regard to understanding and taking medication [18]. Thus, patient education efforts that focus on enhancing medication understanding and use self-efficacy (MUSE) are warranted. Indeed, sustaining medication adherence is crucial to achieve optimal recurrent stroke treatment effects [19]. Despite the advancement of stroke prevention treatment, medication nonadherence prevalence remains notable among patients with high stroke risk factors such as hypertension and cardiac disease [20,21]. Social learning theory explains that a person's behavior depends on adaptation of their thoughts and beliefs, which are influenced by the environment and in turn control the individual's actions [22]. This theory proposes that medication adherence relates to an individual's perception of health issues, which influences self-efficacy toward prescribed medication [23,24].

There are limited studies aimed at understanding the use of video narratives with the integration of health belief constructs and motivational cues. In addition, little is known about the effect of video narratives on poststroke patients in particular. Stroke survivors require motivational support, which could help them to enhance their effort in understanding prescribed medication and taking it appropriately [25]. We believe that video narratives offer an opportunity to facilitate the existing stroke patient education effort of the medication therapeutic adherence clinic (MTAC) [26]. Moreover, the outpatient clinic waiting time and area offer a potential period and venue for patients to receive these inputs [27]. Thus, we aimed to evaluate the feasibility and acceptability of a video narratives randomized controlled trial (RCT) among poststroke patients in Malaysia.

Objectives

This study was an a priori phase of a powered RCT [28] focused on determining the recruitment, retention, and completion rate of the trial. Patients' qualitative feedback and views were collected with respect to the acceptability of the videos. We also analyzed the preliminary changes of MUSE over the course of the intervention and compared the findings with a control group.

Methods

Ethical Considerations

The study received ethics approval from the Malaysian Medical Research and Ethics Committee, Ministry of Health Malaysia (NMRR ID-15-851-24737) and the Monash University Human Research Ethics Committee (ID 9640).

Sample Size, Eligibility, and Randomization

Given the lack of similar studies, there was no referral for appropriate effect sizes. Moreover, a feasibility study without inferential results does not necessarily require a power analysis [29]. Therefore, we estimated the sample size based on practical considerations and experience of the researchers [30,31]. This pretest and posttest design, two-arm RCT was conducted from March 2018 to June 2018 among informed and consenting stroke survivors who had clinic appointments at the Neurology Outpatient Department of Hospital Kuala Lumpur (HKL), Malaysia. We aimed to recruit a minimum of 25 patients per group. Eligible and consenting patients were adults diagnosed with their first stroke within 6 months of the recruitment period, and were prescribed stroke risk preventative medications from HKL. Those excluded were diagnosed with depression (Patient Health Questionnaire score≥1) and cognitive impairment (Montreal Cognitive Assessment score<26). We only included patients who could comprehend the English or Malay language.

Randomization was performed via the block method between 2, 4, and 6 lengths placed in opaque envelopes. The allocations of each block were also randomized. Patients were either

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allocated to the standard care (control) or intervention (with video viewing) group. The full description of the study's methodology is available in our protocol trial report [28].

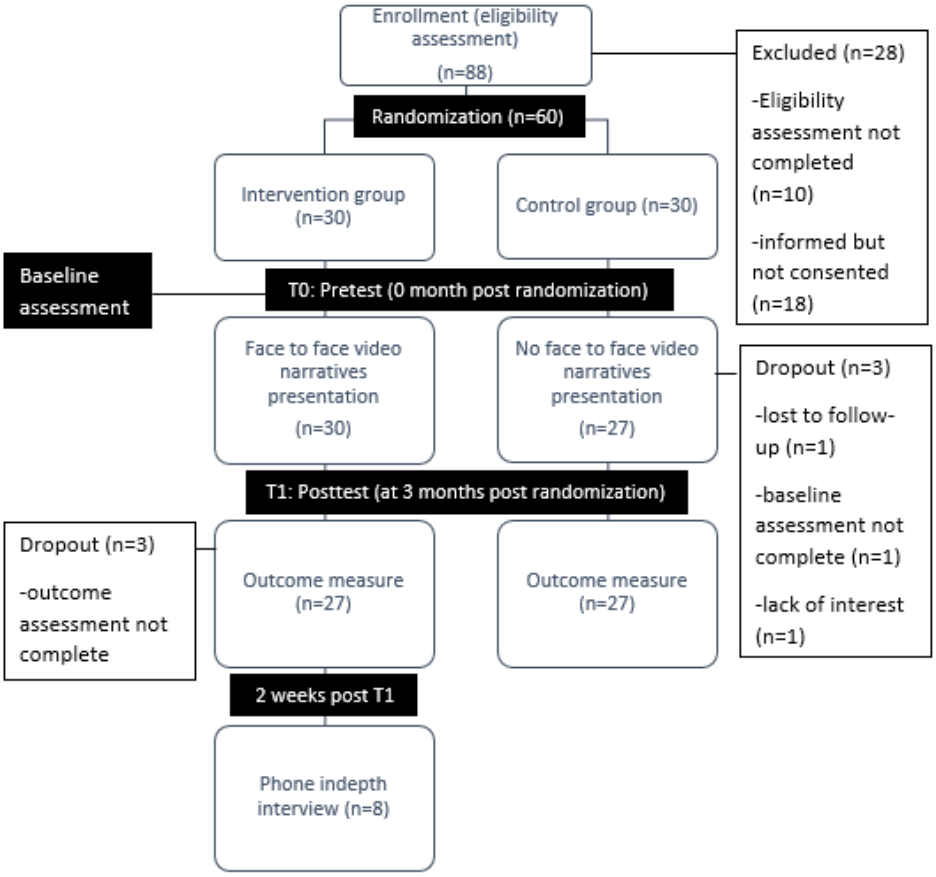
Video Narratives

Based on research interest and considering the motivational need of poststroke patients, we developed a set of video narratives incorporated with health belief model constructs. The validation procedures and narrative contents in the English and Malay languages have been described in detail in our previous paper [32]. The video narratives provided messages (culturally appropriate for the local context), which served as triggers to motivate patients to be resilient in attaining self-efficacy skills as per their perceived needs. To reflect the purpose of role models, a neurologist and a stroke survivor volunteered to narrate their story in a video to render their honest emotion while stressing the need to adhere to stroke preventative medication (see Multimedia Appendix 1 and Multimedia Appendix 2). Short quotes and subtitles were incorporated to increase attentiveness toward the comprehension of their messages [33].

Intervention Design and Study Procedures

The groups in this RCT received treatment with ongoing patient education and counseling as per HKL neurologists' recommendations. The treatment compliance practice included MTAC appointments, self-monitoring checks, and outpatient clinic attendance. Both groups received pamphlets on stroke awareness and its preventative medication information, and the "teach-back method" was used to help reduce discrepancies between the two groups [34,35]. The "teach-back" queries were related to medication dose, frequency, indication, and time as recommended by the MTAC. In addition to this standard care, only the intervention group received face-to-face video narratives. Figure 1 illustrates the CONsolidated Standards Of Reporting Trials (CONSORT) flowchart showing patients' participation throughout the study at data collection time points. We collected the quantitative data at baseline (T0) and 3 months postrandomization (T1), and collected qualitative data via a semistructured interview upon completion of the study. Similar data collection and follow-up procedures as applied in the main study protocol were followed [28]. Blinding was impossible for the patients. This also includes the researchers who conducted the assessment of the questionnaire, except for the treating neurologists.

Figure 1. CONsolidated Standards Of Reporting Trials (CONSORT) flowchart of poststroke patients throughout the study.



