



# Pivoting an MCI Empowerment Program to Online Engagement

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In the Spring of 2020, closures and safe distancing orders swept much of the United States due to the COVID-19 pandemic. This paper presents a case study of pivoting an in-person empowerment program focused on lifestyle interventions for people newly diagnosed with Mild Cognitive Impairment (MCI) to an online program. Working as rapidly as possible to sustain participant engagement, our design decisions and subsequent iterations point to initial constraints in telehealth capabilities, as well as learning on the fly as new capabilities and requirements emerged. We present the discovery of emergent practices by family members and healthcare providers to meet the new requirements for successful online engagement. For some participants, the online program led to greater opportunities for empowerment while others were hampered by the lack of in-person program support. Providers experienced a sharp learning curve and likewise missed the benefits of in-person interaction, but also discovered new benefits of online collaboration. 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.

CCS Concepts: • **Human-centered computing** → **Empirical studies in collaborative and social computing**; • **Applied computing** → **Consumer health**.

Additional Key Words and Phrases: Mild Cognitive Impairment (MCI), empowerment, aging, telehealth, telewellness

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**1 INTRODUCTION**

In March 2020, closures and safe distancing orders swept much of the United States due to the COVID-19 pandemic. Many experienced significant disruptions to daily work, school, and social practices. Activities that were previously conducted face-to-face, in education, healthcare, commerce and more, were re-imagined online as communities determined how to respond to the pandemic. A year later, we can examine what worked, what failed, and how new practices have emerged.

This paper captures reflections on the evolution of work practice in a large multidisciplinary program for people newly diagnosed with Mild Cognitive Impairment (MCI), a precursor to dementia often due to Alzheimer's Disease. The Cognitive Empowerment Program (CEP) is a joint partnership between a private university with a large medical system bringing cognitive and brain health expertise and a public university bringing design and technology expertise. The goal of the program is to empower its "members" to have greater control and independence in their own lives through behavioral and lifestyle interventions. In this program, we emphasize teaching members skills to maintain independence and improve daily functioning through compensatory cognitive training, learning new techniques (e.g., how to talk about MCI with family and friends), and by providing a safe space for them to learn about MCI and share experiences with their peers. For spouses or other care partners of individuals with MCI, the program provides support, education, and an opportunity for respite while members are on-site. Overall our program is focused on instilling confidence in members and care partners that they can learn and implement lifestyle changes that are important to their brain health as well as concrete knowledge of new skills that will help them compensate for cognitive and functional changes over time.

The CEP was originally comprised of in-person interventions combining education, occupational therapy, cognitive training, and social interaction in a center designed specifically for people with cognitive impairments. This program rapidly shifted from taking place in the carefully calibrated built environment to occurring online via an incrementally developed platform. Continuity of their engagement was critical for our program members as MCI is a target window for allaying the impact of neurodegenerative diseases through behavioral interventions.

Our experiences connect to a long tradition of past research encompassing efforts in telehealth, telerehab and telewellness without fitting neatly in one category. 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 [48]. However, telehealth interventions are also associated with challenges, including lack of interactivity, and difficulties with technology buy-in and use [48]. Accordingly, adoption of technology-based interventions in MCI and dementia rehab practice has been slow [3]. The National Quality Forum outlined five major domains for telehealth research (1) access to care, (2) cost, (3) cost-effectiveness, (4) patient experience, and (5) clinician experience [24]. Our work primarily addresses access to care, patient experience, and clinician or service provider experience. Cost and cost-effectiveness were not primary considerations beyond the fact that we had to continue operating within the financial and infrastructure constraints of the program and with what could reasonably be developed in a short time frame.

When the pandemic necessitated a transition from in-person interaction, the program team rapidly re-envisioned the content delivery paradigm, taking advantage of IT infrastructure previously put in place as secondary mechanisms of service delivery. We fashioned new content delivery channels to allow online delivery of services to people with MCI and their care partners with minimal interruption to program participation. Within the framing of Action Research [20] we created new computing artifacts and scaffolding for the staff to support the larger program while also conducting research in computer-mediated interaction, collaboration, and health informatics. This collaborative approach enabled research and experimentation alongside meaningful care addressing the access to care domain of telehealth research.

In this paper, we present a case study of rapidly pivoting an intensive in-person lifestyle intervention to an online program during the COVID-19 pandemic. The initial pivot took place over the course of two weeks. Our design decisions and subsequent iterations point to the constraints due to systemic deficits in telehealth capabilities, as well as our learning on the fly as new capabilities and requirements emerged. We reflect on the long-term potential of telehealth that spans education, training and therapeutic interventions designed for older adults with MCI.

Addressing the patient and clinician experience, we present the discovery of emergent practices by family members and healthcare providers to meet new requirements for successful program engagement. One challenge was shifting from highly interactive interventions for people with MCI to creating content that could be consumed asynchronously at home. In response, another emergent practice was the expanding role of family members to facilitate access and engagement with online interventions. For the care team and family care partners, workload increased, also occurring alongside the increased work and stress brought on by the pandemic response. These emergent practices catalyzed new discoveries in both the consumption and production of therapeutic content as this new partnership allowed for deeper engagement and incorporation of intervention insights into the daily lives of families. However, the impact of deficits in social interaction across the program persisted.

## 2 BACKGROUND

Our work responds to opportunities to address the challenges faced by individuals with MCI, and their family caregivers, through long-term, holistic interventions guided by the overarching goal of empowerment. The pivot to online services draws from and informs telehealth capabilities. Overall our research paradigm of Action Research frames our rapid discovery cycles and pragmatic efforts to sustain program activities during the COVID-19 pandemic.

### 2.1 Interventions for Mild Cognitive Impairment

Mild Cognitive Impairment (MCI) is an early stage of dementia, hallmarked by subtle cognitive decline without significant functional impairment in daily activities, and is most commonly due to Alzheimer's Disease [15, 42]. It is considered to be an intermediate stage between the expected cognitive decline of normal aging and the more pronounced decline of dementia. MCI affects approximately 15-20% of people over the age of 65 [22], and is growing in prevalence. Treatment for individuals with MCI focuses on longitudinal monitoring of cognition and functional status, reduction of modifiable risk factors (e.g., cerebrovascular risk factors, depressed mood, and medication effects), and engagement in lifestyle behaviors that support cognitive functioning [14, 16, 25, 52]. Specifically, healthcare professionals are encouraged to counsel individuals with MCI to engage in regular exercise and cognitive stimulation [21, 27].

Although exercise and cognitive stimulation are included in American Academy of Neurology (AAN) guidelines for MCI treatment, additional lifestyle factors, such as social engagement, sleep, and nutrition, have been found to be potentially neuroprotective (e.g., [2, 25]). Previous research

in health informatics for people with MCI has addressed lifestyle factors from exercise [41], to cognitive training support [50], to memory support during complex multi-step activities such as cooking [8]. Moreover, 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 [32].

Despite this growing evidence base, there are a paucity of programs in the United States that provide long-term (12-month) comprehensive behavioral interventions specifically designed for individuals diagnosed with MCI due to presumed Alzheimer's Disease or related disorder. Instead, most programs have focused on a single lifestyle intervention [39], compare lifestyle interventions that address a single target [29, 55], or focus on facilitating adjustment to diagnosis and occur over relatively short periods of time (e.g., 2 weeks; [49]). To our knowledge, few have attempted to deliver comprehensive interventions via telehealth, and those that have are limited in scope [12]. Thus, the impact of programs currently reported in the literature are limited by reliance on in-person appointments, short time frame, and lack of ongoing support for all stages of an MCI diagnosis. Our focus is on behavioral changes that can have long-term therapeutic benefit during a treatment period prior to greater cognitive decline. As this period of MCI often necessitates substantial adjustments in roles and activities, we orient the program to empowering these positive changes integral to personal definitions of independence and quality of life. In this study we report on our initial findings of the usage, perceptions, and beliefs of people with MCI, their care partners, and the program staff regarding our rapidly re-envisioned online empowerment program.

