Virtual Assessment as a Way to Reduce Help-Seeking Barriers in Older Adults with Subjective Cognitive Decline

Michael R Kann, BE1*, Peter J Zeiger, BS2, Sandra J Rizer, MA1, Stephanie Cosentino, PhD1 and Martina Azar, PhD3

1Cognitive Neuroscience Division, Department of Neurology, G.H. Sergievsky Center, and Taub Institute for Research on Alzheimer’s Disease and the Aging Brain, Columbia University Medical Center, USA
2Vagelos College of Physicians and Surgeons, Columbia University, USA
3Psychology Department, VA Boston Health Care System, USA

*Corresponding author: Dr. Michael R Kann, BE, Cognitive Neuroscience Division, Department of Neurology, Columbia University, 630 W 168(th) St, P&S Box 16, New York, NY, 10032, USA, Tel: +412-439-3794

Abstract

Subjective cognitive decline (SCD) - an individual’s perception of a decline in cognition in the absence of impairment on formal cognitive testing - is very common amongst older adults. Although SCD is often regarded as a personal health concern, most individuals with SCD do not seek help from a healthcare professional. Help-seeking (HS) is a complex, individualized process that can have significant life course implications for individuals experiencing early-stage cognitive decline. Older adults often face several barriers to HS across a variety of personal, socioeconomic, and cultural domains. The pandemic exacerbated many of these barriers by imposing additional limitations on in-person care. In response to this, virtual assessment became a popular method utilized by healthcare practices to conduct remote care. In this critical review, we review the challenges and triumphs that came with the transition initiated during the pandemic from in-person, pen-paper cognitive assessments to virtual cognitive assessments. Additionally, we address the impact that virtual assessment had in tackling barriers that previously limited individuals with SCD from formal HS. We argue that virtual cognitive assessment helps alleviate health access barriers to HS such as cost, transportation, and physician availability. It also allows individuals with different coping styles and levels of social and healthcare comfort to engage in assessment within more convenient environments. It is our hope that the findings presented in this review are used to inform healthcare practice, public education, and future research targeted towards the use of virtual assessment to facilitate help-seeking in older adults with SCD.

Keywords

Subjective cognitive decline, Virtual assessment, Memory complaints, Help seeking barriers, Sociodemographic barriers

Abbreviations

SCD: Subjective Cognitive Decline; AD: Alzheimer’s Disease, HS: Help-Seeking; MMSE: Mini Mental State Examination; WAIS: Wechsler Adult Intelligence Scale; WISC: Wechsler Intelligence Scale for Children; DKEFS: Delis-Kaplan Executive Functions System; GP: General Practitioner

Introduction to Subjective Cognitive Decline

Subjective cognitive decline (SCD) is an individual’s perception of a decline in their cognition in the absence of impairment on formal cognitive testing [1,2]. Although there has long been debate over the utility of SCD as an early marker of Alzheimer’s disease (AD) [3-14], SCD has gained increasing attention in recent years given its association with multiple AD biomarkers [5,9,12,15]. Depending on the sample population and how SCD is assessed, SCD has been reported to affect between 7% to 70% adults aged 50 and older [16-24]. Certain factors that appear to increase the likelihood that SCD represents pathologic versus typical cognitive aging include the presence of concern [10,13,25,26], complaints of an impact on daily activities [25], age...
of SCD onset [13], subjective decline in memory [13,15], and informant-reported memory complaints [25,27]. Early identification of SCD could allow for implementation of clinical, life-style, and therapeutic interventional strategies at an early stage of the disease when they may be most effective.

Help Seeking in SCD

Although SCD is often viewed as a significant personal health concern, most individuals with SCD do not seek out help from a healthcare professional [22,28,29]. In fact, depending on the sample population and how complaints are assessed, studies have found that only between 2.6% to 26% of older adults with memory complaints seek help, and this tends to occur roughly 1-3 years after symptom onset [29-37]. One study found that while 66% of individuals reported SCD (n = 126), only one person mentioned their concerns to a general practitioner [22]. This raises the question: what barriers prevent individuals with SCD and associated concern from seeking medical attention? It is imperative that we gain a strong understanding of these barriers to better support those experiencing SCD and to inform preparatory efforts for future therapeutic interventions that target earlier stages of dementia [37]. The aim of this critical review is to call attention to the health access and personal barriers (e.g., cost, transportation, physician accessibility, patient comfort) to HS for individuals with SCD and explore how technological applications of virtual assessment have the potential to circumvent these barriers. Virtual assessment is often used as an umbrella term to encompass all forms of remote monitoring, including virtual physical and functional examination, computer/internet based interventions, and online educational tools, among others [38]. The potential benefits and drawbacks of virtual assessment for patient healthcare access, delivery, costs, and the physician-patient relationship have been explored in a variety of different disease contexts such as diabetes, hypertension, and surgical outcomes [39]. This review will focus exclusively on novel applications of virtual cognitive assessment (i.e., tele-neuropsychology) and its impact on HS barriers for individuals with SCD.

