Aging with Pride: Innovations in Dementia Empowerment and Action (IDEA)


Article info

Keywords: Intervention, Cultural adaptation, LGBT, Virtual, Dementia, RCT

Abstract

Background: Sexual and gender minority (SGM) older adults and their care partners, compared to the general population, face unique vulnerabilities that exacerbate living with dementia, including elevated disparities in comorbidities, social isolation, and structural inequities, such as discrimination and lack of access to supports. Methods: This paper describes the virtual adaptation process of the first-ever randomized controlled clinical trial intervention, Aging with Pride: Innovations in Dementia Empowerment and Action (IDEA), that was designed for SGM older adults living with dementia and their care partners and built upon the foundation of RDAD and NHAS. Results: The virtual adaptation of IDEA was guided by the goals of accessibility, quality, ease of delivery, sustainability, and cultural relevance. The implementation required the development of a HIPPA-compliant online virtual platform, coach and participant virtual training, and modification of necessary intervention elements and materials, as needed. Based on the preliminary findings, the participants and intervention coaches responded well to the virtual adaptation of IDEA. When comparing to in-person delivery, the virtual delivery decreased attrition among both intervention participants and coaches. Discussion: The virtual adaptation of the IDEA intervention resulted in preliminary, unexpected, yet potentially important benefits, including the ability to expand the reach of the intervention and decreased attrition. Virtual interventions are an emerging field for people living with dementia and their care partners and additional systematic research is needed to fully assess the benefits and limitations as well as to evaluate if specific subgroups are better served by differing delivery modalities.

1. Background

Due to the aging of our population, the prevalence of dementia in the U.S. is currently rising and is projected to increase 100% by 2050 [1], with estimates that it will affect between 10.5 million [1] and 13.8 million [2] Americans. Currently, more than 16 million individuals in the U.S. provide care to those with Alzheimer Disease, the most common form of dementia [3]. Finding and implementing effective interventions for those living with dementia and their care partners is a public health issue, especially for underserved communities, such as sexual and gender minority (SGM) older adults.

Aging with Pride: Innovations in Empowerment and Action (IDEA) (IDEA; Clinical Trials Identifier NCT03550131) is the first ever randomized controlled trial (RCT) intervention specifically designed to address the risk factors and needs of SGM older adults living with dementia and their care partners, as identified in Aging with Pride: National Health, Aging and Sexuality/Gender Study (NHAS), the first longitudinal study of the population [4]. The design of the intervention was guided by the Health Equity Promotion Model [5], which conceptualizes ways structural and environmental contexts intersect with health-promoting and adverse pathways to influence outcomes for SGM and other marginalized communities living with dementia. The IDEA intervention was built upon Reducing Disability in Alzheimer’s Disease (RDAD) [6-8], an efficacious cognitive behavioral intervention designed to increase physical activity and problem-solving in people living with dementia and their care partners. The IDEA intervention was enhanced...
with SGM-specific content to ensure its cultural applicability. Coaches were trained to employ motivational interviewing (MI) and empowerment practice strategies to address common barriers to engagement among SGM older adult populations, including stigma, non-disclosure of stigmatized identities, historical trauma, and social isolation. For the full description of IDEA, see Fredriksen-Goldsen and colleagues [9].

This paper outlines our adaptation of IDEA from the original in-person delivery [9] to virtual delivery. As an emerging field, knowledge about the virtual delivery of interventions is limited for people living with dementia and their care partners, especially among under-served populations. In partnership with the U.S. Department of Health and Human Services (HHS), the National Institute on Aging (NIA) convened the 2020 Dementia Care, Caregiving, and Services Research Summit Virtual Meeting Series, which included identifying emerging challenges and opportunities of technology in dementia care [10]. The lack of large-scale rigorously designed RCTs of assistive technologies (e.g., smartphone reminders to take medications to compensate for memory loss) for people living with dementia and their care partners notwithstanding, harnessing habits and environments in technological contexts of interconnected internet devices holds great promise in mitigating the impact of cognitive decline on the daily functioning of people living with dementia, a concept termed technological reserve [11].