## 2.2 Understanding Family Care Partner Burden

Caregiving is associated with significant physical and mental health impacts, and care partners often experience adverse effects on their emotional social, financial, physical and/or spiritual functioning due to their responsibilities as a care partner [1, 60]. Moreover, women, care partners with lower educational attainment, those that live with the care recipient, and those who feel depressed or socially isolated are at elevated risk for high caregiver burden. There is considerable work to better understand the extent of caregiver burden across chronic and acute conditions ranging from depression [58] through dementia [36].

Of the participants in our program, the majority of care partners are the female spouses of people with MCI, who live with the care recipient, and did not get to choose to become care partners. Thus, Adelman et al. would characterize these care partners as being at significant risk for high caregiver burden [1]. Adelman and colleagues also call for physicians and care teams to include and provide information to care partners, facilitating the care partner to act as a member of care team, rather than feeling like they are solely responsible for the care recipient [1]. In our context, the original in-person programming provided some respite care [36], but the pivot to online, with participants and caregivers homebound, the lack of respite care, and demands of supporting program activities and technology use from home likely contributed to increased caregiver burden.

Researchers have also identified design criteria for technologies to support long-term caregiving in the home and short-term caregiving during hospital visits [35, 54] Miller et al. underscore the importance of designing for asynchronous access to information, so patients and caregivers can go back later and reference information captured during doctors' visits and, in our case, virtual or in-person programming. Such asynchronous access technologies may help relieve pressure associated with caregivers feeling they must constantly be present, and may help relieve guilt if the caregiver cannot be around for some reason [35]. Miller et al. also encourages designing for uncertainty, so that technologies will still be effective as the patient's status changes over time [35]. Finally, Adelman et al. suggest seeking outside care, and even respite care, when the care recipient temporarily receives treatment in a different location [1], although Min et al. reveal the

trust and communication challenges involved in respite care [36]. Additionally, a few programs sought to address dyadic relationships between those with MCI and their care partners (or families) through their sense of competence (Banningh), meaningful activities (Lu), or strategy training (Schmitter-Edgecomb). In this study, we report on the benefits of including care partners more directly in treatment with the program health providers, through its online asynchronous format, as well as the increased effort required by care partners to sustain program engagement.

### 2.3 Health Informatics and Telehealth

There has been sustained interest in telehealth and health informatics as potential solutions for monitoring health and providing home-based care for older adults [31, 38]. Care for older adults generally puts more responsibility onto families; motivating technology support for families caring for aging family members [38]. Finally, due to COVID-19, there has been renewed attention to developing and testing telehealth technologies in the US as providers have had to rapidly adapt to telehealth practices to preserve public health. Currently, the majority of telehealth solutions focus on video consultations, but techniques such as passive sensing may make telehealth solutions more comprehensive [53]. However older adults show lower rates of computer and internet use than younger age groups [9, 45] and individuals with MCI and dementia report significantly greater difficulty learning and implementing technologies compared to cognitively normal peers [9, 45].

Beyond the core task of connecting healthcare to the home, explorations in telehealth have also sought “to also encompass supporting individual wellness to improve health outcomes” [43]. There have been several successful examples of using telehealth coaching to support healthy behaviors in everyday life, including encouraging increased physical activity (e.g. daily steps [57]), and improving self-efficacy in diabetic patients [23, 59]. One telerehabilitation study for individuals with MCI, GOAL (Games for Older Adults’ Active Live) Project [13] uses an 8-week app-based program to complete cognitive (computerized training), physical (guided videos of exercises), and caregiver training [37]. Although the program has demonstrated good attendance and low attrition rates, its efficacy has not yet been established with regard to allaying cognitive decline or improving mood or other outcomes. Likewise, a recent study protocol encompassing a tablet-delivered telerehabilitation program for people with MCI is similar to our approach, though effectiveness data are not yet available [7].

Our current project expands upon existing work and explores rapidly building a telehealth program for people with MCI, examining its impact on patient-care partner interactions. In addition to presenting an online empowerment program with regular interventions, such as online classes, our approach also provides a central hub for static educational resources, online social gatherings, weekly updates, and feedback collection.

### 2.4 Action Research with an MCI Empowerment Program

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. As described by Hayes [20], we are committed to an Action Research paradigm through our collaborative construction and implementation of this new program, our embrace of interdisciplinary expertise and methods, and the respect for and co-design processes with our participants. As we describe shortly, the set of stakeholder participants include individuals with MCI and their family care partners, therapists, technologists, and user interaction designers working together to change the experience of MCI locally for our families, and at scale through our research discoveries. Procedurally we adhere to Action Research’s spiral of steps; cycles of “planning, action, and fact-finding about the result of the action” [20]. Pragmatically our efforts include significant contributions through the creation of robust software for use across the program, sustained interactions with

our program participants and therapists, and intensive planning, implementation, assessment, and decision-making processes with the larger team. With the onset of the pandemic in our local community, the Action Research “spiral” kicked into high speed as we rapidly worked to shift our in-person program to valuable experiences online. The uppermost priorities were the continuity of the program and sustained engagement with our participants.

What emerged was a set of new practices, across our stakeholders, that lent insights into the future program goals, program implementation, potential outcomes, and new research and collaboration methods for the program. Within this paradigm, we organize our results as a narrative case study, drawing from the perspectives of the program staff and integrating the voices of our program participants.

### 3 PROGRAM BACKGROUND AND ACTION RESEARCH TIMELINE

Our research is situated within a comprehensive lifestyle program, the Cognitive Empowerment Program (CEP), that aims to empower individuals diagnosed with MCI and their care partners by making them “stronger and more confident, especially in their life and claiming their rights.” Enrolled participants in CEP are referred to as program “members”. To enroll, members must have a clinical diagnosis of MCI confirmed by a cognitive neurologist and are required to commit to attending approximately 8 hours of therapeutic programming per week for one year. Members are also required to identify a spouse or other family member familiar with their daily functioning; these study partners are called “care partners” within the program. In some cases, care partner “teams” included multiple family members.

In its original format, following assessments, program members participated in twice-weekly classes occurring in a built environment designed specifically for individuals with MCI. “Service providers” taught 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 the classes were designed for members, on occasion care partners would join classes and participate in communal lunches. There was no formal requirement for care partners to attend programming.

Motivated in part by other digital coaches for chronic diseases [4, 26, 33, 51], we designed and deployed a custom mobile app, MyCEP, to provide program information, with the future goal of generating personalized resources based on individual goals and program data. Enrolled participants received an iPad with the application installed. In early March, although the MyCEP app was praised for its visual appearance, there had been little use of the application and there was no content associated with therapeutic classes except for a general library of static content in program domains.

#### 3.1 Rapidly Planning a Pivot to Online

After only six weeks of in-person classes, we rapidly pivoted to an online program during the COVID-19 pandemic. At that time, we had recruited three cohorts ( $n = 26$  dyads of members and care partners) into the program, though only the first two cohorts ( $n = 19$  dyads) had started their interventions. With little infrastructure or training with our members, care partners, and service providers for synchronous online video classes, and the uncertainty surrounding the spread of the pandemic, we opted to discontinue in-person programming and focus on providing online programming via asynchronous recorded materials accessible to members via modifications to our tablet-based application (MyCEP). In this decision we prioritized speed in continuing our connection with program members and flexibility in delivering and consuming program content.

