

Emerging topics in dementia care and services

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Abstract

Background: The National Institute on Aging (NIA), in conjunction with the Department of Health and Human Services as part of the National Alzheimer's Project Act (NAPA), convened a *2020 Dementia Care, Caregiving, and Services Research Summit Virtual Meeting Series*. This review article summarizes three areas of emerging science that are likely to grow in importance given advances in measurement, technologies, and diagnostic tests that were presented at the Summit.

Results: Dr. Cassel discussed novel ethical considerations that have resulted from scientific advances that have enabled early diagnosis of pre-clinical dementia. Dr. Monin then summarized issues regarding emotional experiences in persons with dementia and their caregivers and care partners, including the protective impact of positive emotion and heterogeneity of differences in emotion by dementia type and individual characteristics that affect emotional processes with disease progression. Finally, Dr. Jared Bengt provided an overview of the role of technologies in buffering the impact of cognitive change on real-world functioning and their utility in safety and monitoring of function and treatment adherence, facilitating communication and transportation, and increasing access to specialists in underserved or remote areas.

Conclusions: National policy initiatives, supported by strong advocacy and increased federal investments, have accelerated the pace of scientific inquiry and innovation related to dementia care and services but have raised some new concerns regarding ethics, disparities, and attending to individual needs, capabilities, and preferences.

KEYWORDS

dementia care, emotional function, technology

INTRODUCTION

The National Alzheimer's Project Act, National Research Summits, strong advocacy, and federal investments have accelerated the pace of scientific inquiry and innovation

devoted to advances to avert and attenuate the impacts of dementia care. Most topics addressed at the 2020 National Research Summits on Care, Services, and Supports for Persons with Dementia and Their Caregivers fit well within long-recognized research categories.

Findings from this review were presented at the 2020 Dementia Care, Caregiving, and Services Research Summit Virtual Meeting Series.

However, the Summit organizers recognized that advances in diagnostic testing, potential new therapies and technologies as well as insights about disease manifestations will lead to new challenges and opportunities to benefit the lives of persons living with dementia (PLWD) and their caregivers. This review article addresses the state of evidence in each of three areas of scientific inquiry that are timely significant and meritorious of greater research attention and were presented in an emerging topics session at the 2020 National Research Summit. The article first discusses scientific advances that have enabled early diagnosis of pre-clinical Alzheimer's disease and the resulting promises and challenges. The article next addresses the topic of emotional experiences, by disease type and individual characteristics, in persons with dementia and their caregivers and care partners, including positive emotions associated with caregiving. Finally, the article explores the possibilities of technologies to buffer the impact of cognitive change on real-world functioning in PLWD and the potential utility for safety and monitoring of function and treatment adherence, facilitating communication and transportation, and increasing access to specialists for PLWD in underserved or remote areas. Despite pragmatic challenges and risks, these new technologies hold tremendous promise to benefit the lives of PLWD and their caregivers and merit further support for research development and implementation. In each of these three areas, the science is only now emerging but is likely to grow in importance given advances in measurement, technologies, and diagnostic tests. Specific research recommendations to further develop these emerging topics are presented in Table 1.

Pre-clinical diagnosis: An ethical framework for patients and caregivers

Over the past two decades, Alzheimer's Disease has been re-defined on the basis of biomarkers. Previously, clinical symptoms and signs were used to define three clinical syndromes: (1) age-related memory impairment, in which there are memory complaints without objective deficits; (2) mild cognitive impairment, in which objective signs of cognitive impairment are present but without impact on overall function; and (3) dementia, in which cognitive impairment is associated with functional impairment. More recently, three key biological features—amyloid plaques, tau neurofibrillary tangles, and neurodegeneration—have been used to characterize Alzheimer's disease, including a preclinical phase that may span several decades.¹ Concurrently, advancements in the diagnosis of Alzheimer's disease through imaging

Key Points

- Scientific advances in diagnostic testing that enable early diagnosis of pre-clinical dementia have raised new bioethical considerations for individuals, their care partners, and clinicians.
- Emotional functioning in persons with dementia and their caregivers and care partners is an emerging area of dyadic research with important implications for dementia caregiving research and practice.
- The rapid pace of technological innovation affords opportunities to buffer the impact and improve quality of life among persons living with dementia and their care partners and caregivers.

