Digital Measurement of Subjective Experiences in AD/ADRD

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Abstract

Subjective experiences of well-being, emotions, pain, and loneliness are a primary concern of persons living with Alzheimer's disease and Alzheimer's disease related dementias (AD/ADRD) and their caregivers. Reliable and valid measurement approaches are critical to quantifying these inner processes in treatment studies, but AD/ADRD produce substantial roadblocks to self-report measures of subjective experiences. Technological approaches to gathering passive sensing data about subjective experiences have recently been developed. A promise of passive sensors is their capacity to gather continuous information that could be used to understand within-person dynamics of subjective experiences, and ultimately to better personalize interventions to unique timings and contexts. While there is much enthusiasm about the potential for such measurement tools, there remain a number of challenges (and opportunities for innovation) to generate useful passive measurement tools in AD/ADRD. We briefly summarize some of these challenges and provide suggestions for future innovators in this area.

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Digital Measurement of Subjective Experiences in AD/ADRD

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Subjective quality of life is a primary concern of persons living with Alzheimer's disease and Alzheimer's disease related dementias (AD/ADRD) and their caregivers. Subjective experiences of well-being, affect, pain, and loneliness are frequently primary or secondary outcomes in aging research. Agitation, loss of pleasure, and sadness experiences are among the behavioral symptoms of dementia that lead to the greatest caregiver burden and healthcare costs. Reliable and valid measurement approaches are thus critical to quantifying these inner processes for target identification and treatment studies. AD/ADRD produce substantial roadblocks to the measurement of subjective experiences. Self-report measures of subjective experiences can make substantial demands for cognitive abilities impaired in AD/ADRD (memory, verbal fluency, comprehension) and can be biased by cultural milieu, social situation, and memories and schema of the subjective experience in question. In recent years, technological approaches to gathering data about subjective experiences have been developed implemented, and tested. Passive sensing can be used to gather data proximal to a variety of experiences that would be difficult or impossible to gather without self report. Moreover, a promise of passive sensors and related devices is their capacity to gather continuous information that could be used to understand within-person dynamics of subjective experiences, and, ultimately to better personalize interventions to unique timings and contexts. While there is much enthusiasm about the potential for such tools to support subjective measurement, there remain a number of challenges (and opportunities for innovation) to generate translatable and useful passive measurement tools in AD/ADRD. We briefly summarize some of these challenges and provide accompanying suggestions for future innovators in this area.

Passive sensing occurs when data are acquired by a device without intentional input from the respondent. Sensing typically employs a variety of devices that can be broadly grouped into three clusters: a) smartphones, b) wearables, and c) in-home sensing devices.[1] [2] Common smartphone sensor data streams evaluated in studies of subjective experiences include global position satellite (GPS), accelerometers, Bluetooth and WiFi data streams. These tools can enable quantification of movement and nearby cell phones, eye movements and facial expressions, and ambient noise and speech features.[3] In addition to sensors, smartphones produce meta data such as calls, texts, app use and other device interaction data.[4] Also available on mobile devices are more granular device interaction data that has been used to infer cognitive and emotional processes, such as keyboard analytics like errors or typing speed.[5] Wearable sensors like smartwatches and rings produce data on mobility as well as other physiological parameters, such as heart rate variability, sleep patterns, galvanic skin response, temperature, or respiration rate. In-home sensors have a variety of form factors to include ones that are intended to be "invisible" and interactive ones like robots.[6] In-home sensors include infrared or pressure sensors designed to monitor mobility patterns or other interactions within physical spaces. Audio sensors have been used to gather socially-relevant data such as the quantification of speech.[7] Video data includes collection from 3D cameras that can be used to generate facial or skeletal models that quantify deviations from normative trajectories.[8] Increasingly, researchers have attempted to integrate multiple sensor streams via computational approaches,[9] and create feedback systems to caregivers leveraging passive sensing data.[10]

As consumer-grade devices accumulate greater processing power and novel more powerful sensors are created, it is easy to see why passive sensing research has burgeoned in recent years.

A first principle in considering and reporting on sensor-based subjective experience research is that subjective constructs are inferred. Subjective experiences by definition differ from objective experiences that can be measured directly. Therefore, terminology used in reports should be consistent with the notion that sensing is a proxy for but not directly measuring the construct. This does not mean that sensors cannot be useful for research on subjective constructs. A related point is that the current “gold standard” for validation of passive sensing measures of subjective experience is self-report, which is not free of biases or impact of cognitive impairments. For example, global well-being (*what is your overall well-being?*) can diverge from aggregated immediate experience (*what is your well-being right now?*) measured via ecological momentary assessment (see[11]). Finally, it also should not be forgotten that self-report measures can be adapted to people with cognitive impairment or language production difficulties (e.g., with visual analogue scales[12]), and recent work indicates that active smartphone based assessments ecological momentary assessment are feasible and valid in older adults with mild cognitive impairment.[13]