Outcome Measures

Main Outcome Measure

The main outcome measure assessed at pretest (T0) and posttest (T1) referred to MUSE. The MUSE is assessed on an 8-item Likert-type scale with total scores ranging from 0 to 32, which measures the perceived self-efficacy in understanding and taking prescribed medication. It has good internal consistency (Cronbach α >.70) with adequate construct and predictive validity [36]. We repeated MUSE for each prescribed stroke preventative medication.

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Understanding and taking medication is also associated with other factors such as knowledge, perception, or belief [37]. Therefore, we aimed to observe changes in these factors as well. Hence, the feasibility study assessed the baseline of the following secondary outcome measures.

Stroke Knowledge Test

The stroke knowledge test of 20 items is a measure of stroke knowledge, which is vital in evaluating the quality of stroke education modules. The stroke knowledge test has received acceptable and favorable ratings from health and educational experts, which reflected its excellent reliability and construct validity [38].

Brief Illness Perception Questionnaire

The brief illness perception questionnaire (BIPQ) is assessed on a 9-item Likert scale with a 0 to 10 scoring range that intends to evaluate the perceptive and emotive illustrations of the effect of an illness on a patient. This measure demonstrated good test-retest reliability and high concurrent and discriminant validity [39].

Belief About Medicine Questionnaire

Belief About Medicine Questionnaire (BMQ) is an 18-item questionnaire with two constructs: BMQ-General and BMQ-Specific. Both constructs are further divided into the subscales of overuse harm and necessity concerns. The scales of both constructs have acceptable internal consistency, discriminant validity, and reliability [40]. This measure assesses general and specific medication beliefs and perceptions. Nevertheless, only the BMQ-Specific construct measure was repeated for each prescribed stroke preventative medication in this study.

Short Form (36) Health Survey

Short Form (36) Health Survey (SF-36) comprises a 36-item questionnaire with scoring between 0 and 100. The SF-36 is able to measure perceived physical and mental constraints. It has been translated, validated with acceptable psychometric properties, and used widely in various clinical settings to measure the overall health state [41].

Other Measures

Other measures included systolic and diastolic blood pressure, fasting blood glucose, total cholesterol, and international normalized ratio.

We received the "permission to use" from the authors of the original (English) and the translated (Malay language) versions of the questionnaires, deemed to be locally appropriate for this study [42-45]. The researchers also conducted a face and content validity analysis with 5 patients and experts prior to this study to confirm the understandability and the content validity index>0.80 of MUSE, BMQ-specific, and BIPQ for the named medication(s), for which the word "illness" was replaced with "stroke" in the measures.

Data Collection Procedures

We obtained the patients' sociodemographic and health information using a data collection form that recorded gender, age, ethnicity, educational attainment, and health literacy status using the Newest Vital Sign format [46]. Concurrently, we retrieved clinical health data on the type of stroke and stroke risk factors from the hospital's patient medical records. All consenting patients from the intervention group had the option to volunteer to participate in a 10-minute phone or face-to-face interview within 2 weeks of follow up from the data collection point (T1). This was conducted to obtain feedback on the burden of outcome measures (questionnaires) and the acceptability of viewing the video as an intervention. The researchers maintained data confidentiality and patients' safety as per the protocol [28].

Data Analysis

Quantitative Data

Statistical analyses were performed using IBM SPSS Statistics V.24.0 with $P<.05$ as the threshold significance level. Descriptive statistics (eg, means and percentages) were used to describe the characteristics of both the control and intervention groups, along with the study and intervention's feasibility and acceptability. Chi square tests were applied to explore dissimilarities in patient characteristics between both groups at baseline. Data differences over time between the two time points (T0 and T1), at intergroup and intragroup levels, were also analyzed for the outcome measures using the Mann-Whitney *U* test and the Wilcoxon rank-sum test. The results for outcome measures and mean differences were calculated as means (SD), range, or 95% CI as appropriate. Multiple imputation was applied for missing data.

Qualitative Data

The phone interview recordings were transcribed and translated verbatim. Two researchers reviewed the transcripts, wherein they occasionally met to discuss the developed themes. The themes were then verified by another researcher to assure uniformity and quality. The transcripts and written feedback were analyzed using thematic analysis [47]. We applied the software NVivo 11 (qualitative data analysis software; QSR International Pty Ltd, Version 11, 2015) to identify the themes and to help in organizing the codes.

Results

Participant Characteristics

Table 1 presents the sociodemographic and health information of patients who participated in and completed the trial over the full study period. Both groups comprised more men than women with a dominance of more than 50%, and most patients were predominantly of Malay ethnicity in both groups (>80%). Patients were between 21 and 74 years old, with a mean age of 56 years (SD 13.1) for the control group and 53 years (SD 11.6) for the intervention group. Nearly 50 participants (>85%) had secondary education, which included tertiary attainment, with adequate health literacy and exposure to stroke education. More than half of the patients were unemployed. The majority of patients (>80%) had experienced ischemic stroke and had several underlying stroke risk factors inclusive of hypertension, but not all controllable risk factors were documented, such as diet, obesity, and physical inactivity, due to lack of data in medical records. Among them, approximately 25 patients (50%)

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had diabetes, and more than 50 patients (about 90%) were taking at least three types of stroke preventative medication. There were no significant differences in sociodemographic characteristics and measures between the two groups, except for gender.

The following sections are presented as per study objectives and with subdivisions to the feasibility and acceptability of (1) the RCT procedures, (2) video narratives intervention, and (3) preliminary findings of the effect of the video narratives on MUSE and blood pressure as a stroke risk factor control.

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Table 1. Sociodemographic and health data of patients at 3-month follow up (N=54).

Characteristic	Control (n=27)	Intervention (n=27)
Gender, n (%)		
Male	18 (67)	15 (56)
Female	9 (33)	12 (44)
Age (years), n (%)		
≥60	10 (37)	8 (30)
40-59	13 (48)	16 (59)
≤39	4 (15)	3 (11)
Age (years), mean (SD)	56 (13.1)	53 (11.6)
Ethnicity, n (%)		
Malay	22 (82)	23 (85)
Chinese	1 (4)	1 (4)
Indian	4 (15)	3 (11)
Education attainment, n (%)		
Primary	4 (15)	2 (7)
Secondary	15 (56)	18 (67)
Tertiary	8 (30)	7 (26)
Health literacy level, n (%)		
Adequate	23 (85)	24 (89)
Limited	4 (15)	3 (11)
Employment status, n (%)		
Employed	11 (41)	7 (26)
Unemployed	16 (59)	20 (74)
Type of stroke[a], n(%)		
Ischemic	22 (82)	25 (93)
Hemorrhagic	0 (0)	0 (0)
TIA[b]	5 (18)	2 (7)
Stroke risk factors (comorbidities), n (%)		
Hypertension and other risks[c]	24 (89)	26 (96)
Diabetes only	2 (7)	1 (4)
Other risks only	1 (4)	0 (0)
Varieties of prescribed medication, n (%)		
≤2 types	2 (7)	3 (11)
≥3 types	25 (93)	24 (89)
Received formal or informal information about stroke prevention, n (%)		
Yes	23 (85)	24 (89)
No	4 (15)	3 (11)

[a]Inclusive of modifiable stroke risk factors other than hypertension (eg, diabetes, heart diseases, hyperlipidemia, current smoking/alcohol).

[b]TIA: transient ischemic attack.

[c]Other risks include nonspecific International Classification of Diseases stroke codes.