Why Does this Paper Matter?

Important new areas of diagnosis, treatment, and understanding are emerging, which have practical implications for daily life and clinical care.

and blood biomarkers² raise the possibility that large numbers of older Americans may receive a diagnosis well before a clinical diagnosis of dementia can be established. The numbers of persons diagnosed could increase even more dramatically if direct-to-consumer testing becomes available.³ If use is intended for clinical purposes, it is important that biomarkers be accurate with high specificity. For example, approximately 25–30% of older persons with normal cognitive function have positive amyloid PET scans.⁴ False positive tests can lead to unnecessary worry.

An earlier diagnosis raises ethical issues and tradeoffs between the positive benefits of knowing one's risk versus the burden of learning the likelihood of living with an untreatable condition. In some ways, these two views are subsumed by broader debate in medicine about disclosure and decision making in the situation of a life-threatening condition. A challenge is the heterogeneity among individuals: some persons prefer to be equipped with as much prognostic knowledge as possible, in part to feel in control in planning for the future. Others fear anxiety and worry posed by knowledge, and stigma that comes with it. Moreover, there is variability among those who care for PLWD: some clinicians worry about taking away hope, whereas others define hope as trust to be respected and not abandoned as cognition fails. Given this context, an ethical framework to effectively address

TABLE 1 Emerging topics research questions

Ethical implications of pre-clinical diagnosis

1. Can empirical research with patients and families from different educational, cultural and ethnic backgrounds be used to construct national guidelines for framing decisions to be evaluated for preclinical diagnosis and the follow up that is required?
2. What is the impact on people who receive preclinical diagnosis and how does it change over time with the transition to symptomatic dementia?
3. What are the best approaches to reducing stigma associated with a pre-clinical dementia diagnosis?

Emotional and affective experiences in persons living with dementia and their care partners

1. How do daily experiences of positive and negative emotions independently and simultaneously impact mental and physical well-being for persons living with dementia and their care partners?
2. What self-reported, proxy, and observational measures of positive and negative emotions are valid and reliable for capturing the experiences of persons living at each stage of the disease progression?
3. How do factors such as disease type and severity, gender, and culture affect self-reported experiences of emotion in the context of dementia?
4. Do interventions that target emotional experiences of persons living with dementia improve their own and their care partners' well-being and does targeting the emotions of the couple have synergistic effects?

Technological reserve for health, well-being, and independence

1. What are the most effective technologies to promote independence and well-being in ADRD?
2. What are the most effective strategies for disseminating and implementing these technologies in real world settings?
3. What disparities in technological environments, including availability and technology literacy, hamper or inhibit implementation of strategies in diverse and socio-economically disadvantaged populations with ADRD?

preclinical diagnosis must attend to the following four factors.

