Lessons Learned from Developing a MCI Virtual Empowerment Program

W. Bradley Fain[1], Megan Nare[2], Matthew Doiron[2], Sarah Farmer[1], Jeremy Johnson[1], Salimah Laforce[1], Aparna Ramesh[1], Amy Rodriguez[2], Kayci Vickers[2], Tamara Zubatiy[1] and Elizabeth Mynatt[1]

Abstract

In the Spring of 2020, COVID-19 closures and safe distancing orders required healthcare programs across the US to cease in-person treatment. This paper presents a case study of rapidly pivoting a novel, 12-month comprehensive clinical lifestyle program combining education, occupational therapy, cognitive training, and social interaction to an online application-based education program. The focus of the program is empowerment research for people newly diagnosed with mild cognitive impairment (MCI) and their care partners, and is conducted by the Emory Brain Health Center. Georgia Tech developed an education application (named MyCEP) for use with our MCI and care partner population combining off-the-shelf services and customized user interfaces. We used an iterative design and development process, testing our application with our end users and our treatment providers, and made updates based on our discovery of the need for new capabilities and requirements. We present the discovery of emergent practices by family members and healthcare providers to meet the new requirements for successful virtual engagement.

Keywords

Mild Cognitive Impairment, virtual programming, User centered design, Telehealth

Introduction

Mild Cognitive Impairment (MCI) is a neurological syndrome characterized by mild impairment in one or more cognitive domains without evidence of functional decline. MCI can occur due to a number of underlying etiologies, but is often associated with neurodegenerative conditions such as Alzheimer's disease. [1,2] Approximately 15-20% of people over the age of 65 will exhibit MCI and this condition is growing in prevalence in the aging population. [3] No pharmacological treatments currently exist for MCI, so typical treatment course includes longitudinal monitoring, management of modifiable risk factors (e.g., cardiovascular disease), and engagement in neuroprotective lifestyle factors. [4–6] Although exercise and cognitive stimulation are included in American Academy of Neurology guidelines for MCI treatment, additional lifestyle factors, such as sustained social engagement, improved sleep and nutrition, and the adoption of new habits and activities have been found to be potentially neuroprotective. [5,7]

These types of interventions have a synergistic effect when combined with one another, suggesting the possibility that a comprehensive lifestyle program for individuals with MCI may provide greater benefit to individuals than would any individual intervention [8]. Despite these findings, few programs exist that provide comprehensive behavioral interventions for individuals diagnosed with MCI, especially past initial diagnosis. Generally programs are limited by reliance on in-person appointments, short time frame, and lack of ongoing support [9]. To our knowledge, no studies have delivered a long-term lifestyle program focused on delivery of behavioral interventions for individuals with MCI, and few have attempted this via telehealth to a large number of patients. While development of a comprehensive teleheath intervention was not our original goal, the shift in priorities due to the global pandemic gave us the opportunity to innovate.

In this study we report on our initial findings of the usage, perceptions, and beliefs of individuals with MCI, their care partners, and the program staff toward our "telewellness" solution. For over two decades, there has been growing interest in telehealth and health informatics for monitoring the health status and providing remote care for older adults. This interest is driven by a shortage of caregivers and that the population of adults 65+ in the United States is expected to double [10–12]. These adults will likely be monitored by family members who could benefit from technology support. Also, due to COVID-19, there has been renewed attention to

[1] Georgia Institute of Technology
[2] Emory University School of Medicine
Emails: mnare@emory.edu (Megan Nare), matthew.james.doiron@emory.edu (Matthew Doiron), sarah.farmer@cacp.gatech.edu (Sarah Farmer), jeremy@imtc.gatech.edu (Jeremy Johnson), salimah.laforce@cacp.gatech.edu (Salimah Laforce), aramesh80@gatech.edu (Aparna Ramesh), amy.rodriguez@emory.edu (Amy Rodriguez), kayci.lynne.vickers@emory.edu (Kayci Vickers), tzubatiy3@gatech.edu (Tamara Zubatiy)

Corresponding author:
W. Bradley Fain, Georgia Institute of Technology; Elizabeth Mynatt, Georgia Institute of Technology
Email: brad.fain@cacp.gatech.edu, mynatt@gatech.edu

developing and testing telehealth interventions, particularly for vulnerable populations.