We faced design and technology challenges that needed almost immediate resolution. First, how would our instructors author and organize course content, and second, and how could our members



interact with that content on previously received iPads? We were working through this transition as many secondary schools and universities were also looking for solutions for online teaching. Many extant systems appeared too complex for our members (e.g., Google Classroom). Within a 72 hour window, we opted to adopt a blogging platform, Ghost, coupled with a video service, Vimeo, for storing and retrieving course videos (see Table 1: Timeline)

We encouraged service providers to create short posts using a simplified HTML based editor, tagging their content with their course title, intended audience, and week (e.g. yoga, cohort-1, Mar-30). Providers could also embed additional material, often a video, in their blog posts. Posted videos generally included a service provider talking over PowerPoint slides or providing a demonstration (e.g., physical exercise). For the most part, our course instructors created these materials in their homes. Homework assignments were mostly offline, such as suggested daily exercise, but eventually included in-app questions. To help our service providers author their first content, we created examples and offered informal tutorials, "office hours", as well as on-demand video chats.

Within two weeks, we transitioned to a fully asynchronous online program with weekly materials across the following domains: physical training, cognitive training, emotional well being, nutrition, art, and functional independence. These topics mirrored in-person offerings and the course topics in the app reflected the relationship with the instructors (e.g. "Yoga with Megan" including her picture). Figure 1 shows the home screen and an example of course content on the MyCEP app. To ensure participants were aware of all content and sessions available, the program emailed a weekly checklist to members and care partners outlining new content, expected homework completion, and any programming updates or reminders.

### 3.2 Social Interaction and Continued Online Program Iterations

After launching "online programming" we anticipated staying within this model for a couple of months. A key missing component of our online program was the social interaction that our members so highly valued. During the first month we facilitated members' use of Zoom for secure video teleconferencing with individual program staff within the HIPAA-compliant framework provided by our strategic partner, Emory Healthcare. After the fourth week of online programming, we introduced "coffee chats" as informal social hours for members (cohorts 1 and 2). These Zoom video calls were facilitated by a program staff member. After three weeks of coffee chats, the hour was split into two components. The first 30 minutes remained a social coffee chat, but the last 30 minutes became an educational session called "Brunch and Learn." Brunch and Learn sessions were hosted by service providers and provided an opportunity to discuss and test new educational content in a live format. Around this time, we also introduced monthly support groups for members and twice-monthly support groups for care partners facilitated by our program counselor and social workers. Finally, we also added in-app forms to gather feedback from members to service providers and to facilitate members answering "homework" questions.

We devoted a month of planning for safely resuming in-person programming, but COVID-19 cases continued to increase in the summer. Facing a longer period of online programming than anticipated, we proceeded to onboard our next cohort (Cohort 3, n=7 dyads) with no in-person orientation. Members received their program materials and iPads in the mail and met via Zoom with a program staff member to configure their tablets and learn about the MyCEP app. This cohort provides an interesting contrast to the first two cohorts, as their experience of the program did not include any in-person classes or social interaction.

### 3.3 Baseline Assessment

Within our Action Research framework, we sought to continuously collect data to evaluate our approach and inform future iterations. Data from logging online activity and program satisfaction

surveys informed the work we present in this paper. While rapidly creating the MyCEP app, we integrated a mobile analytics framework (Flurry Analytics) to collect individual metrics of app usage. Data includes unique device identifiers and event timestamps including when the participants entered the app, exited the app, and navigated to different views within the app. Over the course of five months, 22 participants logged into the app a total of 2,754 times. On average, participants logged in 5.7 times per week ( $SD = 4.7$ ) with an average of 2.3 “significant” sessions per week ( $SD = 2.2$ ). Interaction in the app occurred mostly on weekdays (Monday-Friday) and the average length of a significant session was 26.9 minutes (Median = 18.0,  $SD = 26.8$ ) minutes.

To initially assess the experiences of enrolled members and care partners in the online program, we deployed anonymous satisfaction surveys via email to all enrolled members and care partners ( $n = 26$  dyads) after three months of experience in the online program. These satisfaction surveys focused on impressions of asynchronous programs and live social interaction activities, program engagement and social experience, program usage and access, and general feedback about the online program. We strove to use similar questions to allow direct comparison to satisfaction surveys of the former in-person program experience. In total, 19 members and 20 care partners returned surveys.

These results are presented in [56]. In short, satisfaction scores and measures of participation remained high and did not significantly change compared to the in-person program. Although these ratings were positive, we realized that the work of producing the program had changed significantly. We identified major themes warranting qualitative assessment: 1) member engagement and motivation for the online program, 2) program access patterns, 3) increase in care partner involvement for online programming, 4) challenges in transitioning in-person classes to online content and 5) changes in social connection due to the pivot to online.

## 4 METHODS

In this paper we do not assess an optimal design and carefully constructed plan. In contrast, our analysis reflects on the experience of “building the plane while it is flying” with rapid cycles of planning, action, and assessment. Working from our baseline survey, we interviewed program members, care partners and service providers. All reported research was approved by our institutional research boards.

We conducted semi-structured interviews with 11 enrolled members and their care teams (including care partners and when requested, their adult children) following 4 months of online programming. Participants who volunteered for interviews were typically motivated to share advice for improving the online experience, to express gratitude for the program, and to argue for the benefits of returning to in person classes. Demographics of included participants may be viewed in Tables 2 and 3. We also conducted semi-structured interviews with (all) nine service providers to understand their experience shifting their classes online. Demographic and expertise information about our service providers is shown in Table 4. Our interview guides can be accessed online <sup>1</sup> All interviews were conducted online via Zoom calls, lasting 45 to 75 minutes.

We audio-taped service provider interviews and member and care partner interviews and divided into two teams to independently review the data. Interviewers coded responses against interview topics and resolved discrepancies. We use inductive thematic analysis to understand major themes. All interview data were analyzed first by the respective coding teams and then presented to the full research team for their input and discussion. For each interview, and by question, we clustered data, and as patterns emerged, we identified descriptive themes for these patterns. We then looked across both sets of interviews to understand guiding themes relevant to our members and care partners

<sup>1</sup>Interview guides are available at <http://ecl.cc.gatech.edu/projects/cognitive-empowerment-program>.



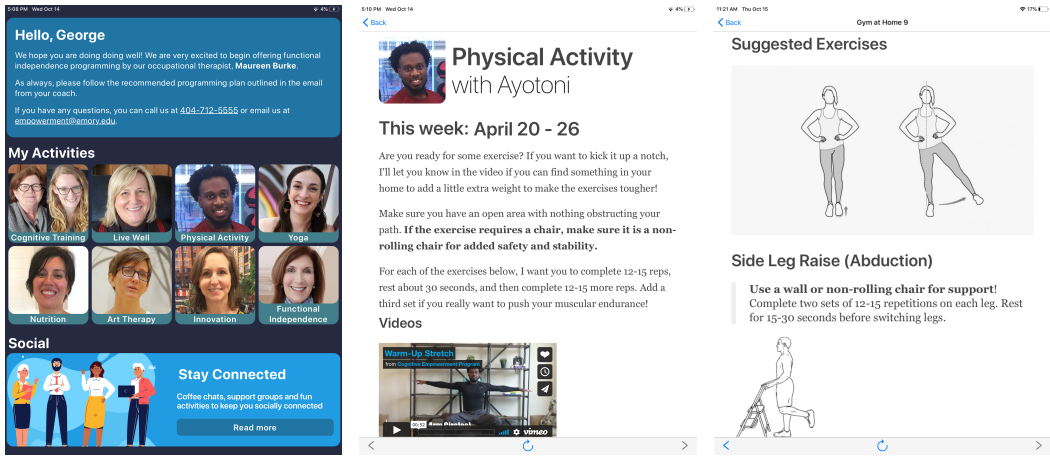


Fig. 1. Three example screens (Home, Activity Page, Sample Content) from the myCEP app

Table 1. Shows the timeline of the CEP program and the transition to online programming

Jan 28	Program doors open. First in-person class held with Cohort 1.
Mar 3	First in-person class for Cohort 2.
March 13	Decision to shift to online asynchronous program
March 30	First online content available to members on program app
April 6	Introduction of in-app forms for feedback and homework
April 21	Video Coffee Chats and Support Groups start
May 19	Brunch and Learn sessions start
May 25	Launch of Cohort 3 with online programming
July 21	First live online class
Sept 7	Pivot to live online classes coupled with in-app content

Table 2. Demographic information for n = 11 members enrolled in individual interviews

Variable	Sample Characteristics
% Female Members	36% (n = 4 of 11)
Age [Mean(SD)]	77.7 years (SD = 7.6 years)

as well as our service providers. Our final themes include Time, Technology, Interaction, Social Engagement, Adaptation, and Empowerment. Figure 2 illustrates the resulting themes from this parallel inductive process. This planning, action and reflection cycle captures our experience from March 13 through August 31, 2020 as we iterated through versions of our asynchronous online program. In our concluding discussion we identify the insights from this cycle that informed our next stage, introducing "live" online classes.