Large-scale, rigorously designed RCTs incorporating such technological innovations that provide cutting-edge avenues to attenuate the impact of cognitive decline and improve quality of life among people living with dementia and their unpaid care partners are urgently needed to support the development of technological reserve among people living with dementia [10].

Our goal in this paper is to describe the process of our virtual adaptation of IDEA aligned with best practices in the implementation science literature. Adaptation includes altering the design or delivery of an intervention to achieve a better fit in a new context [12]. Adaptations can be responsive, meaning they happen in response to an emerging issue that occurs during the implementation process [12], for example, the COVID-19 pandemic and mandatory lockdowns. In this paper, we utilize the Framework for Reporting Adaptations and Modifications-Expanded (FRAME) [13] to elucidate our adaptation process. We will review the adaptation context; the goals we utilized to guide the virtual adaptation of IDEA; the steps we implemented; and the nature of the content modifications made to intervention elements and materials to support virtual adaptation and fidelity to the intervention, as they are aligned with the FRAME model [13]. To guide future research, we also present our preliminary findings, as well as describe both the challenges we faced and the opportunities and benefits that emerged through the virtual adaptation process. The adapted, virtual IDEA addresses an important gap in terms of virtual adaptation and implementation of interventions with underserved populations, in this case, SGM older adults living with dementia and their care partners.

2. Materials and methods

2.1. Adaptation context

According to the FRAME model [13], it is important to track the when, who, reasons for adaptation, whether modifications are planned or unplanned, and the level of delivery at which modifications are made in the adaptation process. Our when was in the spring of 2020. Shortly before the COVID-19 pandemic became widespread, IDEA was launched, using in-home, in-person delivery [9]. As lockdowns and physical distancing were mandated to slow the spread of COVID-19, the sponsoring university’s Human Subjects Division overseeing the RCT IDEA study called a temporary halt to research involving in-person interactions [14]. In response to these restrictions (the why or reasons for adaptation), the IDEA research team (the who) began the unplanned development of a virtual adaptation of the IDEA intervention. Our modifications were made for our target intervention group (level of delivery), SGM older adults living with dementia and their care partners. Although, as will be further described in this paper, our target intervention group’s geographic location expanded during the intervention adaptation process.

2.2. Goals for modifications

To guide our virtual adaptation process, we determined our goals for modifications, a component in the FRAME model [13]. We were guided by five goals in the modification process: accessibility, quality, ease, sustainability, and cultural relevance. In the following sections we will examine these goals, and their foundations, in greater detail.

2.2.1. Accessibility

In-person interventions offering information, training, and support are invaluable in improving the quality of care provided and attenuating mental distress among people living with dementia and their unpaid care partners, yet are resource intensive. As such they may be inaccessible in under-resourced settings due to issues of limited access to transportation and/or respite care, living in more rural areas, or hesitancy in participating in in-person interventions. Internet-based interventions hold great potential in facilitating scalability and consequent access in under-resourced settings and underserved populations that may have the greatest need for such interventions [15]. Yet close to 22 million older Americans do not have broadband access in their homes [16]. To evaluate our adherence to the goal of accessibility, we developed and assessed ways to respond to those who might otherwise be unable to participate due to lack of technology and/or internet access.

2.2.2. Quality

Recent systematic reviews of care interventions for people living with dementia and their care partners have come to the same general conclusion; with extremely few exceptions, published studies of dementia interventions do not provide sufficient evidence, or the evidence provided is too uncertain to be able to draw meaningful conclusions [17]. Reasons include small sample sizes (i.e., <10), and inconsistency in what measures are used to assess baseline characteristics (e.g., subjective cognitive decline vs. dementia) and indicators and outcomes (e.g., measures of depression not validated for people living with dementia). Similarly, the methodological quality of online-specific training programs for caregivers of people living with dementia are characterized as ‘limited and methodologically underdeveloped’ [18]. Lack of robust, quality indicators from conceptualizing study design through execution and analyses poses a significant barrier to understanding which aspects of which interventions work with what populations and in what ways. Addressing this gap requires larger, more-rigorous studies of dementia interventions that include 1) study designs with control groups, 2) multiple time points, and 3) content that is both personalized and interactive [18]. Our initial study design was an RCT with both control and experimental groups. The design incorporated pre and posttest assessments, along with a follow-up assessment 13 months after the intervention was completed. We also developed and implemented personalized and interactive components. For example, supporting individuals in identifying ‘pleasant events’ to engage in, as well as content specific to the unique sociocultural and historical experiences of SGM older adults.