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Feasibility and Acceptability of the RCT Procedures

The randomizing method, administration, and questionnaire retrieval at the outpatient waiting zone were effectively carried out. We experienced minimal challenges and uninterrupted flow at ushering patients individually to an allocated quiet room for video viewing. We received written feedback from 12 patients. Overall, the patients were satisfied with the study procedures, including the usage of a 5.3-inch-wide screen tablet and headphones, but commented on the burden of the self-administered questionnaires (for assessing the outcome measures). A few remarks were related to the exhaustive repetition of the MUSE and BMQ for each type of medication and the extensive length of the SF-36. Furthermore, there were suggestions to receive a token of appreciation for sustaining their participation.

Recruitment Rate

A total of 117 poststroke patients were screened from clinical records within 1 month for recruitment of trial participation, but only 88 patients were eligible according to the inclusion and exclusion criteria, resulting in an eligibility rate of 75.2%. Among all 88 patients, 70 patients provided consent to participate, but only 60 of them completed the baseline assessment. Hence, the recruitment rate was 51.3%. The most common reasons that patients declined enrollment were a language barrier, afraid of increased stress, and refusal.

Dropout and Study Completion Rates

During the baseline assessment (T0) and the 3-month follow-up assessment (T1), the number of patients completing the study dropped to 54 from 60 (90%), which reflected a dropout rate of 10%. The most common reason for not completing the study was an inability to be contacted, which we considered to indicate refusal for further participation.

Feasibility and Acceptability of the Video Narratives Intervention

We sought to gain in-depth information on technical issues and views on the video narratives' usefulness as a motivational trigger to improve MUSE. The results of several subthemes identified are presented in Textbox 1.

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Textbox 1. Themes and quotes associated with the feasibility and acceptability of the video narratives intervention.

Feasibility of the video narratives

Main theme: Engagement and comprehension

- Messages were short, transparent, and easily understood

  You must not make the video too long. Like this one, that is just nice…not boring….What you see on video, the doctor was very good [P2]

- Patients had the option to view it in their preferred language; either in English or in Malay

  Things related to stroke should be explained by patients themselves… not just knowledge but experience… so that others will be aware [P6]

- The narratives were suitable for the elderly

  Most elderly patients are very stubborn about taking medicine. Show the video especially to the elderly patients [P7]

- Appropriate video viewing frequency

  Watching the video once in a while like this is good…. [P3]

Main theme: Generalizability

- There were suggestions to share the video among friends via other media platforms such as WhatsApp or to continuously play it on air in the hospital.

  I can share this video with my friends in WhatsApp [P1]

  I want to send the video for my friends to watch! [P5]

  Maybe what they can do probably is over some TV set… what do you call that…program? Put the show, I mean like this type of video, what'll happen when you have a stroke and all that… So that patients can listen instead of giving TV1 all the time you know? [P2]

Acceptability of video narratives

Main theme: Informative and reminder

- The videos narratives were a "trigger" toward proactivity and enhanced patients' awareness about stroke and its preventative treatment.

  They remind us of important medicine… They remind us of the danger of the second stroke… to take medicine well and to have a healthy lifestyle [P7]

  Helpful….more understanding about stroke [P6]

  Awareness… before that we were not really concerned about our health. Now, after the advice it's different... like a guide [P4]

  Patients can recover from stroke and (it) won't recur if we take the medicine prescribed by doctors according to the right schedule on time [P2]

Main theme: Emotional consolation

- Viewing the video narratives provided some hope and less fear to overcome stroke challenges.

  It's a bit of both worrying and confidence… There is always a worry about what can happen, but it also gives you an idea (on) what to do, and what to be careful, and what to be aware [P3]

- The video was an aid to their plight that there was life after stroke.

  Because you are a stroke patient, you have to look at the guidelines… you want to know (more)… you have to take care of yourself, right? You'll be confident when you have such thing (to guide you) … Before this… you don't know anything… fear about getting another attack… right? [P1]

  Others must know that people who got stroke, just like us, but they can recover. Sometimes, for stroke, people can't really help, except for the patients themselves [P4]

Main theme: Perception and confidence

- The motivational cues inspired the patients and raised confidence among themselves.

  … (sharing) someone's experience to change others' mind. Sometimes, we need to listen to their stories for us to make a change [P4]

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They had a positive outlook towards stroke recovery and were willing to do better to improve their health condition.

I feel that I have to follow the advice, for example, taking medicine, doing blood test… that have been mentioned… (The videos) seem to inspire us to take care of health so that we won't get sick. Perhaps to give encouragement makes me feel that I can recover from stroke if follow all the advice [P5]

Usually, if you never had a stroke before, you don't really care about watching the videos. Once you had (a stroke), you'll realize that… health is important… you have to take care of it… watch their story… that's it! [P1]

Now I ask my doctor more questions if I don't understand…. [P2]

Preliminary Findings

Table 2 presents the results as per the trial protocol of outcome measures at T1 for MUSE and blood pressure control. There were no significant differences in outcome measures at baseline (T0) between the two groups (P<.001). All patients were on antiplatelet therapy, and the majority of patients diagnosed with hypertension were on antihypertensive medication (control group, n=24; intervention group, n=26). Therefore, only the general MUSE and specific MUSE for antithrombotic and antihypertensive medications were applied.

Both groups showed improvement in MUSE scores, but the intervention group presented greater differences from baseline compared to the control group. Similar trends were found for blood pressure control, whereby the intervention group had better systolic pressure regulation compared to the control group (Table 3). The MUSE outcomes of the intervention group were significantly different for the between-group and within-group analysis (Table 4).

Table 2. Outcome measurement of both groups at baseline (T0[a]) and posttest (T1[b]) assessments.

Measure	Control group, mean (SD), range		Intervention group, mean (SD), range	
	T0	T1	T0	T1
MUSE[c]				
All medications	27.0 (4.71), 16-32	27.6 (3.76) 20-32	26.3 (5.81), 16-32	30.1 (3.62), 20-32
Hypertensive[d]	36.2 (4.62), 17-32	27.8 (35.7), 22-32	26.3 (5.59), 16-32	30.1 (3.51), 20-32
Antithrombotic[e]	27.0 (4.70), 16-32	24.4 (3.73), 20-32	27.3 (5.43), 16-32	30.0 (3.57), 20-32
Systolic blood pressure[d] (mmHg)	138.7 (7.84), 127-162	137.9 (10.78), 124-60	147.0 (16.8), 121-186	137.8 (12.74), 117-165
Diastolic blood pressure[d] (mmHg)	79.6 (11.62), 54-107	80.0 (10.93), 60-105	85.7 (11.59), 58-109	85.0 (9.07), 68-100

[a]T0: baseline (control group n=27, intervention group n=30).

[b]T1: 3 months postrandomization (control group n=27, intervention group n=27).

[c]MUSE: medication understanding and use self-efficacy.

[d]Prescribed with antihypertensive medication and diagnosed with hypertension as a primary factor (control group n=24, intervention group n=26).

[e]Prescribed antithrombotic medication as a prerequisite preventative treatment for stroke (control group n=27, intervention group n=27).

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Table 3. Comparison of outcome measurement within groups.

Measure	Control group			Intervention group		
	T1[a] – T0[b] (95%CI)	*Z* value	*P* value[c]	T1 – T0	*Z* value	*P* value[c]
MUSE[d]						
All medications	0.52 (–1.61-2.65)	–0.85	.39	4.57 (1.94-7.19)	–3.63	.001
Hypertensive[e]	1.26 (–0.36-2.89)	1.79	.07	4.35 (2.18-6.52)	–3.60	<.001
Antithrombotic[f]	–0.91 (–1.29-3.11)	–0.37	.71	3.70 (1.62-5.77)	–3.18	.001
Systolic blood pressure[e] (mmHg)	–1.87 (–6.70 to –2.96)	0.54	.59	–13.04 (–22.22 to –3.87)	–2.03	.04
Diastolic blood pressure[e] (mmHg)	0.48 (–6.17-7.13)	–0.59	.56	–0.87 (–6.58-4.84)	–0.144	.89

[a]T1: baseline (control group n=27, intervention group n=30).