## 5 RESEARCH FINDINGS

Our research findings are drawn primarily from interviews with program members, care partners, and services providers informed by past baseline data from program surveys and overall application

Table 3. Demographic information for n = 11 spousal care partners enrolled in individual interviews

Variable	Sample Characteristics
% Female Care Partners	72.73% (n = 8 of 11)
Age [Mean(SD)]	71.57 years (7.35 years)

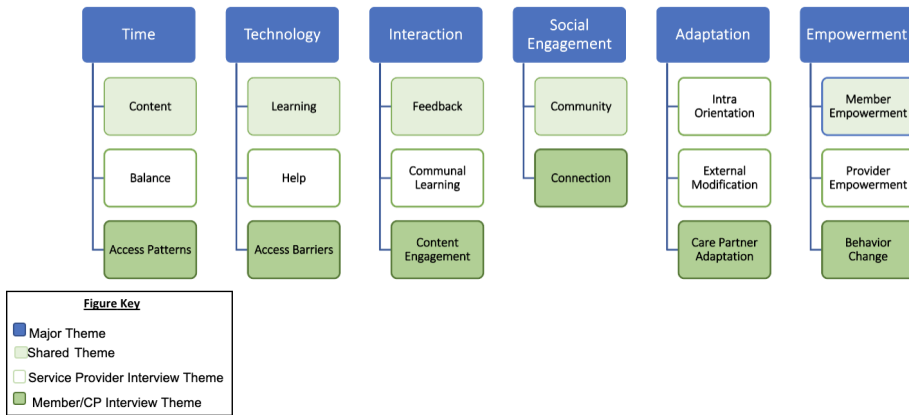


Fig. 2. Integrated Code Scheme with Major Themes

usage. Through these data we reconstruct the collective experience of transitioning our in-person program to an online program.

### 5.1 Member and Care Partner Interviews

Our interviews with program members and care partners gave us an opportunity to empathize with their overall experience in the online program amidst the stress and challenges of the ongoing pandemic. We sought to understand their overall motivation for continued participation in the program and ways that they identified the program making a difference in daily life. We then delved deeper into questions of how they managed their participation in the program, the work required by care partners to help program members be successful, and how the lack of face to face social interaction affected the experience overall. Example questions included: “On a scale from 1 to 10, how excited are you to do CEP activities each week?”; “During virtual programming, how connected do you feel to other CEP members (e.g., your cohort)?”; and [directed to care partners] “To what extent do you facilitate your partner’s involvement in virtual programming?”

**5.1.1 Time & Technology.** An important area of inquiry for the interviews was to gain a greater understanding of the ways in which individuals accessed program content and the amount of time spent consuming virtual content. When queried, a majority of individuals accessed static program content via the MyCEP app on their tablet and engaged in Zoom calls on either their tablet or a personally owned computer. There was significant variability in member engagement, with some dyads consuming nearly all content each week, spending up to 15 hours engaging online (asynchronous and live). Other dyads experienced barriers to completing content, such as lack of care partner involvement due to work schedules or significant initiation difficulties, resulting in little to no content consumption and less than 2 hours online each week. Despite this variability,

based on logging data, a majority of program members completed at least half of the available content each week, coming close to the original program goals of 8 hours per week.

The learning curve for completing the virtual program was steep for members and care partners and the most cited frustration was with technological barriers. As one member stated, “this is all new to me.” Many members were unable to access programming independently due to difficulties navigating the iPad or Zoom environment. For example, one member said they “[want] to go to the main iPad screen, touch a button, and have [the content] up.” Because of these barriers, care partners began attending more programming with members to assist with navigating most components of the program and members who did not have care partners required additional staff assistance, such as weekly Zoom set up or frequent tech support.

**5.1.2 Interaction.** A second emergent theme of these interviews was the member and care partner experience of interacting with the MyCEP app and the program more broadly. We asked program members and care partners to report on their motivation and engagement as it related to online content. Most members felt excited to engage in online activities. When asked to informally gauge their excitement for online programming on a scale from 1 to 10, with 10 indicating more excitement, the average member response was 7.1 (Median = 8). The most commonly cited motivator was feeling that the program would help them better manage their MCI symptoms or see improvements in daily function. One individual suggested that they had already started seeing improvements in their symptoms, stating “*I’ve learned a great deal and it’s made a difference for me...I’ve made some progress.*” Members also said the program was something to look forward to during COVID-19 and provided “*friendship and fellowship.*”

A major theme in our interviews was that online participation was heavily reliant on care partner (or care team) involvement. Seven of the 11 care partners interviewed said they were “100%” responsible for facilitating the member’s engagement in the program and 8 of 11 care partners reported the member could not complete online activities without their help. In addition to assisting members accessing content, some care partners also reviewed content separately from the members to prepare in advance and to increase their own understanding.

Some care partners engaged in the online content with members reported these shared activities helped build understanding and empathy for their partner. “*We are working like a team. It’s nice to have the connection and we’re very active...I never feel like I need to be doing something else. It’s a privilege to do it with [the member].*”

These interviews also revealed the emergence of social practices supported by online content. Some dyads scheduled specific times to complete their favorite content together and even began to share online content with other family members. One dyad said, “*we schedule [art] for Wednesday evening...our daughter is the host and she shares the presentation from her computer.*” Other dyads echoed the sentiment that certain types of content lent themselves to deeper discussion between the member and care partner, and were treated as “date night” and considered a special time shared by the dyad.

**5.1.3 Social Engagement.** One aspect of the online program that was especially difficult to recreate online was the social camaraderie and sense of community felt by members. In general, members reported they felt more connected to the program staff than to one another. They cited difficulties getting to know the other individuals in their cohort, stating “*it’s hard for me to feel connected until I get to know them better;*” and “*I don’t know the people that well, but they’re nice.*” Barriers to social connection included poor memory for faces and names and feeling there were too few opportunities for members to speak directly to members, especially without care partners present. At the time these interviews occurred, the primary social components of the program included coffee chats and member support groups. Of the two, members and care partners reported the member support

groups allowed for more interaction between members, likely because care partners were generally not present.

Deepened social connections between members and their care partners were an unanticipated consequence of the online program. As mentioned previously, many dyads completed content together and felt this interaction was a special time for them to share. Although this outcome was a somewhat unintended consequence of the virtual space, it is nonetheless a critical consideration given the risk for isolation in COVID. Similarly, the online program provided the opportunity for both members and care partners to improve technological skills and become more comfortable using Zoom. Although we did not specifically ask about this scenario, members and care partners provided many examples of times they were able to socially engage outside of CEP using technologies like video chat that had previously been foreign to them.

*5.1.4 Adaptation.* Given the changes inherent in moving from an in-person program to a fully virtual program, members and care partners made many adaptations to keep up with content and to ensure maximum benefit in the absence of in-person scaffolding provided by program staff and service providers.