1. *Clinical decision making*—In the context of clinical care, PLWD are confronted with decisions about the care of concurrent medical conditions as well as care for dementia. Even in the early or mild phases of a cognitive disorder, concurrent medical conditions and medication side effects can have amplified or unpredictable manifestations. Knowledge of these vulnerabilities can be very helpful in every aspect of clinical care. There are also medical (e.g., hypertension treatment) and behavioral (e.g., physical activity, social engagement, and sleep) factors that can help enhance function and may slow progression of symptoms. For some persons, the number and severity of other conditions might shift the focus of clinical decision making toward shorter term goals, such as those that focus on symptoms and quality of life, rather than longer term goals, such as prevention of chronic diseases.⁵ These factors favor wider availability of preclinical diagnostics.
2. *Social context*—People with many kinds of disability, including dementia, face stigma that may lead to stereotyping, loss of status, potential discrimination, and adverse effects that detract from quality of life^{6,7} and inhibit help-seeking behaviors and use of services. As advocacy groups have brought greater visibility, more people are able to understand that personhood is not diminished by memory loss. Early stages of cognitive illness, such as MCI, make this phenomenon an extremely important factor to overcome given the importance of sustaining social function and inclusion in meaningful activities. The moral imperative for clinicians and society is to improve public information, reduce stigma, and alleviate social ramifications of diagnosis on appropriate access to services and supports for PLWD and their families.
3. *Advance care planning*—The long course of ADRD and its devastating effects on decision-making capacity make it particularly important to initiate discussions about future medical care early in the disease trajectory.⁸ Caregiving burden, stigma, and impaired decisional capacity amplify the difficulty and importance of advance care planning for those with MCI or pre-clinical dementia.^{9,10} Facing a likelihood of incapacity increases the value of assigning proxy decision makers, for health care as well as for personal, financial and other matters.^{8,10,11} In the situation of early or “pre-clinical” diagnosis, many other kinds of potential decisions also come into focus, such as preparation for changes in one's living situation.
4. *Participation in research*—Early diagnosis based on biomarkers can present an opportunity to participate in research trials to test interventions before serious clinical decline has occurred, which is a major focus of current pharmacological research. Obvious advantages of early diagnosis include access to clinical trials of agents with the potential to prevent or delay decline, or to ameliorate some symptoms. Benefits to society are also significant, as early interventions are likely to be the most effective. Other advantages to increasing the numbers of people who have early biomarker findings are the power of big data analytics to reveal risk factor patterns, demographic factors, and otherwise hidden variables providing new research directions. Patients may participate in research with the hope that they may personally benefit, but many

also report an intrinsic value in knowing they are contributing to progress that may benefit others and giving meaning to the existential threat created by diagnosis. Conversely, as with all clinical trials, there are burdens (e.g., repeated tests and interviews) and risks associated with participation, including potential adverse effects of experimental treatments in the context of a disease that is still asymptomatic.

In summary, advances of biomarker capability have redefined dementia, with important implications for enhanced efforts to strengthen clinical decision-making and care planning, educate researchers and clinicians about effective strategies to elicit authentic choices from patients and family caregivers, and broader awareness and stigma reduction campaigns to attenuate discrimination and promote inclusion of those living with both early and later stage disease.

Emotional and affective experiences in persons living with dementia and their care partners

Emotional and affective experiences of PLWD and their care partners have received little research attention, despite their strong connections with health.¹² Emotions are often defined as discrete, short-lived “action patterns” that are biologically determined and pancultural (e.g., anger, sadness, happiness, disgust).¹³ Another way of capturing emotions involves measuring “affect,” which encompasses the underlying building blocks of emotion: valence, arousal, and motivational intensity.¹⁴ Measuring affect is consistent with the theory of constructed emotions, which suggests that emotions are constructed by individuals’ experiences whereby the brain categorizes the present moment via interoceptive predictions (awareness of changes in physiology; pleasure, displeasure, arousal, and calmness) and the emotion concepts from one’s culture.¹⁵ There is growing consensus that emotions and affect should be studied, more often, in the context of close relationships, because this is where they are most likely to occur. Dementia caregiving is one of these close relationship contexts.

Most research on emotions and affect in dementia caregiving has focused on negative experiences such as guilt, anxiety, anger, distress, and apathy (see Table 2 for examples of measures). Taxonomies of emotions in psychology research commonly include distress and anxiety as everyday emotions. In clinical sciences, these terms (e.g., anxiety and distress) are referred to and measured as part of diagnosing mental health problems. In dementia caregiving research, greater care partner self-reported

distress is associated with worse care partner physical health, such as cardiovascular disease.^{28,29} There is, however, a growing awareness of the emotional complexity in dementia caregiving and that negative and positive emotions are not mutually exclusive.^{30,31} In terms of positive emotions specifically, the dementia caregiving literature is sorely lacking with exceptions (e.g., gratitude, compassion).^{32,33} Nevertheless, a large literature has demonstrated that positive psychological experiences (e.g., feelings about meaning and purpose in life and perceived appreciation as measured by the Positive Aspects of Caregiving scale³⁴) have benefits for care partners’ health and well-being. No positive emotion or affect concepts are included in the Positive Aspects of Caregiving scale.³⁵