HS behavior is often partitioned into the overlapping domains of formal help-seeking, seeking help from professional sources, and informal help-seeking, seeking help from friends and family. Formal HS is the deliberate decision to seek help from a healthcare professional following the identification of symptoms related to a decline in cognitive abilities [40]. This review will focus solely on formal HS which will be referred to simply as HS moving forward. Various models have been developed to understand and describe HS behavior, including the common-sense model of illness, the theory of planned behavior, and the health belief model [41-43], all of which focus on one’s attitude toward, or perception of, cognitive impairment and how this may be associated with HS. However, it is difficult to capture the multiple dimensions of this complex decision-making process within a generalized model as an individual’s response to perceived illness is influenced by a variety of unique personality, socioeconomic, cultural, demographic, and environmental factors [28,44]. Further research into each of these dimensions is imperative for the implementation of effective and tailored strategies aimed at identifying those less likely to HS and to encourage this behavior in the context of high SCD; otherwise, the risk of delayed diagnosis rises, particularly for those who are at greater risk of cognitive decline.

A large emphasis has been placed on early diagnosis and intervention for dementia related diseases (e.g., Alzheimer’s, vascular dementia, Lewy body dementia, and frontotemporal dementia, among others). In response to this, a variety of government and public policy efforts, such as educational interventions, practitioner incentivization structures (e.g., the Quality and Outcome Framework), and the promotion of a network of memory clinics (e.g., the National Dementia Strategy), have been implemented worldwide to facilitate early neurocognitive diagnosis [45-47]. Without regular community screening for cognitive decline and with caregivers/informants unlikely to bring cognitive concern to the attention of a medical professional until significant impairment is noticed, personal HS is one of the only pathways available to receive early clinical care [37]. Early HS has several benefits that can have drastic life course implications for those who end up being formally diagnosed with MCI or dementia. Primarily, a biomedical explanation can put the minds of individuals, caretakers, and family members at ease by providing a better understanding of the symptoms and clinical course of the disease. Furthermore, a formal diagnosis is sometimes necessary to receive healthcare or insurance benefits. HS also provides early access to therapeutic and non-therapeutic interventions that have the potential to alter the disease course, allows individuals to plan for the future while they still have decision-making capacity [28], and allows individuals and caretakers to be introduced early to support groups, community resources, and local care centers [42]. Many people risk delaying HS until a “crisis” event such as a stroke, major fracture, or severe behavioral change occurs [48], and early HS has the potential to reduce the likelihood of these “crisis” events from happening or better preparing family members and individuals for their occurrence. Additionally, early HS has considerable benefits for cognitively healthy older adults with SCD as the reassurance of a healthcare professional may reduce stress [49] and help address neuropsychiatric disorders such as depression, anxiety, and insomnia that had presented as SCD [50].

Implications of Virtual Assessment

The limitations put on healthcare that were brought on by the pandemic had a drastic impact on older adults...
with SCD, specifically surrounding self-isolation and quarantine, as these areas affected the routines and livelihoods of people all around the world, suspended many cognitively stimulating activities for older adults, and, more importantly, hindered HS [51]. Those who experienced SCD during the pandemic and attempted HS were faced by a changing healthcare landscape as healthcare practices adapted to innovative methods of remote care to replace in-person care. While cognitive assessments have traditionally been administered in the presence of trained personnel such as a neuropsychologist or psychometrician, the pressure to transition towards virtual cognitive assessment was heightened by the limitations of in-person care during the pandemic. Some of the most common, highly validated, and established tests used for cognitive assessment include the Trail Making Test, Stroop Test, Boston Naming Test, Clock Drawing Test, and Mini Mental State Examination (MMSE) [52]. At the beginning of the pandemic, the publishers of traditional assessments continued to recommend that tests not be administered via remote administration without the use of the publisher’s own platform [53]. Nevertheless, teleneuropsychology began to be primarily utilized to meet the demands of clinical practice and research. Adaptations to these tests as they transitioned to virtual modalities involved the use of confidential videoconferencing programs, scaling and scanning stimuli to present to the participant via screen sharing, and showing visuospatial tasks and instructing the participant to copy figures via video without access to the physical copy of the patient’s written material. Equally important to the actual administration of the tests was controlling for factors in the patient’s surrounding environment (e.g., minimizing background noise, taking care of pets, and silencing electronic devices). Given clinicians did not have visual access to the patient’s (or participant in a research setting) environment, pre-assessment measures were taken to ensure the patient was sitting at a table and reduce the likelihood that electronics, family members, or pets could distract or provide assistance to the patient during testing.