Nearly all member and care partner dyads utilized personal strategies and program aids to remember to attend online sessions and to track content consumption. The most commonly cited way dyads remembered to complete online activities was by using the program checklist that staff provided each week via email. This checklist included reminders for all asynchronous content, coffee chats, support groups, and homework for the week. Many members and care partners not only reported using these checklists, but shared these with interviewers. In some cases, dyads maintained all checklists completed during the online program (e.g., on a clipboard) so they could refer back to past weeks and maintain a visual reminder of their progress.

In addition to using the checklist, dyads used scheduling techniques to aid in completing content. This tactic primarily took two forms. First, dyads utilized a schedule or calendar system to keep track of events that were set to occur at specific days and times, such as coffee chats and support groups. It was rare for dyads to schedule asynchronous content on calendars. For content consumption, dyads began to develop their own routines. In some cases, they selected specific days and times to complete content. For example, one care partner reported their family set aside time two days per week to complete online content. They were careful to maintain consistent times each day (e.g., starting after lunch on both days) and focused on completing content the member was likely to benefit from most in those time windows. In their case, any content that was not completed in the routine windows was filled in throughout the week and occasionally was not completed.

Care partners likely adapted most to the virtual environment given the significant shift in scaffolding of participation and engagement as well as content explanation for members. In the initial conceptualization of the in-person program, care partner involvement was encouraged, but not required, and the in-person program activities offered a potential respite for care partners experiencing high burden. However, the shift to online programming necessarily reduced the scaffolding provided by staff during onsite classes, and shifted these types of responsibilities to the members and care partner.

Broadly, our interviews revealed the depth of care partner involvement and the role of care partners in program engagement. In addition to assisting with program access, 7 of 11 care partners endorsed frequently explaining content to members. In many instances, care partners contextualized information by translating what was being taught in the program to the member's life and experiences. One care partner stated they had to "*ask [the member] again and then we also have to adapt the questions for her,*" suggesting scaffolding happened not only with regard to memory (repeating the questions), but also in supporting comprehension of material. Through multiple

interviews it was clear that within the online space, care partners were key to adjusting content for consumption by members, effectively scaffolding these experiences in the way service providers did in-person.

Despite the significant shift in the care partner's role as a consequence of the pivot to online programming, most care partners interviewed were pleased with their level of involvement. *We're competitive, the core of us is our family. Coming together, we knew we were all in, so my heart goes to those that only have one care partner. We communicate, we have a calendar and everyone receives the email, we know our weeks, we use google docs with their medicine charts. We had that system before, we've just adjusted it (to this program).* Although care partners were generally positive about this change, it created new barriers for care partners unable to provide significant or tailored scaffolding. For example, one care partner who worked during the day said, *"I'm not able to join because of work, so I set [the member] up and then they lose interest."* This care partner reported feeling guilt because her partner was not able to benefit fully from the program.

**5.1.5 Empowerment.** Given the overarching goal of the CEP program is to empower individuals, we queried members and care partners about ways they felt the program had impacted their life or their relationship to the MCI diagnosis. Members said things like, *"It's terrific...I'm learning a lot."* One member said *"[the virtual program] makes a big difference to me, my brain is very stimulated."*

Members and care partners also noted changes they ascribed to engagement in online programming, including increased awareness of MCI symptoms, increased engagement in exercise, improvements in memory and alertness, trying new things (e.g. new foods), and the use of strategies discussed in programming (e.g. physical/paper reminders).

Likely as a consequence of the increased care partner engagement, many care partners noted behavior changes that occurred at the level of the dyad. For example, many reported trying new things with their partner, like exercise classes and new foods. In line with this observation, many care partners said they had more conversations with the members about topics important for brain health and developed a stronger sense of empathy for their partner's condition.

Additionally, care partners described developing a greater sense of empathy for their partners and a better understanding of and comfort with MCI symptoms. One dyad said, *"we understand each other better....and it's gotten me more aware that I need to improve in some areas."*

## 5.2 Service Provider Interviews

We also interviewed program service providers (n = 9, Table 4). Service provider (SP) expertise included clinical counseling, cognitive neuropsychology, clinical neuropsychology, human factors and usability, architectural research, exercise science/physiology, classical Hatha yoga, studio art/art history, and nutrition. The goal of the interviews were to better understand their experiences during the transition from in-person to online programming by capturing thoughts about, observations of, and experiences with creating and delivering digital content. Interview questions addressed not only the transition experience, the technologies, workflow, and resources needed to create content, but also service providers' perceptions of member engagement with the content and achieving program goals. Example questions included "What has your experience been like during the transition from in-person to virtual programming?"; "Can you describe how you got the help or guidance you needed to create your virtual content?"; "What sort of additional resources would you like to have?"; "How do you think your virtual programming helps empower CEP members?"; "Are there any goals of the program you feel unable to address via virtual content?"

**5.2.1 Time and Technology.** The pivot from in-person to online programming involved, out of necessity, a switch in equipment and teaching methods. With this switch, service providers experienced a learning curve as they acquired skills to produce content on a new platform. For some,

Table 4. Demographic information for n = 9 service providers enrolled in individual interviews

Variable	Sample Characteristics
% Female Service Providers	88% (n = 8)
Age [Mean(SD)]	42.55 years (SD = 13.76 years)

this learning curve was quickly overcome; for others, the curve was steeper and more challenging to crest. Because providers found themselves suddenly thrust into the new work practice, online content was being created before best practices and how-to guides for the providers emerged. As a result, providers went through a process of trial and error. Informally, because the content was online, another source of guidance was the availability of viewing other service provider's work. *"Learned what works from each other."*

There was bonding over the shared experience of learning how to create and deliver online content. When asked, "How do you feel about interactions with other service providers compared to in-person?", many expressed that the online environment improved transparency in that they were *"getting to see other service providers' content and better understand them."* Eventually, formalized help came in the form of step-by-step tutorials, how-to guides, and a content review and feedback process. Providers cited the step-by-step tutorials created by our team as being the most helpful tool in learning new technologies. Learning the new systems was *"...a breeze because of the step-by-step guides provided."*

In addition to the time required to learn new systems, providers also found that recording content in advance was more time-consuming than the preparation they did for in person teaching:

*"The hours jumped up significantly"*

*"Tedious at times"*

*"Time is the most scarce resource for me."*

A couple of months into the online programming, however, most providers saw a decrease in the amount of time required to produce content each week. Those providers who have not seen a decrease in the time required to create content have noted that though the hours per week remain steady, the quality of content produced has markedly improved. Service providers also indicated excitement over creating a library of content that can be reused for future cohorts or, potentially, to reach wider audiences:

*"We're creating an archive of content that can be used for a long time."*

*"How can we make this body of work more widely available? Could be life-changing for people."*

**5.2.2 Interaction.** In the initial phase of online programming, in-person classes shifted to a new practice where members received weekly lessons and activities across the service providers' content areas. Online programming could be characterized as asynchronous, didactic teaching. As a result, service providers reported a decline in interactivity with and feedback from members. Interaction, the two-way communications between members and service providers that service providers relied on in-space to "read the room" and acclimate their tone or content was lacking.

*"I don't feel like I'm getting much feedback from them, which I wish I was getting more. It's such a different experience from working with them in a class and seeing in real-time how those light bulbs are coming on. ... There's such a [feedback] delay. It's really hard to know if what I'm doing is effective or if they're able to sit and have conversations with loved ones or even think about questions themselves and process the things that I'm asking. It'd be really wonderful if there was some sort of back-and-forth."*

Many interviews noted the absence of face-to-face interactions as difficult to overcome in an asynchronous online environment. When the service providers were "in-space," the delivery of content was based on dialogue, and the members were encouraged to drive the conversations and



enhance the experience of the topic being discussed by making it relevant to their lives through off-the-cuff reactions, questions, and commentary. Now, service providers find “*replicating] inquiry-based conversation into an online format difficult because it’s just a one-way conversation.*” Further, it’s “*Hard to drive content based on what members are interested in. Before, I could steer content based on what members said or asked about.*”

Many noted that their content is “designed to be interactive,” and in the online, asynchronous environment, what was intended to be a communal experience transformed into one-to-many type communications, with one-to-one reactions. While we introduced in-app forms as a mechanism to gather feedback about the content and provide prompts that encourage reflection, providers reported that only a small group of “super-users” consistently completed the forms. The low rates of participation may have been due to the “additional layer of complexity” that an online environment introduces, including usability concerns with the technology and increased individual responsibility to engage with the online content.