To date, research on emotion and affect in persons with dementia has rarely involved asking persons with dementia about their own experiences; the field has been dominated by proxy-reported measures and observational rating systems. For example, clinician or care partner ratings of anxiety in the person with dementia have been widely studied,³⁶ and measures of agitation and other emotions are commonly included in dementia symptom inventories, such as the Neuropsychiatric Inventory.²⁴ The rise of person-centered outcomes research has stimulated awareness of the importance of asking PLWD about their own experiences. However, most efforts to date have relied on measures designed for the general population (e.g. the Positive and Negative Affect Scale¹⁷) due to a lack of established measures for use among persons with dementia. Much work is needed to adapt existing self-report emotion and affect scales to accommodate some degree of cognitive impairment and still be reliable. A shift is also needed in the emphasis on emotions and affect as they occur in everyday experiences rather than clinical psychological diagnosis.

Reciprocity and bidirectionality of emotions and affect and outcomes for both persons with dementia and care partners is another important area of inquiry with implications for interventional research. For instance, greater compassionate love reported by the person with dementia is associated with greater compassionate love in the care partner, as well as less burden (but not depressive symptoms) and greater positive appraisal of caregiving.³³ A recent laboratory study found that independent observer-rated genuine smiles from persons with dementia toward their caregivers were associated with better caregiver mental health.³⁷ These studies emphasize the need for dyadic interventions that address the emotions of both individuals.

There is tremendous heterogeneity in the experience and expression of emotions and affect, and this applies to the context of dementia.³⁸ For example, persons with

TABLE 2 Examples of measures of emotion and affect experiences in dementia caregiving research

Measure	Description	Respondent in prior dementia research
Positive and Negative Affect Scale ¹⁷	Ten items measuring positive affect (e.g., excited, inspired) and 10 items measuring negative affect (e.g., upset, afraid). Each item is rated on a five-point scale (very slightly to not at all) to measure the extent to which the affect has been experienced in a specified time frame (e.g. the past week)	Care partner self-report; Person living with dementia self-report
Differential Emotions Scale ¹⁸	Thirty-item adjective checklist, with three adjectives of each of the 10 emotions that are considered fundamental by Izard: joy, surprise, anger, disgust, contempt, shame, guilt, fear, interest, and sadness. Each item is administered on a five-point (never to very often) scale	Care partner self-report
Dementia Mood Picture Test ¹⁹	Six pictures of line drawing faces (e.g., happy, sad, good mood, bad mood) are shown one by one to the individual, and he or she is asked, "Are you in a good [bad, angry, sad, worried, happy] mood?" If the answer is "yes," the participant is then asked, "Are you in a very good [bad, angry, sad, worried, happy] mood?" The answers are rated as "yes," "no," or "very much"	Person living with dementia self-report
AD-RD Mood Scale ²⁰	Thirty-four items in two positive subscales (spirited and contented) and three negative subscales (hostile, apathetic, and sad). Five-point scale (never to always) in the last 7 days.	Proxy report about the person living with dementia
Emotion Facial Action Coding System ²¹	A system to taxonomize human facial movements by their appearance on the face. Combinations of action units are associated with the following emotions: happiness, sadness, anger, surprise, disgust, fear, and contempt. Establishes the presence of an emotion during a video or still picture.	Observations of person living with dementia and the care partner
Observed Emotion Rating Scale ²²	Observers rate during a 10-min observation with a PLWD the amount of each type of affect: pleasure, anger, anxiety/fear, sadness, and general alertness on a scale from 1 (never) to 5 (more than 5 min)	Observations of the person living with dementia
Brief Agitation Rating Scale ²³	Observer rates 10 items (hitting, grabbing, pacing, repetitious mannerisms, restlessness, screaming, repetitive sentences, strange noises, complaining) on a scale from 1 (none) to 7 (several times a day) over the past 2 weeks in long-term care settings	Observations of the person living with dementia
Neuropsychiatric Inventory ²⁴	Twelve sub-domains of behavioral functioning: delusions, hallucinations, agitation/aggression, dysphoria, anxiety, euphoria, apathy, disinhibition, irritability/lability, aberrant motor activity, nighttime behavioral disturbances, and appetite and eating abnormalities. Rate yes/no. If yes, then frequency on a four-point scale and severity on a three-point scale, and distress the symptoms causes on a five-point scale	Care partner observations of the person living with dementia
Compassionate Love Scale ²⁵	A 21-item scale designed to measure feelings of compassionate love toward close others. Compassionate love toward close others is defined as an attitude toward close others that involves	Care partner self-reports; Person living with dementia self-reports