[b]T0: baseline (control group n=27, intervention group n=30).

[c]Wilcoxan signed-rank test

[d]MUSE: medication understanding and use self-efficacy.

[e]Prescribed with antihypertensive medication and diagnosed with hypertension as a primary factor (control group n=24, intervention group n=26).

[f]Prescribed antithrombotic as a prerequisite preventative treatment for stroke (control group n=27, intervention group n=27).

Table 4. Comparison of outcome measurement between the control and intervention groups.

Measure	Difference in T1[a] (95%CI)	*Z* value	*P* value[b]
MUSE[c]			
All medications	2.74 (1.29-4.19)	–3.14	.002
Hypertensive[d]	2.35 (0.87-3.81)	–2.65	.008
Antithrombotic[e]	2.78 (1.28-4.29)	–3.14	.002
Systolic blood pressure[d] (mmHg)	0.96 (–6.58-8.49)	–0.17	.86
Diastolic blood pressure[d] (mmHg)	6.04 (0.94-11.14)	–1.84	.07

[a]T1: mean score/measurement differences between intervention and control groups at 3 months postrandomization.

[b]Mann-Whitney U test.

[c]MUSE: medication understanding and use self-efficacy.

[d]Prescribed with antihypertensive medication and diagnosed with hypertension as a primary factor (control group n=24, intervention group n=26).

[e]Prescribed antithrombotic as a prerequisite preventative treatment for stroke (control group n=27, intervention group n=27).

Discussion

Principal Findings

The aim of this study was to assess the feasibility and acceptability of a planned intervention in an actual clinical setting. We successfully tested the intervention processes as per the trial protocol from the initial stage of recruitment, randomization, baseline assessment, and at the first outcome phase.

Feasibility and Acceptability of Study Procedures and Outcome Measures

The recruitment period of 1 month was found to be appropriate as we were able to enroll more than the minimum planned sample size. The recruitment rate of 51.3% was comparable to the average trend of stroke trials conducted from 1990 to 2014, whereby there were no substantial increase or decline rates over the past 25 years [48]. At 3 months, the attrition rate was below the a priori projection of 15%. The positive recruitment rate might reflect concerns and interest to enhance stroke recovery. Nonetheless, we believe that more effort would be needed to sustain the dropout rate expected for the full 12-month trial, as reflected by the desire for monetary compensation indicated by a few patients. Despite this, we found that poststroke patients were able to cope with the study flow, and the extent of participation persuasion was not coercive, which was within the trial ethics jurisdiction and funding capacity [49].

The repeated MUSE on each stroke preventative medication group was necessary to elicit a significant association of self-efficacy with medication categories. However, there were concerns that the questionnaire administering process was time-consuming and created a feeling of redundancy among the patients. As the majority of poststroke patients were primarily hypertensive [50], it was crucial to obtain responses from patients within the three categories in the full trial. Owing to the inability to recruit more samples with other primary diagnosed stroke factors such as diabetes and hyperlipidemia, it remains to be investigated whether an influx of broader

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inclusion criteria would change the patient sample proportion. Similarly, comments related to the SF-36 received were similar with respect to the burden of its lengthiness. Nonetheless, it was not possible to substitute this questionnaire with other versions [51] due to the constricted contract for the Malay language version. Therefore, with all these issues taken into consideration, the full trial protocol was carried out as planned without significant changes in its outcome measures and study procedures.

Feasibility and Acceptability of Video Narratives

The video contents were comprehensible (layman terms) and had a sensible touch of emotion suitable for the local culture and language with a clear benefit for aging poststroke patients. There was a rising awareness of how audio-visual technology can influence different age groups and social environments. This feedback was comparable to similar trials with positive outcomes [52-54]. Nevertheless, face-to-face video viewing was maintained in this trial to prevent restriction of sample inclusion and exclusion criteria.

It was not surprising that the videos were perceived to be motivational for the poststroke patients. The qualitative results showed positive responses, which increased our anticipation that the videos incorporated with health belief constructs could facilitate standardized ongoing patient educational efforts in a clinical setting. The concise keywords used as cues added with authentic emotions triggered awareness and inspiration among patients toward being more self-efficacious in understanding and taking medication appropriately. Recent studies in different settings and samples have reported similar findings [55,56]. Other than that, educational video narratives could also improve the doctor-patient relationship. Paralleling previous studies, the combination of both personal views of the doctor and patient in this study potentially caused small positive perception changes in MUSE or initiated regular health monitoring [57,58]. Therefore, the preliminary outcomes in the intervention effectiveness analysis corresponded with our justification.

Preliminary Findings

In an associated review, it was clear that the presentation of “real people” has a motivating effect for peers with similar underlying illness [26] (stroke in this case). Hence, the initial impact on MUSE and systolic blood pressure provides insights toward a purposeful trial. The 3-month gap of video viewing to moderate the burden and the dropout rate was also appropriate, as indicated in a previous study [55]. Thus, we concluded that the measurement of self-efficacy among poststroke patients at the per allocated period could be assessed effectively [59]. Furthermore, these results were consistent with studies indicating a significant improvement in MUSE, which paralleled improved stroke risk factors control, such as systolic blood pressure [60,61]. Nevertheless, as we observed variation (coefficient of variation>1) for all variable differences with inconsistent confidence intervals, a bigger sample size would confirm its significance; otherwise, these positive results would have to be interpreted judiciously.

Strengths and Limitations

In designing the study, we spared no effort at not disrupting the workflow of a real-life outpatient clinic environment. However, there were unavoidable circumstances. For example, the blood pressure measurement was to be carried out by the physician or neurologists in their clinic only. We also foresee an issue since individual follow-up of neurology outpatient clinic appointment dates varied from 2 to 5 months and coincided with other clinical appointments (eg, diabetes clinic, heart disease clinic, rehabilitation, physiotherapy, and MTAC). Therefore, it was appropriate to consider documenting blood parameters at T0, T2, and T4 for the intervention effectiveness analysis. Hence, it was a challenge to ensure patients to view the videos within the 3-month gap from baseline. Nevertheless, we overcame these issues with transport reimbursement provided to the patients so as to maintain the retention rate and self-posted questionnaires to avoid further loss of data.

Several other limitations are the exclusion of patients who were unable to comprehend the English and Malay languages, which would have increased bias and limited the generalizability of the preliminary results. In addition, as a cost-effective approach, we were not able to carry out this study for more than 3 months. Despite all these limitations and challenges, the study procedures and outcome measures strategy were considered to be robust to inform the design of a successful 1-year RCT [28]. This study demonstrated versatile and helpful methods in achieving unanimous consensus.