2.2.3. Ease

‘Older adults’ decision-making processes regarding whether to adopt a novel technology are complex and are influenced by an array of factors, including 1) perceived usefulness and benefits, 2) ease of use, and 3) affordability [19]. Even when people are familiar with a given technology (e.g., smartphones), taking up a similar but different device (e.g., iPhone® vs. Android®), can be confusing and frustrating to learn due to differences in device architecture and operating systems.
Confusion and frustration reinforce negative perceptions of the technology and significantly decrease the likelihood of an individual adopting it [20]. The easier a new technology is to learn and use, the more confident and comfortable participants will be in using it and the more likely they will find it acceptable. Older adults value independence and will consider using a technology if they perceive it to be useful, reliable, and providing obvious benefits in supporting their independence [20]. In developing the transition from in-person to virtual delivery of IDEA, the study team kept ‘ease of use’ front and center for participants, as well as for coaches and lead interventionists. This included, for example, developing simple to follow pictorial instructions for participants, and clear, specific instructions for coaches on best practices in adapting aspects of the intervention from in-person to virtual delivery.

2.2.4. Sustainability

Results of recent systematic reviews of intervention sustainability find that when sustainability is referenced, strategies to facilitate it are generally not planned for in the study design [21,22]. Researchers often explicate sustainability as ‘the ongoing delivery of implementation strategies’ [21,22]. In the development of IDEA, we conceptualized sustainability as the following: 1) the intervention itself, 2) the implementation strategy; and, 3) the efficacy of the primary and secondary outcomes [22]. The primary focus of sustainability in the shift to virtual delivery was the implementation strategy – whether older SGM adults and intervention coaches would find the virtual delivery platform acceptable. Acceptability of the intervention, which was foundational to sustainability, was tested first.

2.2.5. Cultural relevance

The National Institutes of Health have explicitly acknowledged that researchers and the national research infrastructure itself harbor implicit biases, and are committed to addressing them [23]. Such bias can become embedded in intervention inception, design, development, and implementation, further marginalizing already historically marginalized groups. Efficacious, culturally responsive, clinically appropriate interventions for underserved and historically marginalized groups are critically needed [24]. Three principles that can facilitate cultural relevance are 1) the intervention should be predicated on the cultural values of the target group; 2) intervention strategies should be congruent with the group’s subjective culture; and 3) elements of the intervention should be grounded in the expectations and behavioral preferences of the group [25]. Cultural relevance was a keystone to the original IDEA intervention enhancement. The study team has focused its research on the health and well-being of SGM older adults for more than two decades and SGM cultural relevance was central to the study team’s collective development of the Health Equity Promotion Model [5]. This model is the foundation for the NHAS study and conceptualizes the underlying mechanisms by which health-promoting and adverse pathways (e.g., sexual/gender identity stigma, identity concealment) mediate and moderate social, behavioral and structural risk factors (e.g., social exclusion, interpersonal discrimination, victimization) that become embodied and result in health inequities.

2.3. Adaptation process steps

In the sections that follow, we describe the specific steps of our process adapting the in-person delivery of IDEA to a virtual delivery modality, including challenges and successes in the process. We will articulate our steps aligned with the FRAME model [13], including contextual modifications, training, and content and nature of content modifications. Throughout these sections we highlight where fidelity to the core elements of IDEA and our goals of accessibility, quality, ease, sustainability, and cultural relevance were embedded in the adaptation process.