A few months into the pandemic, the Inter Organization Practice Committee, consisting of professional organizations in neuropsychology such as the National Academy of Neuropsychology and the American Academy of Clinical Neuropsychology, published much needed guidance and recommendations about telemarketing. [54] It was also around this time that publishers started to release specific telehealth guidance [53,55]. Additionally, other researchers attempted to understand problems with tele-administration and provide guidance on troubleshooting such issues [56]. Several traditional assessments such as the Wechsler Adult Intelligence Scale (WAIS), Wechsler Intelligence Scale for Children (WISC), and Delis-Kaplan Executive Functions System (DKEFS) already had tablet-based programs called Q-interactive [57], but relatively little guidance was provided on how to administer traditional paper-pen tests via standard web conferencing software. Despite these challenges, preliminary research shows that remote cognitive assessment of traditional assessments has good to excellent reliability when compared to in-person data [58].

While the transition from in-person to virtual cognitive assessment presented challenges due to lack of established standardized testing norms [59], many benefits have come out of this transition. In particular, adjustments to remote virtual cognitive assessment initiated during the pandemic era served to tackle many of the health access and personal barriers that previously limited individuals with SCD (as well as other health concerns) from HS [42,48,60-62]. While cultural barriers (e.g., religious beliefs, linguistic differences, cultural norms) to HS may also be impacted by virtual assessment [63], that is beyond the scope of this review and thus not discussed further. Similarly, while virtual cognitive assessment can take on different forms (phone calls, emailed surveys, etc.), we focus on internet-based platforms and video-conferencing software’s that were used to support remote clinical care. Our review of the literature highlights the benefits of virtual cognitive assessment for those who may not be able to seek out help from the established, more traditional in-person pathways.

Health Access Barriers Related to HS

Health access barriers encompass any obstacle that prevents one from obtaining affordable, convenient, and appropriate healthcare services for illness prevention, diagnosis, or treatment [64], and they continue to be referenced as one of the main obstacles to HS for memory concerns [48,61,65,66]. While interwoven with other challenges such as decreased educational opportunities [67], health access barriers due to cost, transportation, or lack of specialized care will be our focus as these are the barriers most impacted by virtual cognitive assessment. For example, a study in Israel, conducted using semi-structured interviews with a community sample of 79 adults aged 55 and older, found that the cost of formal assessment and the lack of treatment availability were the key barriers to formal HS for memory complaints [61]. Additionally, limited access to general practitioners (GPs) is another health access barrier that poses an obstacle to HS. GPs play a significant role in the pathway to a dementia diagnosis as they are commonly the first healthcare professional one sees for cognitive concerns and often act as the gatekeeper to more specialized care. A study examining older adults aged 60-64 found that an increased number of GP visits in the preceding 6 months was significantly associated with HS for memory complaints [30]. This suggests that increased access to GPs could facilitate
HS behavior by giving individuals more opportunities to consult with a doctor about their memory. Likewise, in a study done in patients with memory concerns who previously experienced a stroke, a lack of familiarity with their GP and the difficulty in making and getting an appointment was found to be a commonly named barrier to HS [68]. As a result, increased access to consistent GP visits could largely impact HS behavior for cognitive concerns in older adults.