Conclusion

Preliminary studies are crucial in assessing the success of a novel intervention [62]. This innovative method has been applied in various clinical settings in developed countries [52,63]. However, it has not yet been investigated for the poststroke patient population in Malaysia. This study successfully assessed the feasibility and acceptability of the video narrative intervention. The feedback and lessons learned from the baseline until the first follow-up assessment increased the awareness of both foreseen and unforeseen challenges. More importantly, we tested the initial requirement for full RCT accomplishments such as patient recruitment, feasibility, and acceptability of all outcome measures. Future research on the effectiveness of using culturally appropriate video narratives for a more extended period is warranted.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Screenshot of video narratives of neurologist.
[PNG File , 249 KB - aging_v3i2e17182_app1.png]

Multimedia Appendix 2
Screenshot of video narratives of patient.
[PNG File , 215 KB - aging_v3i2e17182_app2.png]

Multimedia Appendix 3
CONSORT checklist.
[PDF File (Adobe PDF File), 145 KB - aging_v3i2e17182_app3.pdf]

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Abbreviations

BIPQ: Brief illness perception questionnaire
BMQ: Belief about medicine questionnaire
CONSORT: CONsolidated Standards Of Reporting Trials
HKL: Hospital Kuala Lumpur
MTAC: medication therapy adherence clinic
MUSE: medication understanding and use self-efficacy
RCT: randomized controlled trial
SF-36: Short Form (36) Health Survey
T0: baseline
T1: 3 months postrandomization

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Original Paper

Secondary Prevention of Hip Fragility Fractures During the COVID-19 Pandemic: Service Evaluation of “MRS BAD BONES”

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Abstract

Background: Management of osteoporosis is an important consideration for patients with femoral neck fractures due to the morbidity and mortality it poses. The input of orthogeriatric teams is invaluable in coordinating secondary fragility fracture prevention. The COVID-19 pandemic resulted in the rapid restructuring of health care teams and led to the redeployment of orthogeriatricians.

Objective: This study aimed to determine the impact COVID-19 had on the secondary prevention of fragility fractures among patients with femoral neck fractures, and to optimize management in this population.

Methods: A retrospective audit was conducted of patients with femoral neck fractures before and after the lockdown in response to the COVID-19 pandemic in the United Kingdom. A reaudit was conducted following the development of our new mnemonic, “MRS BAD BONES,” which addressed key factors in the assessment and management of osteoporosis: *m*edication review, *r*heumatology/renal advice, smoking cessation; *b*lood tests, *a*lcohol limits, *D*EXA (dual energy X-ray absorptiometry) scan; *b*one-sparing medications, *o*rthogeriatric review, *n*utrition, *e*xercise, supplements. The Fisher exact test was used for comparison analyses between each phase.

Results: Data for 50 patients were available in each phase. The orthogeriatric team reviewed 88% (n=44) of patients prelockdown, which fell to 0% due to redeployment, before recovering to 38% (n=19) in the postintervention period. The lockdown brought a significant drop in the prescription of vitamin D/calcium supplements from 81.6% (n=40) to 58.0% (n=29) (P=.02); of bone-sparing medications from 60.7% (n=17) to 18.2% (n=4) (P=.004), and DEXA scan requests from 40.1% (n=9) to 3.6% (n=1) (P=.003). Following the implementation of our mnemonic, there was a significant increase in the prescription of vitamin D/calcium supplements to 85.7% (n=42) (P=.003), bone-sparing medications to 72.4% (n=21) (P<.001), and DEXA scan requests to 60% (n=12) (P<.001).

Conclusions: The redeployment of the orthogeriatric team, due to the COVID-19 pandemic, impacted the secondary prevention of fragility fractures in the study population. The “MRS BAD BONES” mnemonic significantly improved management and could be used in a wider setting.

(JMIR Aging 2020;3(2):e25607) doi:10.2196/25607

KEYWORDS

osteoporosis; fragility fracture; guideline; mnemonic; acronym; COVID-19; bone; morbidity; mortality; fracture; elderly; older adults; geriatrics; audit; prevention

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Introduction

Osteoporosis, characterized by the progressive degradation of the microarchitecture of bone tissue and resultant loss in bone density, is a leading cause of femoral neck fractures in the elderly [1]. In the United Kingdom, there are approximately 536,000 new fragility fractures each year, of which 79,000 are femoral neck fractures [2]. This is a significant cause of increased morbidity and mortality among the elderly, with an average cost of treatment to the National Health Service (NHS) estimated at £12,000 (US $16,311) per patient [3,4]. Furthermore, patients who suffer an osteoporotic fracture are at a greater risk of sustaining a second osteoporotic fracture [3].

The management of femoral neck fractures has evolved over time. Best practice tariffs have been established to optimize the care of these patients, which should include postoperative rehabilitation and assessment for secondary fracture risk under the guidance of geriatrician-directed multidisciplinary teams [5]. Orthogeriatric comanagement has significantly reduced 30-day mortality in patients with hip fractures from 13.4% to 10.3% [6], with positive influence on functional outcomes and future fracture risk [7]. The National Institute for Health and Care Excellence (NICE) guidelines specifically support the management of bone health during admission for femoral neck fractures and recommend initiating bisphosphonate therapy (or an alternative) in addition to calcium and vitamin D supplementation to all patients with fragility fractures [8].

This year has brought an unprecedented challenge to health care services worldwide, with the declaration of the global pandemic of SARS-CoV-2 on March 11, 2020 [9]. The pandemic resulted in the rapid restructuring of health care teams to respond to the large influx of medically unwell patients across hospital sites. Within our Trauma and Orthopaedic (T&O) department, this resulted in the redeployment of the orthogeriatric team, who had previously been responsible for coordinating the management of secondary prevention of fragility fractures in patients with femoral neck fractures.

This project was part of a quality improvement initiative. The aim of this study was to determine the impact COVID-19 had on the secondary prevention of fragility fractures in patients with femoral neck fractures, and to optimize management in this population.

Methods

All requirements to carry out the study were sent to the research and development department to assess risks to patient identification. The department approved the study (ID number: 698), and confirmed that as the project was a local audit without use of patient identifiable information, there was no need for further ethical approval. This study was based on patients with femoral neck fractures admitted to the major trauma center at University Hospital Coventry and Warwickshire (UHCW) between February 2020 and June 2020. Patients were recruited consecutively by admission date, and the same inclusion and exclusion criteria were applied. The inclusion criteria involved all patients with a low-energy femoral neck fracture aged ≥60 years on admission. The exclusion criteria involved patients with periprosthetic fractures, patients who were managed nonoperatively, patients who were taking bone-sparing treatment preadmission, patients for whom it was documented as inappropriate to commence bone-sparing treatment due to a palliative approach, and patients who died while in hospital.

Data were collected in 2 phases from 50 consecutively admitted patients; the first phase recruited patients admitted immediately prior to the national UK lockdown on March 23, 2020, to determine the department's baseline compliance. The second phase refers to those admitted immediately after the lockdown.

All patients were assessed as to whether the secondary prevention of fragility fractures had been carried out upon discharge as described by UHCW trust guidelines. Figure 1 describes the local guidelines used for managing vitamin D and calcium deficiency in illustrative form. This involved measuring serum vitamin D, parathyroid hormone (PTH), adjusted calcium, and estimated glomerular filtration rate (eGFR), followed by prescribing appropriate supplements [10]. The frequencies and percentages of patients who had these parameters measured were recorded. Figure 2 demonstrates the osteoporosis treatment local guidelines in the femoral neck fracture population. Women under 75 years of age and all men met the criteria for dual energy X-ray absorptiometry (DEXA). The DEXA scan service continued as normal during the lockdown period. Women aged ≥75 years met the criteria for bone-sparing medications, taking into consideration gastrointestinal side effects and renal function.

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Figure 1. Assessment and management of patients with femoral neck fractures at risk of vitamin D deficiency, as described by the University Hospital of Coventry and Warwickshire guidelines. Vit D: vitamin D; eGFR: estimated glomerular filtration rate; PTH: parathyroid hormone; aCa: adjusted calcium, OD: once daily; O/W: once weekly; BD: twice daily.