The limited real-time feedback had differential impacts based on the content category. Physical activity and yoga rely on hands-on interactions to correct posture and form and to assess how the members are progressing from week-to-week. Both activities were delivered via recorded video, where the members completed the sessions on their own time. While there are benefits to the asynchronous delivery of content, the most cited constraint was reduced interactivity. Likewise, for content that relies on experiential, tactile learning to augment the educational material, such as nutrition and art therapy, the immediate reaction and response to, for example, tasting a sardine for the first time, was not captured. These reactions come days or even weeks later. Prompting one provider to say, “*A little bit of the magic is gone. I talk a lot more. I would much rather it be the opposite, that they talk and what they say triggers ‘Oh here’s this really cool art history fact’ and they feel validated that they’ve had this insight.*”

**5.2.3 Social Engagement.** Not surprisingly, a social engagement theme emerged from the qualitative interview data. Related to, but distinct from the interaction theme, social engagement encompasses creating and maintaining relationships through shared experiences. In-space, the program activities provided opportunities for planned and organic socialization. Replication of these social activities in an online, technology-mediated manner, quickly became a pressing need and is reflected in the service providers’ responses. When asked “Are there any goals of the program you feel unable to address [via online content?]” Respondents stated:

“*Static content does not allow for connectedness.*”

“*I found it really difficult to create a similar type of social environment [online].*”

The service providers collectively found socializing in an asynchronous, online environment more difficult, stating that it’s “*Hard to get to know their personalities.*” And many mentioned the lack of spontaneity as an impediment to bonding. Stating that camaraderie and rapport were missing and “*that joking around is hard to do [online].*” The technology-mediated activities, for some service providers, did not assuage that sense of “separation,” as the lens and screen aroused feelings of self-consciousness, not experienced when engaging in-person.

Conversely, the social Zoom gatherings were perceived as advantageous to member-to-member engagement and service provider-to-member engagement. When asked, “What role do you feel coffee chats and other Zoom gatherings play in member interactions?” Respondents addressed both relationships:

“*Fulfill the role of social riffing.*”

“*Interpersonal relationships facilitated via coffee chats.*”

“*Can see personalities which is nice. So I definitely enjoyed that, and I can see how it’s a useful tool.*”

Despite service providers' perceptions about their ability to meet social empowerment goals in an online setting, the use of live Zoom gatherings allowed for some maintenance of a supportive and vibrant social community. *"Empowering people to tell their stories and not feel alone."*

**5.2.4 Adaptation.** Initially, all programming occurred in-person, and in-app content was planned to augment the day program experience. Abruptly, the online environment became the sole source of programming. As such, service providers faced the need to quickly develop new technological, ideological, and pedagogical skill sets to create and deliver online content, manifesting in both intrapsychic adaptations and adjustments to their programming to accommodate the new online environment. Regarding the former, SPs reported feeling more "pressure" and "self-conscious" about recording content that would live online. While they liked being able to refine content, the heightened self-awareness about being on-screen led some to feel the need to *"redo when everything isn't perfect."* However, the SPs overcame these feelings by *"Pacing ... becoming comfortable with being on camera."* As a result, providers owned their online content, from ideation to realization, and this ownership was evidenced in adapting content to be *"more relevant to what's currently happening in the world."* Service providers reported that recording content ahead of time allowed for more thorough planning of how to best present content to be accessible and useful for members. One provider stated that online content has *"made me braver in addressing more difficult topics."*

One of the biggest challenges faced by providers was conceptualizing how to take interactive, in-person content and turn it into static, online content. Providers questioned how to *"make online programming engaging"* and how to adapt from thinking on their feet and following the interests and inquiries of members during in-person programming, to attempting to anticipate and plan out content that would be of interest to members. In some cases, the content presented in-person could not be translated to online content. Certain physical training activities could not be included online: *"have to limit what you show for safety, so members don't get injured."* As service providers trialed new approaches, however, they found what works online and what does not. For example, the art exploration sessions during in-person programming focused on discussion of an artist's work followed by a hands-on art-making activity. Without the ability to interact, and without art supplies, it was difficult to replicate that experience. However, online art programming experimented with new mediums, such as photography using the program-provided iPad, and simple self-portraits in pencil.

**5.2.5 Empowerment.** The guiding ethos of the program is empowerment. Service providers perceived key successes of their online content empowering members, despite a general agreement that the *"social empowerment goals are not easily addressed."* For example, self-agency is inextricably linked to a sense of control and freedom to choose how and when one engages in life's activities; possessing the power to direct one's self. In the pivot to an online program, a structured in-person program with set hours, became an always-open menu of activities. This format change enabled the members to choose the content they wanted to consume and when. *"Members can do it [the programming] on their own time, which in of itself is empowering."*

Providers noted one way to measure member empowerment is to understand the degree to which members internalize experiences with the online program and transfer those learnings to their lives outside of the program. "Some of the things they have heard, they have applied to real-life," said one respondent. Similar to the service provider experience of the transition, member engagement required adapting to a technological environment. To maintain their participation, members learned how to access the content using the mobile application, navigate a tablet computer, and use video conferencing technology. For many, the level of immersion in the online space was new terrain and could have resulted in program abandonment. Instead, members were *"Empowered to use technology to open their worlds up."* Another commented, *"Seeing members become more comfortable with the*

*format and in asking for what they need is empowering.*" The hope is that gains in self-efficacy related to technology use will transfer to the telehealth environment that, in response to COVID-19, also went from novel to norm. *"This will hopefully transfer to things like telehealth visits! Talking to doctors more comfortably."*

Finally, within the empowerment theme, references to connectedness signify the importance of community and is related to assuaging that sense of separation. The COVID-19 response required social distancing and stay-at-home orders that, for a person living with MCI, could have a compounding effect on feelings of isolation. However, service providers suggested that the program's continuation, online, relayed the message that *"we're not on hold – we still want to know what you think."* Further, online social gatherings were *"Empowering people to tell their stories and not feel alone."* Likewise, service providers' comments about improving the members' online experience, by and large, were related to improving connectedness. They want the *"ability to communicate with us and one another more easily, that's what the members value, it's the relationships, the camaraderie."*

## 6 DISCUSSION

### 6.1 Reflections on Telehealth

The COVID-19 pandemic forced a rapid shift to telehealth across the US healthcare delivery systems due to the need to prioritize onsite health capabilities for COVID-19 treatment demands, and to protect patients and providers from potential exposure. Access to care became the critical issue for older adults that were no longer able to meet in person because of the pandemic. In their global survey on eHealth, the World Health Organization identified telehealth as a critical service in responding to a pandemic [40]. Previously in the US, telehealth practice was poorly adopted, hampered by regulatory and reimbursement barriers, and met with muted customer demand in part due to poor usability and uptake of "patient portals" [28, 47]. Fast forward a year and many healthcare providers and practices have adapted to offer "tele visits" that support existing patient follow-up, monitor symptoms of previously diagnosed conditions, triage new concerns, and relay laboratory results. Perceived barriers have fallen in the face of overwhelming need. However, the lack of preparation and past slow adoption within the healthcare system have revealed a lack of basic access to technologies or supports for telehealth, as well as a lack of experience to manage this transition [19]. Furthermore, the lack of familiarity with technologies such as tablet computers, applications, and content delivery platforms was previously thought to impose a limit on the use and long term adoption of telehealth content delivery for people with mild cognitive impairment [44]. This study documents a successful continuation of access to care as we rapidly constructed the infrastructure needed to support telehealth programs despite the challenges associated with creating rich user experiences for people with cognitive deficits.