2.3.1. Contextual modification: selection of virtual platform

Our virtual adaptation required changing the context of the IDEA intervention setting and format from in-home and in-person to a virtual platform. To accomplish this, we researched video conferencing platforms and evaluated them using four standards: 1) secure and HIPAA-compliant, 2) promotes ease for participants, 3) affordable, and 4) provides access for multiple users simultaneously given the dyadic nature of the intervention and coach delivery. Our study staff researched, and pilot tested video conferencing platforms to ensure they were secure, password-protected, and easy-to-access and utilize (goals: accessibility, ease). We also wanted to ensure that the platform allowed for the coach, person living with dementia, and their care partner to be in different locations for intervention sessions, which was necessary in situations in which dyads did not live together and physical distancing limited in-person interactions (goal: accessibility). Virtual delivery also allowed coaches to deliver the program from different locations. After robust testing of several virtual platforms, Doxy.me @ [26] was selected for its ability to meet the intervention goals, and ensure simplicity for participants (e.g., clicking a single link to join a meeting (goal: ease). Participant readiness for virtual delivery and participation was also assessed. iPads® were made available to study participants who did not have access to Wi-Fi or a device for study participation, along with easy-to-follow pictorial instructions to utilize the iPad to connect to Doxy.me intervention sessions (goals: accessibility, quality, ease). If needed, participants were also provided with a data plan free of charge to connect to the internet.

2.3.2. Virtual training

Modifications to the training of IDEA coaches was part of our adaptation process. Coaches were selected based on their professional experience in the health and human services, college level training, and cultural awareness and comfort working in SGM communities. They received in-depth training regarding the virtual adaptation and delivery of the intervention. The components of the training centered on the best practices for virtual delivery that were developed by the research team: 1) review of virtual intervention elements; 2) practice with the use of the technology for delivery; 3) virtual role playing of session content; and 4) the assessment of participants’ use, comfort with, and effectiveness of virtual delivery (goals: accessibility, ease, quality). Weekly coach meetings with Lead Interventionists (coach supervisors who were expert instructors and PhD qualified researchers), were an important element of the initial study to monitor and ensure fidelity among the intervention coaches (goal: quality). These weekly meetings were easily adapted to also problem-solve issues that arose with virtual delivery, and to identify any significant difficulties or concerns that needed to be resolved by the study team (goals: accessibility, ease, quality).

Lead Interventionists worked with and instructed coaches on the implementation of best practices for the use of the video conferencing platform and virtual delivery on an ongoing basis. These practices included: 1) visual monitoring of intervention sessions; 2) the use of document sharing for completion of intervention exercises; and, 3) ways to promote successful, and fidelity-consistent virtual engagement in all intervention components. Coaches were also provided with virtual training materials, including a Virtual Adaptation Manual Addendum. Important tips and considerations were explored during training and in the supplementary materials provided to coaches (See Table 1). In addition, Considerations for Online Delivery of Intervention Protocol handout was developed and distributed to coaches (See Table 2) and demonstrated how to incorporate and be responsive to virtual considerations (goals: ease, quality). Coaches were prepared to supplement any training needs not only in the virtual delivery of IDEA and updated materials, but also with tips and best practices for video conferencing and the delivery of the virtual protocol (see Tables 1 and 2) (goals: ease, quality). Moreover, because physical distancing requirements prevented in-person interactions between members of the research team and coaches, delivery of ongoing coach training was also provided on a
involved the modifications to the intervention manuals outlining any necessary modifications. Each in-home session. However, with coaches unable to be physically present and, in some cases, physical distancing requirements inhibiting dyads who did not live together from being in coaching sessions in the same location, we made adaptations to ensure the safe delivery of this virtual component. The exercises were reviewed and modified to be completed while seated and we distributed a handout with graphics and descriptions of the seated exercise, including the functional importance of each movement (goals: accessibility, ease, quality, sustainability).

The nature of content modifications also included adding elements to virtual IDEA. Closed-captioned YouTube videos were developed and provided to each of the participants so they could observe the proper technique of all exercises between coaching sessions. Links to these videos were provided after the coach demonstrated and observed in-session exercises. Materials were also distributed to the person living with dementia and the care partner separately, given virtual delivery. Paper copies of all materials were mailed to the dyad prior to the start of the 6-week intervention and were also available to be emailed upon request. For the IDEA arm, additional local community resource guides were provided, aligning with the expanded dyad locations.