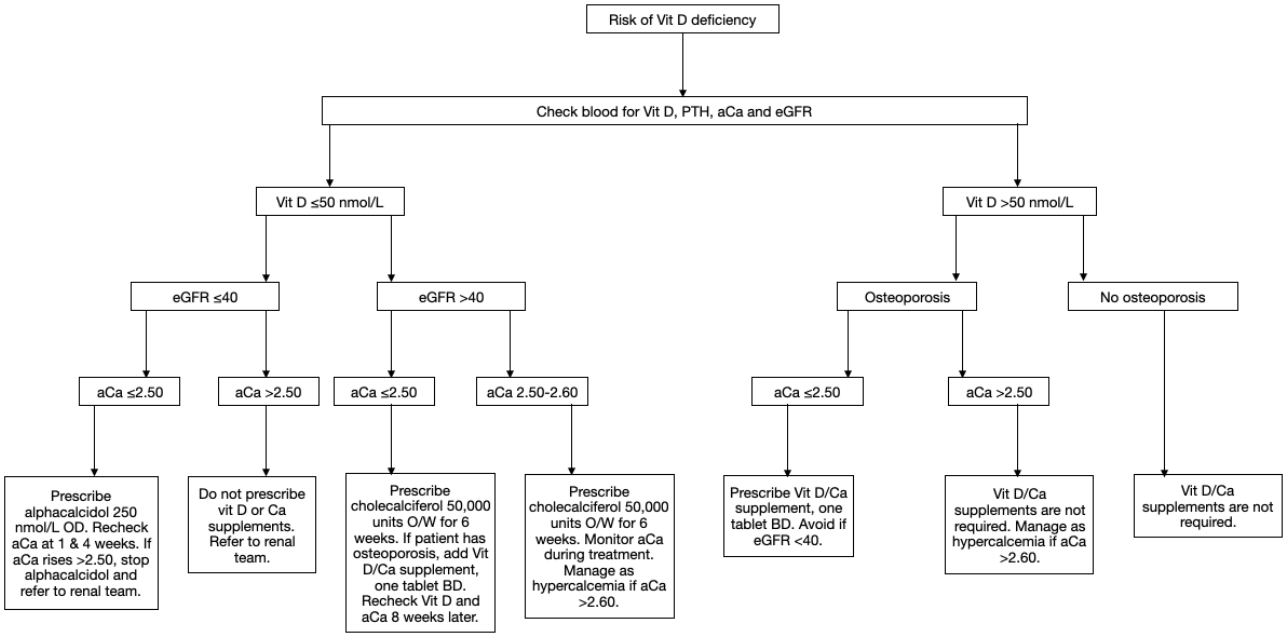
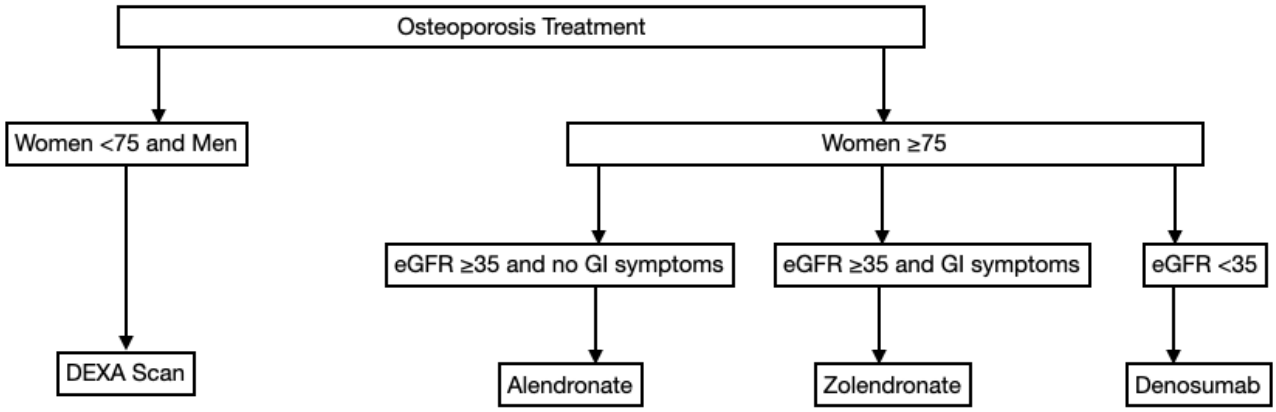


Figure 2. Osteoporosis assessment and treatment for patients with femoral neck fractures as per the University Hospital of Coventry and Warwickshire guidelines. eGFR: estimated glomerular filtration rate; DEXA: dual energy X-ray absorptiometry; GI: gastrointestinal.



Available case notes, primarily orthogeriatric review, drug charts, discharge summaries, DEXA scan request forms, and laboratory results, were reviewed, with local laboratory parameters used. The lowest measurable value in our laboratory for vitamin D serum levels is <10 nmol/L, so for the purposes of analysis, this was substituted for a value of 10 nmol/L. eGFR was calculated using the Modification of Diet in Renal Disease equation (ml/min/1.73 m^2). Adjusted calcium in mg/dL was calculated using (0.8 × [normal albumin – patient's albumin]) + serum calcium level. A normal albumin level was defaulted to 40 g/L.

For these first 2 phases, data were collected retrospectively using information available from electronic patient records. Consequently, we were only able to assess orthogeriatric reviews, blood test results, DEXA scan requests, bone-sparing medications, and supplements prescribed.

The results of the review were presented at the monthly T&O quality improvement projects meeting. A new mnemonic, "MRS BAD BONES," was developed as a tool to improve junior doctor, advanced nurse practitioner, and medical student awareness of secondary fragility fracture prevention. The mnemonic represents the following:

- Medication review
- Rheumatology/renal advice
- Smoking cessation
- Blood tests: calcium, eGFR, PTH, and vitamin D
- Alcohol limits
- DEXA scan
- Bone-sparing medications: bisphosphonates
- Orthogeriatric review
- Nutrition
- Exercise
- Supplements: calcium and vitamin D

A third and final phase of data was then collected prospectively following the dissemination of the acronym at the quality improvement projects meeting. Due to the limitations of data

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available from phases 1 and 2, we decided to only measure the same 5 parameters in phase 3, despite there being 11 in the mnemonic. All data were analyzed using SPSS v24.0 (IBM Corp). The mean was used for averages. The Fisher exact test was used when comparing groups of categorical data to provide exact *P* values. *P* values <.05 were considered statistically significant.

Results

Baseline Characteristics

Data for 50 consecutive patients with femoral neck fractures were collected during the periods pre-UK lockdown, post-UK lockdown, and after the "MRS BAD BONES" intervention. During data collection, a number of patients were excluded from analysis: 8 patients with periprosthetic fractures, 8 patients who were managed nonoperatively, 12 patients who were taking bone-sparing treatment preadmission, 9 patients for whom it was documented as inappropriate to commence bone-sparing treatment due to a palliative approach, and 14 patients who died while in hospital. The demographics of the patients can be seen in Table 1. The percentage of patients who were reviewed by the orthogeriatric team prelockdown was 88% (n=44), but this fell to 0% following the lockdown, due to redeployment in response to COVID-19 pressures. During the postintervention period, this rose to 38% (n=19) as the orthogeriatric team returned to the T&O wards with the easing of local COVID-19 pressures.

Table 1. The demographics of patients with femoral neck fractures whose data were analyzed for this study. The mean ages, the female:male ratio, and the number and percentage of patients who received an orthogeriatric review are shown.