This work makes three main impactful and unique research contributions. First, we present reflections regarding design decisions amidst pivoting an intensive in-person lifestyle intervention to a virtual program. Namely, our iterative design were made to address systemic deficits in telehealth capabilities, including gaps in patient readiness and provider training and infrastructure. We reflect on the long-term potential of telehealth and telewellness for interventions that span education, training and occupational therapy. Second, we present the evolution of practices by care partners and healthcare providers to meet the new requirements for successful virtual engagement. One challenge for providers was shifting from highly interactive class settings to creating content that could be consumed asynchronously by patients at home. We found that care partners facilitated access and engagement with virtual interventions, and this partnership between members, care partners, and healthcare providers allowed for deeper engagement and incorporation of intervention insights into the daily lives of families, despite the impact of deficits in social interaction and engagement. Finally, this work demonstrates how lifestyle interventions and technology can empower individuals with MCI and how care partners can facilitate those gains.

Cognitive Empowerment Program

The Cognitive Empowerment Program's focus on dyads consisting of MCI members and care partners may be a more productive path for both technology-mediated, online lifestyle interventions and also in-person care. The importance of our conclusions and take away points stem from a demonstration of the feasibility of rapidly pivoting an intensive in-person lifestyle intervention to a virtual program consisting of the integration of multiple off-the-shelf services. We demonstrate that lifestyle interventions, delivered remotely, can nevertheless empower individuals with MCI. In addition, we report on the importance of technology and care partners in the facilitation of this online comprehensive clinical lifestyle program. This work will prove useful to individuals with MCI and their family care partners, physicians, therapists, and researchers, as well as other healthcare teams interested in creating online lifestyle interventions.

The premise of the Cognitive Empowerment Program is a systematic collaborative approach for design, research, service, and long-term change in the lives of people with MCI. Our research is situated within a comprehensive lifestyle program that aims to empower individuals diagnosed with MCI and their care partners by "making people stronger and more confident, especially in their life and claiming their rights." Enrolled participants are referred to as program "members"; all members carry a clinical diagnoses of MCI due to a presumed neurodegenerative condition and, in the original face to face program, are required to commit to attending approximately 8 hours of therapeutic programming per week.

Members are also required to identify a spouse or other trusted individual familiar with their daily functioning; these study partners are called "care partners" within the program. Following assessments, program members initially participated in twice-weekly classes occurring in a specially built environment for individuals with MCI.

"Service providers" teach interactive courses under domains such as physical training (e.g. physical exercise, yoga), cognitive training (e.g. compensatory strategies, calendaring), emotional wellbeing, nutrition, art, and functional independence for daily life activities. Although classes are designed for members, on occasion care partners would join classes and participate in communal lunches.

MyCEP Application

Motivated by mobile apps to support chronic disease management, we designed and deployed a custom mobile application to provide program information [13,14]. Enrolled participants received an iPad with the application installed but it provided little value to the in-person activities at the start of the program.

With the emergence of the COVID-19 pandemic and the uncertainty surrounding the virus, our team realized the urgent need to discontinue in-person programming and focus on providing virtual programming via asynchronous recorded materials that would be accessed by members via the MyCEP application. Asynchronous materials were chosen because they offered the ability to be accessed by members with differing schedules and did not require the complexity of participating in synchronous video classes. Our initial challenge was to create an application that could act as a platform to facilitate the interaction between our instructors, who would create and organize course content, and our members and service providers. The primary interface to the MyCEP application was a personalized schedule and checklist view (See Figure 1).

For some participants, the virtual program led to greater opportunities for empowerment in the form of self agency, expansion, transference, empathy, and connection. This work lends insights and potential new avenues for understanding how lifestyle interventions can empower people with MCI and the role of technology in that process. Technology-based interventions for improving health behaviors have been shown to have many advantages over traditional clinic settings, including convenience, cost, and the ability to tailor plans and feedback to individual needs. [15–19] However, telehealth interventions are also associated with challenges for both health-care users and providers, including lack of interactivity and difficulties with technology adoption. [20] Accordingly, adoption of technology-based interventions in MCI and dementia rehabilitation practice has been relatively slow. [21] Our technology team collaborated with experts in therapeutic care to develop an easy to use application tailored to users with MCI in order to support the larger program while also conducting research in computer-mediated interaction, collaboration, and health informatics.