Central to validation of passive sensing measures in AD/ADRD research is this question: What if “gold standard” subjective experience measurement (e.g., a questionnaire) is difficult or impossible to obtain due to the effects of cognitive impairment? As Kourtis et al.[14] point out that, in late-life depression and Alzheimer’s disease, multiple passive sensors show promise in detecting multiple subjective experiences, like mood, loneliness, suicide risk, agitation, daily life functioning, and dementia onset and progress, but work is only beginning with these measures. For example, An-Yeung et al.[15] evaluated a home-based mobility sensor in adults with a dementia diagnosis, and documented mobility patterns in effort to examine within person dynamics of agitation and apathy. A pilot study by Galambos et al.[16] tested an early dementia detection model in older adults, with home-based sensors detecting changes in the amount of time spent in the bedroom, in the living room, and mealtime activities that have congruence with health assessments. Other passive sensing methods use infrared sensors to assess time spent in the house versus out of the house[17] as well as the speed of ambulation through the house[18] that have correlated with cognitive function changes. Another study[19] found that wireless home-based sensors captured differences in activities of daily living patterns between dementia and healthy individuals. Smartphone-based Bluetooth detection of nearby cell phones, actigraphy, and GPS data have been used for predicting loneliness in college students[20] and between Bluetooth features and depression[3], but this work is only beginning in AD/ADRD.

As several reviews of the literature of sensor based systems of subjective experiences have concluded,[1,21] the great majority of research studies to date have been at the “proof of concept” phase. Few studies have been replicated and few technologies have been evaluated in samples designed for rigorous validation. For research on passive sensing to advance the replicability of sensing, it could be useful to adapt systematic and coordinated methods being used to improve self-report. An enormous amount of effort has gone into developing researcher toolkits like PROMIS and NeuroQoL.[22] These NIH-sponsored projects spearheaded development of common measures of subjective constructs by rigorous item development, reliability and replicability testing in diverse samples so as to mitigate bias, and application of advanced psychometric techniques toward item selection, short-form development to maximize scalability, along with establishment of convergent and divergent validity. Perhaps some processes involved in these coordinated efforts could serve as models to enhancing the utility of passive sensing.

Key roadblocks to creating a such a uniform approach to enhancing replicability of passive sensor data is the intricacies of feature extraction and computational processing of data streams. To move passive sensing toward a more standardized and sharable methods, there are open science solutions to enhance transparency, including platforms to harmonize data standards (for example the Collaborative Aging Research using Technology Initiative (CART)).[23] Repositories for research protocols and other collaborative approaches, such as checklists[24], are available to support best practices in data collection, processing and validation. These initiatives should support greater aggregation of results across studies to enable address fundamental questions about sensing relevant subjective experiences that persist: Which sensor or combination of sensors is most accurate and reliable in sensing aspects of which subjective experiences? How long and at what data density is required to obtain valid results? Which sensors offer the greatest balance of practicality in implementation, unobtrusiveness, cost and data processing demands and validity/reliability?

While the coming years will undoubtably bring a plurality new more-sensitive sensors and new approaches to measuring aspects of subjective experience applicable to ADRD, it is essential that this research accompany robust consideration of privacy preferences and informed consent. For the same reasons that self-report is hampered, so is informed consent in ADRD. Tools to simplify informed consent and assess and improve decisional capacity are available,[25] [23] but the technical and privacy considerations surrounding passive sensing (e.g., comprehension) can present marked challenges even for people without cognitive impairment. Resources such as guidelines to identify best practices in obtaining proxy or individual informed consent and granular choices surrounding the type of data collected could maximize respect for the individual in the informed consent setting.[26] Industry has a major role in this, such as the deployment of health research infrastructure and gate keeping functions to ensure privacy standards are met and maintained during the research alongside software updates.

Another piece of the puzzle is engagement in the community in regard to the setting of the sensor and also the results of research. Few sensors or devices used in the collection of data in sensor studies were designed with older adults in mind. For example, wearable sensors may not be calibrated to age associated factors such as the thinning of skin, and conclusions from those sensors may be erroneous[27]. Therefore, part of the researcher's task is to partner with older adults, caregivers, and other stakeholders through user centered design before deployment.[28] As part of this process, researchers should query participant desires for return of information of sensing data, including at the individual level.[29] Community engaged research approaches may be one way to expand diversity of inclusion in sensor based research, which will be essential to understand biases that may be present.

Paradoxically, these many challenges to passive sensing in AD/ADRD stem from the very same reasons why such approaches offer promise pressing unmet needs. The behavioral symptoms of dementia, including agitation or loss of pleasure, are among the single largest drivers of caregiver distress and institutionalization. There are emerging systems that infer these subjective symptoms by use of passive sensing alongside contemporaneous dynamic data from potential contributors to the onset and sustainment of these symptoms that could be targets for intervention. Given the continuous nature of passive sensing, idiographic approaches are possible, wherein personalized interventions could be applied in a just-in-time fashion based on data garnered from the individual. Making the case for passive sensing in behavioral symptoms even more compelling are the potential risks, costs and harms of existing approaches (e.g., institutionalization). Thus, coordinated efforts at addressing roadblocks to translation of passive sensing of subjective experience in ADRD could lead to transformative approaches that address critical unmet needs.

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