Variable	Prelockdown	Post lockdown	Post intervention
Patients, n	50	50	50
Age (years), mean (SD)	83.8 (8.34)	82.4 (9.16)	82.7 (8.98)
Female:male ratio	33:17	27:23	36:14
Orthogeriatric review, n (%)	44 (88)	0 (0)	19 (38)

The percentage of patients who had blood tests performed per local guidelines, which includes eGFR, adjusted calcium, and vitamin D, was high (96%-100%), with no significant difference between all 3 phases (*P*=.78) (Table 2). However, only 5 PTH blood tests were performed, all in the prelockdown period, with an average of 7.0 (range 4.3-10.8). This represents just 10% of the prelockdown population sample, which is just over 3% of the total sample population.

Table 2. Patients receiving blood tests according to guidelines during each phase, which includes vitamin D, parathyroid hormone, adjusted calcium, and estimated glomerular filtration rate (eGFR).

Blood test	Prelockdown	Post lockdown	Post intervention
Vitamin D, n (%)	49 (98)	50 (100)	48 (96)
Adjusted calcium, n (%)	50 (100)	49 (98)	48 (96)
Parathyroid hormone, n (%)	5 (10)	0 (0)	0 (0)
eGFR, n (%)	50 (100)	50 (100)	50 (100)

Average vitamin D, adjusted calcium, and eGFR serum levels for the cohorts can be seen in Table 3. Results show deficiency in serum vitamin D but normal adjusted calcium levels and eGFR, when adjusted for age, sex, and ethnicity.

Table 3. Average vitamin D, adjusted calcium, and estimated glomerular filtration rate (eGFR) serum levels.

Blood test	Prelockdown	Post lockdown	Post intervention
Vitamin D (nmol/L), mean (range)	46 (12-113)	37.8 (10-90)	49.1 (10-116)
Adjusted calcium (mg/dL), mean (range)	2.30 (2.06-2.65)	2.28 (2.05-2.54)	2.29 (2.06-2.78)
eGFR (ml/min/1.73 m^2), mean (range)	80 (18-179)	86 (12-183)	83 (8-156)

Secondary Prevention of Fragility Fractures

The purpose of this audit was to assess whether the correct bone health management procedures had been initiated following the UK-wide COVID-19 lockdown. This was broken down into the steps advised by local guidelines, with the following treatments: vitamin D/calcium supplementation, bone-sparing medications, and DEXA scanning. We also noted a subgroup of patients who met the criteria for a DEXA scan but did not have a DEXA requested and instead started bone-sparing treatment. The frequencies and percentages of patients who received the correct osteoporosis management is displayed in Table 4, and Figure 3 to Figure 6.

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Table 4. Patients who received the correct osteoporosis management procedures during the 3 phases. The patients who met the criteria for a DEXA (dual energy X-ray absorptiometry) scan but were treated with bone-sparing medications instead are also represented.

Osteoporosis management	Prelockdown	Post lockdown	Post intervention
Vitamin D/calcium supplements, n/N (%)	40/49 (81.6)	29/50 (58.0)	42/49 (85.7)
Bone-sparing medication, n/N (%)	17/28 (60.7)	4/22 (18.2)	21/29 (72.4)
DEXA scan, n/N (%)	9/22 (40.1)	1/28 (3.6)	12/21 (60.0)
No DEXA scan; started bone-sparing medication, n/N (%)	9/13 (69.2)	2/27 (7.4)	8/9 (88.9)

Figure 3. The number of patients receiving correct vitamin D (vit D)/Ca2+ supplements after the lockdown was significantly reduced (*P*<.05); post intervention, there was a significant increase in the correct administration of vitamin D/Ca2+ (*P*<.01), compared to post lockdown.

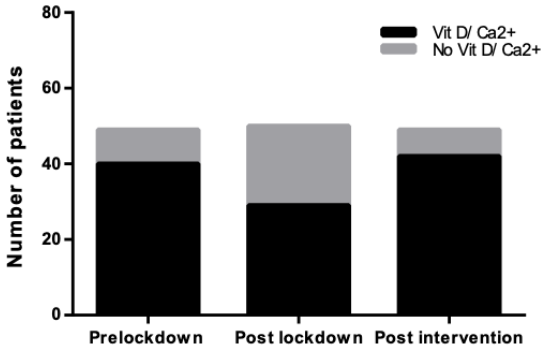

Figure 4. The number of patients receiving correct bone-sparing medication (BSM) after the lockdown was significantly reduced (*P*<.001); post intervention, there was a significant increase in the correct administration of BSM (*P*<.001), compared to post lockdown.

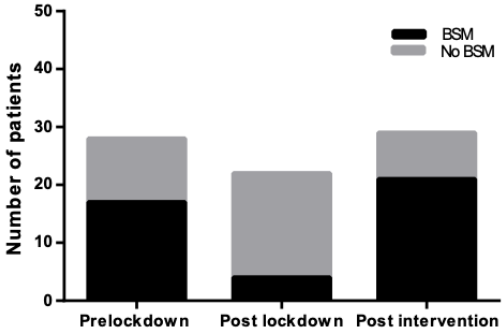

Figure 5. The number of patients being offered a DEXA (dual energy X-ray absorptiometry) scan after the lockdown was significantly reduced (*P*<.001); post intervention, there was a significant increase in patients being requested a DEXA scan (*P*<.001). While numbers of DEXA scans offered increased post intervention compared to the prelockdown period, this was not statistically significant (*P*>.05).

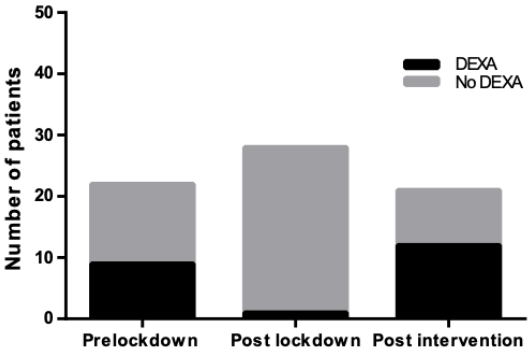

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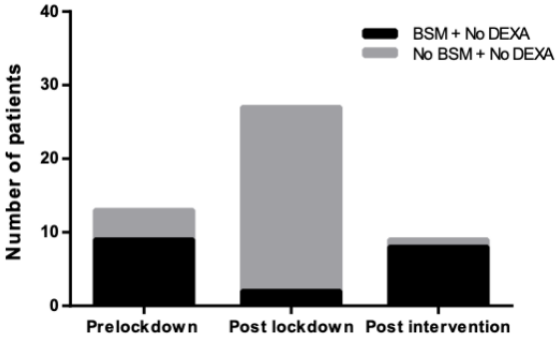
Figure 6. The number of DEXA (dual energy X-ray absorptiometry)-eligible patients who did not have a DEXA scan requested but were started on bone-sparing medication (BSM) significantly dropped following the lockdown (*P*<.001). Post intervention, this significantly increased (*P*<.001), with greater numbers of patients prescribed BSM.



Vitamin D/Calcium Prescription

The number of patients receiving the correct vitamin D/calcium treatment following the lockdown was significantly reduced (*P*=.02) with a drop from 81.6% (n=40) to 58% (n=29). Following the implementation of the "MRS BAD BONES" mnemonic, it was found that prescriptions increased to 85.7% (n=42) (*P*=.003), and this was significant when compared to the postlockdown data (Figure 3). However, there was no significant difference between the postintervention and prelockdown findings (*P*=.69).

Bone-Sparing Medication Prescription

As seen in Figure 4, following the UK lockdown, only 18.2% (n=4) of patients, compared to 60.7% (n=17) of patients prelockdown, were prescribed bone-sparing medication. This represents a significant drop (*P*=.004). However, following the implementation of the "MRS BAD BONES" mnemonic, the prescription of these medications significantly increased to 72.4% (n=21) compared to post lockdown (*P*<.001).