Health access barriers to HS (e.g., transportation, lack of specialized care, limited resources) for memory concerns are particularly heightened in traditionally underserved populations such as minoritized race and ethnic groups, as well as rural populations [32,61,68-74]. For instance, a recent literature review exploring cross-cultural differences in dementia found that minoritized ethnic older adults tended to present with worse cognition and at later stages of dementia than non-Hispanic Whites at the time of their first evaluation [42], suggesting distinctive HS barriers between these two groups, among other factors (e.g., illness perception differences, culturally associated beliefs, personal beliefs, language proficiency, level of acculturation, etc.) [42,48,75]. In a deeper exploration of these barriers, a study of older Hispanics with cognitive impairment (n = 65, mean age of 68 years) found lack of transportation, time, and distance from the health clinic as reported barriers to healthcare access [75]. Additionally, many individuals from rural populations may have difficulty obtaining an appointment with or traveling to healthcare professionals specialized in cognitive care. In interviews with primary care providers in rural regions of the United States, a study found that patients’ access to care was limited by the long distances and travel time to reach providers specializing in cognition [69]. Furthermore, research at a memory clinic located in rural areas of the Canadian province of Saskatchewan found that some patients referred due to concern for memory problems declined follow up appointments not conducted over telehealth due to the difficulty of traveling great distances to in-person appointments [70].

Virtual cognitive assessment provides individuals with increased access to specialized care as well as greater flexibility and convenience in scheduling healthcare appointments. While routine, community-wide memory screenings could improve access to cognitive evaluations and delayed detection of cognitive impairment, they have often been regarded as implausible due to low yield of disease detection and lack of available resources (e.g., trained healthcare personnel, clinical space, associated costs, time within general medical visit, etc.) [29,37,76]. However, there are documented initiatives designed to circumvent these challenges. To increase care access and expedite community wide cognitive screens, the United Kingdom government in 2009 pushed for a “memory clinic in every town” program and dementia screens in every patient over the age of 75 [77]. Virtual cognitive assessment could have a similar impact on a greater scale, increasing testing efficiency and providing access to GPs, specialized healthcare professionals, and cognitive assessments to anyone with internet access. Likewise, virtual cognitive assessment would drastically reduce the HS barriers of transportation distance, time, and cost by allowing individuals to conduct cognitive assessment from more convenient locations. In fact, a study from Iran indicated dementia patients, caregivers, and neurologists reported high satisfaction ratings from virtual cognitive assessment administered through the Yaadman Institution for Brain, Cognition, and Memory studies. Specifically, virtual assessment was found to be more convenient for the patients and decreased caregiver burden by reducing travel time and medical costs while increasing access to specialized care [60]. Additionally, at-home computer and tablet based virtual cognitive assessments now have the potential to improve access to early screeners for memory concerns. One study including participants with SCD, MCI, and dementia found that a computerized cognitive self-assessment consisting of ten tasks was correlated with performance on the MMSE. Performance on this assessment also distinguished between participants with SCD and those with MCI and dementia [78]. These results demonstrate the ability of at-home virtual testing to act as an early screen for cognitive functioning, and its application could drastically reduce care access barriers for individuals with memory concerns. The once implausible solution of proactive and routine memory screening may be remediated with the help of virtual cognitive assessment.

A Brief Note on Personal Barriers in Relation to HS

In addition to health access barriers, there are a variety of personality factors and beliefs spanning social and cultural groups that may largely impact HS in individuals with SCD [28,44,79]. Perceptions of cognitive decline are often accompanied by the feeling of embarrassment, and coping mechanisms targeting the physical and emotional stress associated with SCD, such as social withdrawal and personal isolation, may serve as obstacles to HS [28,41,79-81]. In a study comparing help-seekers and non-help seekers with SCD (n = 98, age > 50 years), non-help seekers were more likely to cope by distancing themselves [28]. For those who feel more comfortable talking with a healthcare provider alone in the privacy of their home or are worried about the stigma associated with going to the hospital for a cognitive evaluation, virtual neuropsychological assessment and telehealth consultation may provide them with an optimal alternative for obtaining help from a healthcare professional. Personal beliefs regarding the cause of memory impairment and its future implications also play a role in one’s HS decision making process. For
example, some individuals may believe their symptoms are not severe enough to mention to a GP [22]. For fear of wasting the time of a perceived busy physician, or possible embarrassment, individuals may keep their concerns to themselves [79,80]. However, some of these barriers may be overcome via virtual consultations where the image of a busy waiting room will not lead to embarrassment or frustration that could act as a barrier to individuals mentioning their concerns. Furthermore, historic prejudice and discrimination within the healthcare system has fostered a sense of distrust and discomfort of medical care and healthcare professionals among individuals across various ethnic groups, leading to a reduction in HS [62]. A recent review emphasized the need for conveniently located, non-threatening environments in which minority ethnic older adults can obtain dementia health-related services that allow for earlier diagnosis and treatment for dementia related disorders [42]. Remote virtual assessment offers minoritized groups the opportunity to obtain cognitive evaluation within familiar home environments which may make them feel more at ease. However, many individuals may be in a situation in which they do not feel safe or have the privacy necessary for cognitive assessment within their home environments. As a result, further investigation is necessary on the ability of virtual cognitive assessment to combat personal barriers (e.g., coping style, social comfort, healthcare related beliefs) to HS in individuals with SCD.