From the outset, we developed the MyCEP application to be simple to operate with usability principles at the forefront of all design decisions. [22] Key information was one click away and all text was presented in a large print, high contrast font. We used simplified language throughout the application and separated content into tiles that could be consumed

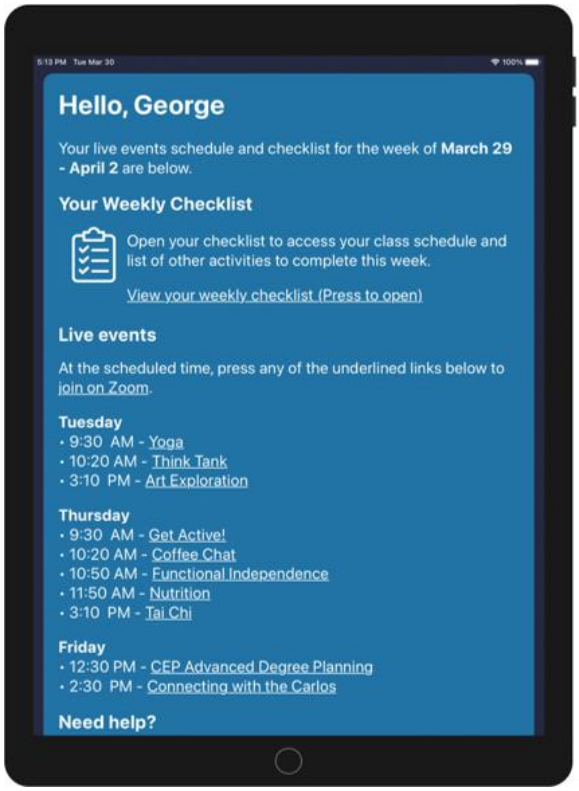

Figure 1. MyCEP Schedule and Checklist View.

Figure 2. Sample MyCEP Activity Video.

in manageable segments. Content was personalized to the individual member to remove clutter that might impact the overall user experience, and new content appeared weekly "at the top of" each class to minimize confusion.

We concluded that online platforms being utilized by K-12 institutions and universities (e.g. Google Classroom and Blackboard) appeared to be too complex for our end users. Therefore, we adopted a blogging platform, Ghost, coupled with the video service, Vimeo, for storing and retrieving course videos. Our technology team provided guidance and aids to assist the service providers in authoring their weekly class content. A typical class consisted of a short blog and videos (see Figure 2) that embedded slides and audio narration. In under two weeks, the program pivoted from traditional in person classes to weekly audio-visual lessons accessible from member homes.

Observations and Conclusions

Despite the technological hurdles alongside the disruption of the COVID-19 pandemic, the majority of member and care partner dyads continued active participation in the CEP. They watched class content, interacted online with their instructors and fellow members, and sought to learn more about MCI and make productive changes in their lives. Through this work, we have demonstrated the feasibility of providing valuable virtual therapeutic content to older adults with MCI and their care partners.

Despite the challenges we faced during the rapid transition to virtual programming, our members were able to adapt. Members overcame instances of technology aversion and reluctance to embrace technology as the primary means of obtaining therapeutic programming to actively participate and contribute. Likely because, members were already familiar with the tablet and had previously received detailed instructions on the basic operation of the tablet, members remained flexible and adjusted to the role that the tablet played in the program. The transition to virtual programming would have been more difficult had members not been accustomed to using the tablet and navigating an older version of the MyCEP application.

We noted that some members and care partners utilized the tablet in ways that we did not originally anticipate. Some members preferred to consume the weekly content all at once with their care partners during scheduled sessions. Other members consumed content as it was made available to them. We encouraged members to utilize the content in ways that worked best for their lifestyle. Some care partners consumed the content without their members when the members were unable or unwilling to participate because they saw value in the programming related to comprehensive lifestyle change.