### 3. Results

While the research team anticipated challenges transitioning to the virtual delivery of IDEA, both study participants and the intervention coaches adapted well to the transition. With the change to virtual delivery, study participant engagement remained high, and attrition was low. During the three-month transition period, 23 dyads were enrolled and queued to initiate intervention sessions. Two dyads that expressed discomfort with shifting to virtual delivery withdrew, all other dyads in both arms remained in the intervention. Many dyad members shared...
virtual participation was more convenient and it was easier to schedule sessions given differing availability (goals: accessibility, ease, quality). In addition, the study was able to reach dyads where care recipients had Mini Mental State Exam (MMSE) scores as low as four, which suggests the care recipient was severely cognitively impaired. When comparing intervention retention rates post completion of the six intervention sessions, 78% of those in the virtual intervention delivery completed the intervention vs. 58% of the dyads with the in-person delivery.

Lead interventionists and coaches initially expressed trepidation about the use of video conferencing technology for the delivery of the intervention. For example, intervention coaches faced a relatively steep learning curve to integrate both the use of technology, and simultaneously coach virtual treatment sessions. However, with trainings, weekly coach meetings, and individual support from study staff, all coaches adapted relatively quickly. At about the midpoint of the intervention (i.e., Session 4 of 9), coaches were explicitly asked about the difficulty of implementing the virtual intervention – 87% reported only a little or not at all difficult; 12% somewhat difficult; and only 1% reported it was difficult (goals: ease, quality, sustainability). And, if coaches moved out of the immediate area, they no longer needed to terminate coaching, but rather could continue coaching virtually, decreasing coach attrition.

Coaches also offered feedback regarding challenges and benefits of delivering IDEA virtually. They reported virtual implementation was extremely difficult when either the dyad or the coach experienced internet connectivity problems. They also reported difficulty in fully observing both members of the dyads while participants were completing the seated exercises. Benefits of the virtual delivery cited by coaches included greater flexibility in scheduling meetings, and the elimination of potential delays, such as encountering unexpected, heavy traffic when traveling for an in-home coaching session. Coaches also noted that it was more convenient for them in the event a dyad had to cancel a session with little or no notice, as compared with driving to a dyad’s home and only learning upon arrival the session was cancelled. In the virtual setting, coaches also reported being able to effectively maintain intimacy and a feeling of being “in” the participants’ homes. They also described the materials created for the virtual adaptations, including the exercise video and availability of handouts online, to be particularly useful. Coaches expressed support for virtual delivery of the intervention as it helped mitigate further isolation and potential negative outcomes during COVID-19, especially among SGM older adults living with dementia, with many already disparately isolated compared to older adults in the general population (goals: accessibility, ease, quality, sustainability).

Pivoting to a virtual intervention also allowed for the expansion of recruitment efforts, and therefore expansion of our target intervention group. The adaptation from in-home delivery to virtual enabled the extension of the IDEA project’s initial recruitment efforts that were centered on direct referral from three original partnering agencies located in their respective metropolitan urban areas. Once virtual engagement was implemented, the catchment area was expanded in waves and became available nationally, including to those living in rural areas, a severely underserved dementia population. The study enrolled dyads from 28 states. Coaches also benefited from interacting with participants from across the country and expressed support for making the intervention widely accessible nationally, as opposed to a single or limited geographic area as in the original IDEA formulation.

4. Discussion

The purpose of this paper is to describe the virtual adaptation process of an intervention specifically designed to address the needs and risk factors of an underserved population, SGM older adults with dementia and their care partners. For this population, the COVID-19 pandemic created a cataclysmic event that intersected with the challenging and progressive nature of dementia. Given the restrictions regarding in-person interactions as the result of COVID-19, the IDEA research team had to make a difficult decision: stop offering the intervention for SGM older adults living with dementia and their care partners or make a pivotal change and deliver the intervention virtually in the context of COVID-19. The team decided it was imperative to continue to reach this socially isolated and disproportionately affected population. Given the context and changing circumstances of the global COVID-19 pandemic, the need to adapt the IDEA intervention to a virtual delivery was evident. We moved forward, adapting IDEA in a step-by-step process, aligned with the FRAME model [13].