DEXA Scan Requests

There was a significant drop (*P*=.003) in DEXA scan requests from 40.1% (n=9) to 3.6% (n=1) among eligible patients in the postlockdown period despite a normal service. In the postintervention phase, this number increased to 60% (n=12) and was of significance (*P*<.001) compared to the postlockdown data, as represented in Figure 5. While the percentage of patients with DEXA scans requested increased from 40.1% (n=9) in the prelockdown period, to 60% (n=12) in the postintervention period, this was not statistically significant (*P*=.37). A number of patients were eligible for a DEXA scan as per the guidelines but did not have one requested. Alternatively, they were treated with bone-sparing medication. As seen in Table 3 and Figure 6, prelockdown, 69.2% (n=9) of this subgroup had bone-sparing medication prescribed. Following the lockdown, this dropped to 7.4% (n=2), which was a significant drop (*P*<.001). Post intervention, this significantly increased to 88.9% (n=8) (*P*<.001) when compared to the postlockdown figures.

Discussion

Principal Findings

A significant percentage of the patients with a femoral neck fracture who attended UHCW did not receive the correct secondary fragility fracture prevention treatment following the UK lockdown due to the COVID-19 pandemic. Other than PTH, blood testing was performed per guidelines during the 3 phases, but these serum results were not actioned appropriately post lockdown. The redeployment of the orthogeriatric team, who primarily action these results, was the biggest factor leading to this. Clinical management of patients with fragility fractures is often suboptimal even under normal circumstances; a prior study on the secondary prevention of fragility fractures showed that despite steps being taken to increase awareness among junior doctors and nurse practitioners, improvements were still below target [11].

The direct implications on patients who did not receive adequate bone protection are unclear; a follow-up of this cohort may be useful for outcome studies. However, the literature suggests a 10%-13% overall risk of sustaining a secondary contralateral femoral neck fracture, which leads to a 1-year mortality of 31.6% compared to 27.3% for the index fracture. Furthermore, a risk of 28.6% is seen for any other osteoporosis-related fractures. It is clear this injury causes a significant morbidity and mortality among the elderly, as well as financial burden to the NHS [12,13].

The blood tests revealed deficiencies in serum vitamin D, which is to be anticipated in this population [9], but normal adjusted calcium levels and eGFR. No PTH measurements were performed post lockdown, with very few prior; no particular reason for this was identified. Parathyroid pathologies are relatively common endocrine disorders, particularly in elderly women [14]. PTH is vital for the maintenance of calcium homeostasis through its catabolic and anabolic actions that regulate bone remodeling. Hypoparathyroidism can lead to osteoporosis. PTH replacement therapy has been shown to remedy this abnormality [15]. Equally, patients suffering with primary hyperparathyroidism, particularly the normocalcemic variant, have more skeletal complications than is classically seen in hypercalcemic primary hyperparathyroidism. One study found osteoporosis in 57% of a population with normocalcemic primary hyperparathyroidism [16]. Hence, measuring serum PTH, per local guidelines, is important in this cohort and needs to be improved.

NICE recommendations to consider DEXA scanning and treatment of target groups to prevent fragility fractures are based on the extensive evidence that they reduce the risk of hip

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fractures and are cost-effective when compared to untreated osteoporosis [17,18]. In younger patients, bone mineral density assessment is needed to confirm the diagnosis of osteoporosis since high-energy trauma is often required to fracture the proximal femur. However, appropriate treatment can be commenced in elderly patients with a fragility fracture without the requirement for a DEXA scan [19]. Hence, it is good clinical practice to address this while the patient is still in hospital.

Strengths

This study highlighted the positive impact on patient care that can be achieved by service changes implemented at a junior level. Following the dissemination of our findings and implementation of the "MRS BAD BONES" mnemonic, there was a significant improvement in the management of bone health compared to the postlockdown period, and was comparable to the prelockdown data. Mnemonics are used in various sectors for teaching purposes. Though used in a hospital environment here, this acronym has the potential to be beneficial in a wider setting, including primary care and medical education. Studies have demonstrated the role of mnemonic strategies in reshaping brain networks and improving memory performance [20]. Finally, though utilized during the COVID-19 pandemic, the use of this mnemonic has the potential to have an ongoing positive impact in the post–COVID-19 era.

Limitations

Not all parameters included in the "MRS BAD BONES" mnemonic were assessed in this study due to restricted access in requesting archived written documents during the pandemic. Consequently, data were primarily collected using information available from electronic patient records. Those parameters not assessed include medication review, rheumatology/renal advice, smoking cessation, alcohol limits, nutrition, and exercise. The authors opted to use "MRS BAD BONES" despite this limitation because of the importance of each parameter as well as being a memorable acronym that provides a holistic approach to managing fragility fractures as endorsed by NICE. Drugs, particularly glucocorticoids, can induce osteoporosis, which makes a medication review an important assessment. Rheumatology or renal advice can be sought in complex cases where specialist treatment input is required, particularly in patients with severe renal impairment or intolerance of first-line bisphosphonates. Lifestyle changes, including smoking cessation, drinking alcohol within recommended limits, optimizing nutrition, and regular exercise, can all improve bone health and reduce the risk of fragility fractures [17]. Further research may provide insight into whether these factors were significantly affected by the use of the mnemonic. Furthermore, the return of the orthogeriatric team to the orthopedic unit will have contributed to improvements. Due to the unpredictability of the pandemic, their arrival was an unforeseen factor during the intervention phase. However, 62% of the patients in the postintervention phase did not receive an orthogeriatric review because they were discharged prior to their return. Hence, a large proportion of these patients had optimized management prior to the gradual return of services. Another limitation is that the guidelines state all male patients, as well as female patients <75 years old, should have a DEXA scan. Our results showed a significant proportion of patients eligible for DEXA scanning were instead treated with bone-sparing medications. The local guidelines do not take into consideration the experience and clinical judgment made by the orthogeriatric team who on occasions will commence all male patients and female patients <75 years old deemed high risk for osteoporosis onto bone-sparing medications without the need for bone density assessment. An update on the local guidelines to reflect this should be considered when next reviewed. A final limitation of this study is that 50 consecutive patients with femoral neck fractures were collected during 3 phases over a 5-month period. This may be considered a small population over a short duration. A longer period of analysis including the recruitment of patients with nonhip fragility fractures may be useful to further evaluate the findings. Additionally, dissemination of this mnemonic to other orthopedic units might be useful to further validate our results.

Conclusion

Management of bone health is an important consideration for patients with femoral neck fractures due to the morbidity and mortality osteoporosis poses, and the significant financial burden fragility injuries cause the NHS. Orthogeriatric team input is invaluable in coordinating secondary prevention of fragility fractures. However, with the uncertainty of future COVID-19 outbreaks, subsequent orthogeriatrician redeployment may be required. Despite this, ensuring that fragility fracture management is not forgotten is vital. Here, we present the use of a mnemonic, "MRS BAD BONES," aimed at junior doctors, advanced nurse practitioners, and medical students, which could be used to improve awareness of major areas of assessment and management of secondary prevention of fragility fractures, and maintain optimal quality of care.

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Conflicts of Interest

None declared.

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Abbreviations

DEXA: dual energy X-ray absorptiometry
eGFR: estimated glomerular filtration rate
MRS BAD BONES: medication review, rheumatology/renal advice, smoking cessation; blood tests, alcohol limits, DEXA scan; bone-sparing medications, orthogeriatric review, nutrition, exercise, supplement
NHS: National Health Service
NICE: National Institute for Health and Care Excellence
PTH: parathyroid hormone
T&O: Trauma and Orthopaedics
UHCW: University Hospital of Coventry and Warwickshire

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