(Continues)

TABLE 2 (Continued)

Measure	Description	Respondent in prior dementia research
	behavior, feeling, and thinking that is all focused on “caring, concern, tenderness, and an orientation toward supporting, helping, and understanding the others, particularly when the others are perceived to be suffering or in need.” Close others are significant others in one’s life, including friends and family members. Respondents answer each item on a seven-point Likert-type scale ranging from 1 (not at all true of me) to 7 (very true of me)	
Caregiver Guilt Questionnaire ²⁶	Twenty-two items assessing five domains: guilt about doing wrong by the care recipient, guilt about not rising to the occasion as caregivers, guilt about self-care, guilt about neglecting other relatives, and guilt about having negative feelings toward other people. Participants rate on a 4-point (never to always) in the past week	Care partner self-reports
Gratitude Adjective Checklist ²⁷	Three-item measure comprised of the sum of affect adjectives: grateful, thankful, and appreciative. It can be framed over short or longer time, by varying the time specified in the instructions, for example right now, think about “yesterday,” or think about “the past few weeks”	Care partner self-reports

Note: This list of measures is not meant to be comprehensive but rather as a reflection of the state of the field.

Frontotemporal Dementia tend to have incongruent emotional reactions to emotion-eliciting stimuli (e.g. sadness in response to a film meant to elicit happiness) than persons without dementia or Alzheimer’s Disease.³⁹ They also are more likely to experience negative emotions, making caregiving for these persons more difficult.⁴⁰ Pervasive gender differences have been found such that female dementia care partners report more distress than male dementia care partners.⁴¹ Concepts such as familism among Latinos, filial obligation among Asians, and religious coping among African Americans are proposed as mediating factors through which some groups perceive caregiving more or less positively. Thus, such factors as disease type and severity, gender, and culture affect self-reported experiences of emotions in the context of dementia, though this evidence has not been systematically compiled to date.

Interventions with promise for affecting emotions and affect in both PLWD and their care partners include mindfulness-based programs⁴² and physical activity.⁴³ Mindfulness interventions have shown moderate to large effects on distress in care partners⁴² and may enhance quality of life in persons with dementia⁴⁴ based on quality of life measures that include emotions (e.g., the QOL-AD includes a mood item⁴⁵). Physical activity interventions for dementia caregivers appear to lower distress

and increase positive affect.⁴³ Cognitive behavioral therapy (CBT) addresses emotional experiences and may be the easiest to disseminate to both caregivers and PLWD.⁴⁶

Few dementia caregiving interventions have targeted and measured specific emotions or affect beyond distress and anxiety. An exception CBT⁴⁷ and interventions that incorporate aspects from Acceptance and Commitment Therapy and Compassion-Focused Therapy⁴⁸ have been found to decrease care partner guilt. Another example is a positive emotion regulation intervention called Life Enhancing Activities for Family caregivers that improved positive emotions (i.e., a composite including interest, enjoyment, awe, gratitude, hope, and love).⁴⁹

Toward technological reserve-smart systems for health, well-being, and independence

Digital technology increasingly permeates all aspects of daily life, and those living with ADRD are no exception.⁵⁰ Leveraging technological habits and environments equipped with networked or internet connected devices holds potential to mitigate the impact of cognitive decline on real world functioning in those with ADRD, a potential we term *technological reserve*.⁵¹

The promise of technological reserve

While numerous technologies to address facets of ADRD care are available, current approaches tend to fall into three broad categories (see Table 3). The first are cognitive prosthetics, where a device or service directly compensates for cognitive lapses in complex instrumental daily activities. For example, smartphones can help to compensate for memory loss by providing contextualized reminders such as prompts to take medications at a particular time or location.^{52,53} Automatic billpay permits persons with ADRD and their families to streamline financial tasks that are frequently impacted by cognitive decline⁵⁴ as the individual does not have to remember to pay a bill or the steps of writing a check. Numerous promising technologies have been developed in this space, though, large randomized trials, best practices, and widespread adoption of any given cognitive prosthetic are, thus far, generally lacking.^{55,56}