Despite initial hurdles in adapting the intervention content and addressing the need of training coaches and participants in the use of video conferencing technology, opportunities and benefits related to virtual delivery emerged. Nearly all the coaches were able to deliver virtual sessions without difficulty and nearly all the participants chose to continue in the intervention. Unexpectedly, the virtual adaptation was associated with decreases in both participant and coach attrition. The experienced research team, structure of weekly Lead Interventionist support for coaches, and hands-on training from study staff allowed for intervention accessibility, quality, ease, sustainability, and cultural relevance. Our virtual adaptation benefitted from serving both members of the dyad and incorporating a strong theoretical foundation [5,9] in a rigorously studied RDAD dementia intervention [7], which likely assisted the virtual adaptation process. Furthermore, the virtual adaptation expanded our reach beyond the original 3-city recruitment area to a much larger scale. Not only did we recruit from 28 states using virtual delivery, but we also reached dyads living in rural areas and not connected to SGM-specific communities or dementia services. Research has shown that SGM older adults who live in rural communities have access to fewer SGM-specific services, and greater fear of discrimination [27, 28]. Virtual delivery allowed us to reach those individuals in rural areas, who were at greater risk of isolation during a global health pandemic.

Our study, as well as other emerging evidence, suggests virtual based interventions can be effective for people living with dementia and their care partners. Existing research found that such interventions can reduce depressive symptoms, perceived stress, anxiety, and self-efficacy among unpaid caregivers [29]. In addition, virtual balance training programs targeting older adults with cognitive impairment have been shown to be both feasible and acceptable [30]. Moving forward in virtual based intervention research, systematic reviews have called for virtual dementia interventions to be tailored to user preferences, needs, personal situations, and dementia severity [29,31].

The lack of knowledge concerning technology and the internet continue to be serious barriers in virtual interventions [32]. To address these barriers, our study staff purchased equipment, provided participants with iPads® and internet access if needed, and supplied training and easy-to-follow materials with pictures and descriptions for accessing all aspects of our virtual platform and intervention, including closed-captioning on all YouTube exercise videos. While current research indicates people with dementia can learn to use technology even if they have had no prior exposure [33], more research is needed to evaluate if specific subgroups are better served by differing delivery modalities. It may be that in pivoting to a virtual intervention our implementation reach was affected, and we were not able to access some segments of the population for whom technology is a primary barrier for engagement, such as the oldest old and dyads living with more advanced dementia. Following completion of all data collection activities, our next step will be to evaluate the efficacy of the intervention in terms of study aims and to assess the differing delivery modalities and the impact on recruitment and retention in the intervention.

5. Conclusion

The IDEA study pivoted dramatically due to COVID-19 and the need to adapt the intervention to a virtual framework. While this research has moved our knowledge of SGM intervention research forward, there are
several issues that need to be explored through future research. Further research is needed to fully test the theoretical relevance of the HEPM in guiding virtual dementia research. In addition, recruiting additional participants can help us understand the role of a virtual intervention for rural residents and determine how they differ demographically as well as how they respond to interventions. A larger study can also allow for expanded exploration into the areas of psychological well-being of unpaid care partners including areas such as depressive symptoms, perceived stress, and anxiety. Next steps can also address methodological barriers that exist currently such as inconsistency of assessment tools. Additionally, in expanding the size of the study we can further evaluate sub-group differences in the efficacy of the virtual delivery of the intervention.

Assessing the potential for this intervention to be implemented in real-world practice will advance the potential for dementia interventions to address growing, diverse populations living with dementia and their care partners. The knowledge we have gained through the IDEA adaptation provides a platform to move virtual intervention research forward with SGM older adults living with dementia and their care partners.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence writing.