During the transition period, the larger healthcare provider that refers patients to our program went from effectively no telehealth offerings to increasing adoption of video-based patient interactions to rates nearing in-person capacity. Our service providers survived a steep learning curve and are now offering suggestions and requests for more immersive, interactive content experiences. If we had started with this foundation, we could have created a fundamentally different online program. It is important that the healthcare industry capitalizes on the lessons learned during this unexpected shift and does not lose these hard fought gains. It is equally important that we also address persistent gaps in patient access and quality of care that now further exacerbate healthcare disparities.

Patient experience online was a prime consideration. Any technology or user experience designed for people with cognitive impairment has to consider the needs, abilities, preferences, and limitations of not only the person engaging with the technology but their support network as well [10]. By

not considering patient experience we would have faced low engagement, low adoption, and an increased burden on the user's already stressed support network as they struggled with the experience.

Perhaps equally important was our consideration of the clinician or service provider experience. The vast majority of our service providers had little to no experience in providing telehealth experiences for people with mild cognitive impairments. The service providers were concerned about workload, privacy and security, and the potential for lack of engagement due to reduced social interactions. Our platform had to be able to capture the content that each service provider was producing in a way that minimized the level of effort required to translate that content to an online experience. Choosing established technologies and providing detailed training on those technologies was integral to managing the transition.

Looking back, we have demonstrated the feasibility of providing valuable and actionable therapeutic online content remotely to older adults with MCI and their care partners. We successfully maintained access to care with minimum disruption. We developed a telehealth platform that created a user experience that balanced the needs of individuals with mild cognitive impairment, their care partners, and the service providers. This initial success is critically important to the future of our program and others that we hope will follow. While our high-touch, in-person program in a beautiful facility is an optimal experience, there are considerable barriers to replicating this program at scale. Likewise many patients will not be able to devote the time and travel required for an in-person program of this nature. While we seek ways to broaden the reach and impact of our multifaceted lifestyle interventions for people with MCI, we have demonstrated that members and care partners working together can learn new skills, experiment with and adopt new healthy behaviors, and develop a deeper understanding and empathy for the challenges they face together.

## 6.2 Importance of Social Engagement and Interactivity

While we celebrate the feasibility of some aspects of our online program, it fell short compared to our former in-person program due to the decrease in social engagement and interactivity between members. In-person, social interaction happened naturally during and between classes. By shifting therapeutic interventions from synchronous in-person classes to a menu of content consumed asynchronously, we decimated almost all social interaction and engagement.

To address this gap, we added synchronous Zoom gatherings with groups of program members, care partners, and program staff, and asynchronous feedback forms alongside program homework. We initially tried to replicate events that had worked well in space, such as informal coffee chats, but found that these interactions were limited by the need for facilitation by a service provider and by technology access issues. Open-ended feedback to course content was generated by only a few program members, likely due in part to the awkwardness of typing on the tablet. Moreover privacy regulations and practices that prevent sharing information, such as the names and pictures of patient program members, hamper the use of well known online social tools. Not surprisingly interaction between program participants who did not meet face to face before COVID-19 seemed to be less rich than the exchanges between participants with more established relationships. These limitations were addressed by encouraging some sessions where members attended alone, providing active facilitation for all "social" events, and ensuring an additional staff member was available to help with technical issues without interrupting session flow.

As we have discussed, interactivity is key to the flow and engagement between our "instructors and students" allowing course content to be driven by member needs and instruction calibrated in real time based on perceived interest and comprehension. More fundamentally, higher levels of social engagement among individuals with MCI is associated with lower risk for progression to dementia as well as slower rates of progression for individuals who go on to develop dementia [25, 34]. At

least in part, this outcome likely relates to the multifaceted nature of these types of activities, which are inherently cognitively stimulating and seamlessly incorporate other neuroprotective factors (e.g., physical exercise, emotional wellness). Moreover, face-to-face conversations via the Internet have been found to support naturalistic interactions among older adults with MCI and have been posited as an intervention for allaying cognitive decline in this population [11].

What we can say with certainty is that our current patchwork of mechanisms for social interaction, while meeting some needs, is an area for improvement for our online program. Although social interaction has improved over the course of our time in online programming, and our team has flexibly responded to these demands, future directions here include iterating on these lessons learned to support more frequent and meaningful interactions for our members both within the interventions provided, and by continuing to encourage interaction with families outside of formal CEP activities.

### 6.3 Scaffolding and Structure

Scaffolding [5] refers to the systematic sequencing of prompted content, materials, tasks, and support to optimize learning and support greater independence in the learning process [30]. Practically, scaffolding is the process by which learners are given decreasing levels of support when completing new tasks as they show increasing competence through demonstrating task mastery. The goal is to shift responsibility from the instructor to the learner over time. In this way, scaffolding supports self-efficacy and learner empowerment.

In the original conceptualization of the empowerment program, scaffolding was built into the program in the form of materials and content aimed at supporting members and care partners, in the physical design of the program setting, and dynamically created by therapeutic service providers in group settings. For example, service providers moved members from class to class to reduce confusion. During in-person sessions, service providers were also more likely to pick up on learning cues of individual members and appropriately scaffold (or support member independence), depending upon demonstrated competence in the activity being completed. Moreover, in the physical space, service providers had the opportunity to appropriately encourage scaffolding between members and to provide group structures that allowed for learner empowerment for many skill levels. However, in the online space, scaffolding opportunities for service providers decreased alongside the ability to “read the room” and the responsibility for scaffolding member learning fell largely to care partners who were present during learning periods.

In retrospect, it is not surprising that care partners stepped in to fill this gap and supported members in accessing and benefiting from online program content. Although we created the specially designed program app following strict design guidelines for minimizing cognitive load and creating a usable experience for older adults [10], accessing the program content was nevertheless challenging as our members could forget the existence of the program, could suffer from low motivation and initiative, and become distracted. Even those members who would complete a program task, such as listening to a weekly segment about nutrition, would have difficulty in navigating to and initiating another task, such as learning about a visual artist. We believe that the care partners who were able to dedicate time and attention took it upon themselves to sustain member engagement with the program when in-person sessions were suspended. Care partners printed out checklists, scheduled coffee chats on large, shared paper calendars, and created routines and rituals for completing weekly content.

What followed was an evolution of the role of the care partner who became a companion student and co-instructor, providing individualized relevance and insights, and often becoming compatriots in trying new behaviors, from practicing yoga to trying new foods. In interviews care partners (spouses and adult children) remarked that they would pause program videos to “explain” and

discuss with the program member, sometimes viewing the materials in advance to be ready to help. In studies that incorporate strategy training for memory, findings consistently indicate that training is less effective among patients with “late” MCI and that patients frequently have difficulty spontaneously transferring strategies learned to novel types of information [17, 18]. Therefore, it makes sense that individuals in the program, in some cases, benefited from contextualization by their care partners. Moreover, the need for additional scaffolding is likely to increase as individuals move along the MCI spectrum toward dementia. Given the importance of these types of supports, we recognize that scaffolding the learning of members relies, in part, on care partners, and that the degree of transference depends upon the level of member cognitive impairment. Moreover, the finding that telehealth interventions for individuals with cognitive impairment require increased care partner engagement has been consistently found in other studies of this nature and is not idiosyncratic to our study [6]. As we discuss next, the additional involvement of care partners led to emerging interpretations and outcomes for the program’s overarching goal of empowerment.

#### 6.4 Empowerment

Our program mission is to empower people with MCI and our therapeutic programming focuses on teaching compensatory strategies for mitigating cognitive loss and sustaining daily activities; encouraging and informing healthier lifestyles through improved physical fitness, social engagement, and nutrition; increasing awareness and acceptance of an MCI diagnosis; and enabling new avenues for expression and community participation.