A second broad class of technologies are those that serve as a scaffolding to support safety, independence, and well-being more basic activities of daily living in the home. Seminal work in this area, such as the Gloucester smart home,⁵⁷ automated prompting systems for hand washing,⁵⁸ and now sensor and robot-assisted environments⁵⁹ offer powerful demonstrations of how technological innovation can facilitate aging in place among individuals with ADRD. While these technological scaffolds continue to proliferate, results from a recently completed large pragmatic clinical trial that involved comparing outcomes from a group of individuals with ADRD randomized to receive an individualized assistive technology plan with prompting technologies, safety monitors, leisure supports, and telecare versus controls⁶⁰ did not show an effect on the average duration of living outside an institution. Thus, additional study is needed to identify the most effective components of technological scaffolding for widespread use.

Technology may also promote connection, and thus ameliorate loneliness, social isolation, and depression that are significant predictors of overall quality of life in those affected by ADRD.⁶¹ As the recent pandemic has highlighted, video-enabled calls with family, friends, and medical providers can be critical (if imperfect) platforms for supporting individuals who may otherwise be isolated.⁶² Recent research on service robots, such as the EU-funded MARIO project, demonstrates the promise of technological interventions to improve perceived social support of those with ADRD.^{63,64} Technological platforms may also aide care partners, via accessibility of social support^{64,65} and health information. In sum, initial studies into technology-enabled platforms for reducing psychosocial burden of ADRD are promising,⁶¹ but again

TABLE 3 Benefits and limitations of technological innovations in dementia care

Benefits: Ways technology can support those with dementia

- *Cognitive prosthetics:* Devices or services that directly compensates for cognitive lapses in complex instrumental daily activities
 - Automated bill pay
 - Smartphone reminders that use GPS location, time, and person based information for activities in the community
 - Global position system (GPS) mapping, sensor systems, and self-driving technologies to support driving
- *Scaffolding:* Devices or services that support safety, independence, and well-being in more basic activities of daily living in the home
 - Remote monitoring via internet enabled cameras
 - GPS locators for wandering identification and prevention
 - Automated systems to prompt and monitor for errors in hygiene tasks
 - Service robots to provide in home health for a variety of tasks
- *Connection:* Technologies that allow for continued connection and engagement
 - Video, text, and social forums to reduce loneliness and isolation
 - Service robots that provide social stimulation, games, and interaction
 - Virtual support groups and electronic portals for readier access to health care providers

Limitations of technology research in dementia care

- *Access:* Increasing the availability, accessibility, and usability of technology
- *Security:* Ensuring privacy and information security in research and practice
- *Platform Stability:* Creating stable and usable platforms for research and practice
- *Policy and Regulation:* As effective approaches are developed, payors and regulatory practices have to be developed in parallel

no particular system or platform has been broadly adopted among those with ADRD.

Ongoing challenges to technological innovation

Despite the potential of technological reserve, several broad challenges in the area of technology for ADRD remain. First, as previously noted, assistive technologies for ADRD have generally been studied in the context of small trials and demonstration projects rather than large-scale rigorously designed trials. Trials of technological innovations are complicated by the rapid pace of change and by the divergent needs of technology companies to continuously innovate to meet market needs or take advantage of new features, those living with ADRD who

seek to capitalize on ownership of and familiarity with existing devices/services, and researchers who require stable and standardized platforms⁶⁶ when conducting trials that may last several years. Finding ways to harmonize the pace of innovation, the needs of individuals with ADRD, and the time required for rigorous clinical research remains an ongoing challenge.