The transition to virtual programming was made easier by utilizing the concepts and terminology that was familiar to them while they were in the physical space. For example, instead of application icons, we heavily relied on pictures of the instructors that the members were familiar with when they were in the physical space (see Figure 3).

In order to find the content that they wanted they just needed to find the picture associated with the person that previously led that activity in the physical space. This "virtual scaffolding" served to anchor the members and helped them navigate complex materials.

The provision of content in this manner was not without challenges. Service providers, those generating new content for members, struggled with the challenges of virtual programming. Not only did service providers need to learn

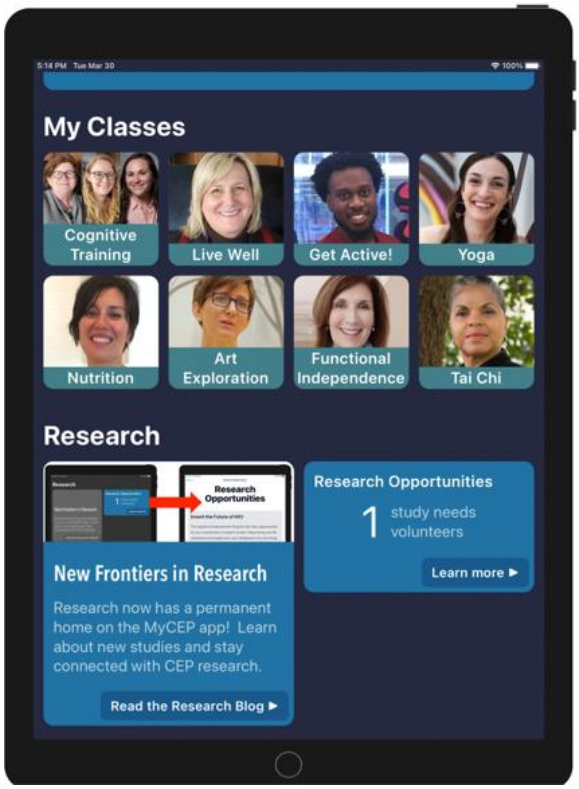

Figure 3. MyCEP Icons.

how to use the content creation platform, they had to fundamentally change the way their content was delivered. Service providers could no longer provide real time feedback to members in the way the did when they provided in-person programming. Frequent phone calls and Zoom group chats mitigated some of the issues associated with lack of feedback.

Many of our design decisions were motivated by the need for a fast pivot to retain member engagement and by the assumption that the need for remote programming would last only a few months. While our blogging platform enabled content authors to quickly produce weekly materials, it did not scale well as a long term content management platform. As new members joined the program and providers sought to reuse past content, the tagging mechanism for blogging was, in the long term, cumbersome and confusing.

Finally, we found that members and care partners greatly missed the socialization benefits to in-person programming. Members were given opportunities for socialization both as part of the structured programming and during the free time between classes. To address this relative lack of social interaction based on feedback from surveys, during the middle of July we introduced "live" online classes two days a week. With COVID-19 cases continuing to increase during the summer and our team facing a longer period of virtual programming than anticipated, we proceeded to onboard our next cohort with no in-person orientation or technology training. This all-online cohorts provide an interesting contrast to the first two cohorts, as their experience of the program did not include any in-person classes or social interaction. Despite attempts to provide socialization via video chats, we did not capture the high degree of social engagement that participation in physical space offered. New innovative ways to promote socialization are needed.

While our in-person programming offered at a state-of-the art clinical facility is likely a more optimal experience, there are considerable advantages to being able to offer high-quality and effective virtual programming. Many patients may not be able to devote the time and travel required for an in-person program, and the emergence of the COVID-19 pandemic has demonstrated the need for flexibility in offering therapy options, both in-person or online. While we seek ways to broaden the reach and impact of our multifaceted lifestyle interventions for people with MCI, we have demonstrated that the use of a virtual, 12-month comprehensive clinical lifestyle program can enable MCI members working with their care partners to learn new skills, experiment with and adopt new healthy behaviors, and develop a deeper understanding and empathy for the challenges they face together. The results of this research will advise future projects for audiences with MCI and help researchers interested in developing a platform to support empowerment.

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