Conclusion and Future Directions

SCD is consistently ranked by older adults to be an area of high concern when compared to other health issues such as angina, asthma, or hypertension [22]. However, older adults rarely seek a medical professional to address this concern [22,30-35,37] and this HS behavior is likely influenced by several socioeconomic, personal, and cultural barriers. Virtual cognitive assessments increasingly used throughout the pandemic have helped alleviate health access barriers to HS (e.g., transportation, cost, and increased access to GPs and more specialized care). Virtual assessment also offers the opportunity for individuals with different coping styles and levels of social and healthcare comfort to engage in assessment in more convenient and familiar environments. Future work should focus on the adaptation and validation of traditional assessments administered virtually to increase access to cognitive assessments, lead to earlier diagnosis and intervention for dementia and related disorders, and provide a viable option when individuals prefer virtual rather than in-person assessments or in-person testing is not possible due to extenuating circumstances.

The shift to telehealth services and virtual cognitive assessment that emerged from the pandemic brought with it innovative diagnostic tools that could drastically benefit individuals with SCD who do not seek formal help. Not only can more traditional tests be adapted to a virtual format, but the enhanced data capturing abilities associated with online testing allows more insights to be drawn from each test (e.g., capturing the process of one’s response in addition to the outcome). For example, by utilizing a digital pen with the Clock Drawing Test, a widely used traditional neuropsychological assessment [52], additional metrics (e.g. time between each drawing motion, the number of times a pen was picked up from the page, etc.) can be measured and analyzed in relation to cognitive decline [82]. Additional research in the field will uncover the utility of virtual assessment methods in increasing the effectiveness of traditional cognitive assessments and introduce innovative cognitive assessments that take advantage of the increased capabilities of the virtual, online environment.

However, it is important to emphasize that remote virtual assessment and telehealth services more broadly do not solve all health access barriers to HS. Barriers remain for those without internet access, online videoconferencing software, or access to private testing environments within their home. In a study that focused on the experiences and challenges of teneuropsychological assessment in adults, more than 50 percent of respondents (n = 87) reported internet connectivity problems, environmental distractors, limited access to technology, and other video conferencing problems [56]. Of note, several active research studies have already begun taking increased measures to address these remaining accessibility barriers by loaning the necessary technology (e.g., computer or tablet) to study participants [56]. For example, the multi-institutional National Institute of Aging sponsored Long-Life Family Study [83] sends tablets and digitized pens to study participants to ensure those with limited internet or technology access could continue participation throughout the pandemic [56]. Likewise, the VA Healthcare System in the US sends iPads to Veterans without computer access and offers technical assistance to help set up the device and related software [56,84]. Measures such as these may pave the way for additional strategies to increase access to virtual testing so that populations globally can take advantage of advancements in remote cognitive assessment. As such, future work focusing on remaining HS barriers for those with SCD has the potential to increase the efforts of healthcare policy, public programs, education, and clinical research to facilitate HS and ultimately improve the early detection of and intervention for cognitive decline in older adults.

Acknowledgements

Conflict of interest
None.

Sponsor’s role
None.
Author Contributions

M.K. and P.Z. conceptualized the idea for this article in coordination with M.A and S.C. M.K. and P.Z. conducted the literature review, and M.K. wrote the manuscript with contributions from all co-authors. S.R. contributed to the literature review and wrote the section “Implications of Virtual Assessment”. S.C. reviewed drafts of this manuscript and provided suggestions for revision. M.A. provided supervision, reviewed and edited original and prior drafts of this manuscript, and helped establish article scope and structure.

References


83. (2023) National Institute on Aging (NIA). Long life family study (LLFS).

84. (2023) Affairs USDoV. VA.