A recent review of empowerment through interactive technologies characterized empowerment along four dimensions: the concept of power, psychological components of feeling, knowing and doing, the persistence of empowerment, and the design mindset [46]. Based on this framework, our program uses a participatory design mindset to provide persistent empowerment that gives power to members across the feeling, knowing and doing components. Schneider et al. underscore that empowerment is contextual [46]. For example, the program also empowers care partners, in the same design mindset, but not using the same tools. The scaffolding solutions or support groups may have empowered care partners, while adapting through the transition experience may have empowered the service providers.

Our unplanned experiment with online programming necessitated by the COVID-19 pandemic has led us to reexamine our assumptions and plans for empowering people with MCI. As evidenced in our interviews with service providers, our shift to a technology-mediated asynchronous programming created new opportunities for empowerment, and increasing agency and self-efficacy, as members and care partners learned how to use new technologies for regular engagement with the program and developed their own practices at home for engaging content based on their preferences and priorities. These sentiments were echoed in our interviews with members and care partners who reported the excitement of their grandchildren who they now spoke to via video chats and the new rituals with adult children such as Wednesday evening art sessions.

Benefits from online engagement, however, did not occur through singularly empowering the program members with MCI. The major successes in the program during this challenging summer were the product of care partners and members creating their own paths, including adopting new behaviors and developing understanding and empathy for a shared life changed by MCI. By aptly adjusting to these demands, we were able to create a program which supported these emergent practices, and thereby empowered dyads in an unexpected way by encouraging them to navigate our program on their own terms, often as a team.

Our original empowerment program stressed interaction and training for people with MCI while simultaneously offering care partner respite if desired. Twice a week, our members would be safely engaged with our therapeutic staff for 5-6 hours a day freeing up care partners to attend to other



matters and their own self care. Our online program has little of those benefits. A majority of care partners have filled those gaps and even now attend live social sessions with their spouses. However some care partners are unable to fill these roles. Will empowerment happen without them? The likely answer is a qualified yes but those limitations pose many questions. Should we rethink the design of our program, directly integrating care partners into many activities and tapping into their local knowledge, priorities and initiative for change? What about people with MCI, such as some of our members, who do not have a care partner who can serve that role? And what can we learn from our summer's experience with asynchronous online programming? This model could potentially scale far past the limitations of in-person experiences. Here the participation of the care partner appears to be mandatory. Should we design an online only program aimed at dyads/families? Perhaps our definition of empowerment should be: "making families stronger, increasing individual and shared confidence, especially in pursuing life goals and claiming their rights."

### 6.5 Insights for Practice

Our research insights stem from "learning on the fly" in contrast to evaluating a fully designed online program. Nonetheless we offer these lessons (see Figure 3) to inform future online programs serving older adults, especially those with MCI. We have organized these suggestions along the major themes in our data: Time, Technology, Interaction, Social Engagement, Adaptation, and Empowerment. Here we revert to the more common terminology of provider, patient and caregiver to contextualize future use of online tools.

## 7 CONCLUSIONS AND FUTURE WORK

In conclusion we demonstrated that it is feasible to deliver a comprehensive lifestyle program for individuals with MCI in an online environment. However, we quickly learned that an asynchronous program eliminated an important aspect, and one of the things most needed in this time of COVID-19, social connection. Additionally, we learned that although satisfaction with asynchronous programming was high, so was the burden for some families. Nevertheless, for other families what transpired was an opportunity for connection and empowerment that might never have come to pass without the need for care partner and family facilitation and engagement in the online environment. We anticipate designing and evaluating multiple models for MCI empowerment at scale through online programming that take into account the benefits and costs of active facilitation by care partners. Indeed, the work of building the plane while flying it has provided important insights about programmatic, personal, and contextual factors that have implications extending well beyond our online program.

Our rapid shift to an online platform has informed our current approach to delivery of lifestyle interventions to members and care partners. Based on the feedback from surveys and interviews, we have implemented live online programming days in which groups of 2 cohorts take part in live sessions one day per week via Zoom, with additional opportunities to attend sessions that are open to all cohorts. While we have not fully replicated in-person programming, there are several important similarities. Specifically, live programming days include a series of domain-specific interactive sessions, opportunities for social engagement, and facilitated breaks. One aim of this approach was to create interactive experiences between members and service providers that shifted the focus of sessions from disseminating knowledge (as in asynchronous programming) to collaborative learning and training skills.

Another aim of this approach was to address issues related to scaffolding and care partner burden. We have retained the weekly checklists to allow members and care partners to track participation and completion. However, we aimed to reduce member's reliance on the care partner

<b>TIME AND TECHNOLOGY</b>
<b>Allow flexibility in prioritizing online activities and with requested online feedback and homework.</b> In our experience, twice weekly face to face classes fit best into a weekly publication of online content and activities.
<b>Provide training and on demand assistance for telehealth delivery.</b> Do not expect that patients, or even expert healthcare providers, are knowledgeable and have sufficient access to communication technologies
<b>Provide content templates and mechanisms for re-using content.</b> The flexibility of face-to-face classes shifted to more standardized online postings likely due to the overhead of content creation.
<b>INTERACTION</b>
<b>Foster a systems perspective that emphasizes connectivity and consistency across the online platform and tools.</b> Provide visibility of user experiences across roles to inculcate consistent language across diverse content providers.
<b>Minimize complexity, adhere to design guidelines for older adults, and overall strive for simplicity.</b> Platforms for similar experiences, e.g. online college, can still present significant barriers for older adults.
<b>Provide mechanisms that “pull” the user from one online activity to the next.</b> Despite our simplified interface geared to older adults, members had difficulty initiating a new activity even after completing a similar task.
<b>Minimize required typing on tablet-based interventions.</b> Open ended responses via typing were disliked due to the difficulty of using screen-based keyboards.
<b>Provide low overhead mechanisms to provide feedback and reward mechanisms to encourage lightweight interaction.</b>
<b>SOCIAL ENGAGEMENT</b>
<b>Reinforce relationships and social interactions.</b> Members responded positively to material couched in relationships, e.g. “Yoga with Megan”, and reported sustained connectivity with these service providers.
<b>Create tools to facilitate informal social interaction,</b> when possible, between patients accessing online materials. Developing shared empathy and camaraderie bolsters patient motivation and patient engagement.
<b>ADAPTATION</b>
<b>Provide checklists for completing activities and tools to plan for online work around caregiver schedules.</b> Our care partners created new schedules and rituals to facilitate online program engagement.
<b>Provide mechanisms for curating content collections and reusing content between different patient groups.</b> Our providers quickly saw the advantages in repurposing content across their classes.]
<b>Foster cross-domain transparency for creating online content.</b> Providers benefitted from increased transparency typically not feasible in traditional, in-person settings.
<b>EMPOWERMENT</b>
<b>Provide tailored materials to aid diverse care givers who then scaffold online access for older adults.</b> Care partners benefitted from concise summaries and structured lists to plan and support online activities.
<b>Encourage transferability of new skills.</b> Patients leveraged their new video conferencing skills to begin socializing online with their grandchildren.
<b>Conduct holistic assessments of the patient, care giver and provider experience.</b> Online program success required a combination of patient motivation, care partner support, simplified technology, and cross program support.

Fig. 3. Recommendations for practice for online activities focused on adults with MCI.

for participation by using a single Zoom link for the entire live programming day and we provide facilitation in all sessions and breaks by program staff. Similar to our in-person programming, care partners are encouraged but not required to attend sessions. Finally, with live online programming days, we aimed to foster and create social engagement within and across cohorts and between members and staff. In addition to the social connection that occurs during sessions, there is time before and after sessions for casual interactions, as would commonly occur during in-person programming. The next steps in our research will focus on satisfaction with this model of online programming and how it impacts member, care partner and service provider experience.

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