Social and demographic characteristics of those affected by ADRD may limit access and use of promising technologies.⁶⁷ Infrastructure such as internet access is often a prerequisite to technology use, but as of 2019 more than 41% of older adults reported that they did not have high-speed broadband service.⁶⁸ Little is known about the availability of broadband internet and access to other digital technologies in senior housing, assisted living, and in nursing facilities, where individuals with ADRD often reside. Cohort differences in technological literacy may also be present, and adjusting technologies to meet individual differences in baseline familiarity with technology may need to be considered when developing and interpreting the effectiveness of interventions.^{67,69} Those with lower incomes are less likely to have internet access and smartphones,⁶⁸ so as effective technologies become available researchers must partner with policy makers and economists to understand how to pay for technologies when scaling up their use.

Finally, digital technologies often record precise locations, health history/status, and financial transactions among other personal information, posing privacy considerations that may be amplified in the context of memory loss. If such “big data” are used responsibly, then these databanks can improve diagnoses, track progression, and improve the lives of those with ADRD. If such data are used irresponsibly, then individual data may become identifiable⁷⁰; the technologies may become or be perceived as invasive, and ethical and legal issues may emerge. Further, dementia diagnoses can carry social stigma and result in adverse outcomes including impacts on employability or insurance eligibility.⁷¹ Against this backdrop, working to develop robust security around technologies that identify and support ADRD is paramount. Such privacy concerns are new challenges for behavioral scientists, institutional review boards, and open data sharing practices. Techniques and ethical frameworks to understand and mitigate these risks are relatively unexplored, particularly in cognitively impaired populations.^{72,73}

The path forward: Developing technological reserve in those impacted by ADRD

The social and behavioral technological research agenda will require a multi-pronged effort (Table 3).⁷⁴ First, more

work is needed to overcome barriers to the timely and transparent evaluation of technological interventions for persons living with ADRD in rigorous efficacy trials and implementation studies that facilitate partnerships between researchers and technology innovators. In parallel, additional work is needed to understand, promote, and make accessible the technological environment of those with ADRD in diverse groups. This will include evaluating how socioeconomic, infrastructure, and demographic patterns limit or facilitate the utility of day-to-day technologies, ensuring access of technological interventions to those who need them, and informing public policy to address disparities in access and provide cost effective care. Behavioral researchers also need to collaborate closely with technologists in order to develop ADRD-accessible interfaces that are stable and standardized. Such groups, in conjunction with those with ADRD, care partners, and legal experts, need to develop standards for securing information and protecting privacy while also allowing researchers and clinicians access to relevant data. Finally, as technologies develop, regulatory agencies including the Food and Drug Administration and Health and Human Services will need the assistance of research and broader ADRD community to ensure safety and security as technologies are implemented.

DISCUSSION

National policy initiatives, supported by strong advocacy and increased federal investments, have accelerated the pace of scientific inquiry and innovation related to dementia care and services. With such successes also come challenges that will become increasingly clear with time. The reclassification of Alzheimer's disease from a clinical syndrome to a disease with onset and pathological stages defined through biomarkers raises both hope and concern, hope for earlier treatment to prevent disease or progression. Yet the potential adverse consequences on persons with Alzheimer's disease and their families including the possibility for exacerbating population-level disparities in detection and treatment are only beginning to be understood. The impact of dementia on PLWD and caregiver emotions, including differential effects and coping strategies by disease phase and etiology and in various cultures, is incompletely understood, with implications for individual and dyadic behavioral strategies, as well as pharmacologic treatments. Technology, which has radically affected the lives of Americans, holds a yet unrealized promise of compensating for some losses and making others more bearable with disease progression, while raising concerns regarding inequities in access and the exacerbation of disparities.⁷⁵ These three areas of emerging science will

certainly generate a next generation of gaps and opportunities for research, clinical care, and daily practice.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to report.

AUTHOR CONTRIBUTIONS

Study concept and design: Jennifer L. Wolff and David B. Reuben; Acquisition of subjects and/or data: Jennifer L. Wolff, Jared F. Benge, Christine K. Cassel, Joan K. Monin, David B. Reuben; Analysis and interpretation of data: Jennifer L. Wolff, Jared F. Benge, Christine K. Cassel, Joan K. Monin, David B. Reuben; Manuscript preparation: Jennifer L. Wolff, Jared F. Benge, Christine K. Cassel, Joan K. Monin, David B. Reuben. All authors approved the final version of the manuscript for submission.

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