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Developing an animated COVID-19 e-curriculum for adults with dementia and caregivers: Challenges and solutions

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ABSTRACT

Objectives: Effective education and support for adults with dementia and their caregivers around pandemic issues is critical for protecting them. Animation-based learning has shown promise in patient education. We collaborated with educators and support staff at Alzheimer’s Association Connecticut (AACT) to conduct a mixed-methods study and develop an animated e-curriculum addressing pandemic related challenges.

Methods: We conducted focus groups and surveys with dementia and caregiver educators and support staff at AACT for the initial needs assessment and the later e-curriculum evaluation. An interdisciplinary team of educators followed a step-wise process to transform the needs assessment results into an animation based e-curriculum.

Results: Participants identified the following pandemic challenges: 1) social isolation, 2) caregiver fatigue, 3) safety, and 4) difficulty navigating the healthcare system. The overall quality and usefulness of the e-curriculum was “very good” or “excellent”.

Conclusions: An animated e-curriculum addressing pandemic related issues relevant to adults with dementia and caregivers had positive reviews and was associated with improvement in self-reported ability to perform curriculum objectives among community dementia educators.

Practice implications: The pandemic challenges identified may facilitate the development of further resources. Additionally, this project may serve as a guide for clinicians interested in incorporating animation into education efforts.

1. Introduction

A growing body of evidence suggests that COVID-19 effects are more severe for adults with dementia. They are more likely to experience severe illness, hospitalization and death due to COVID-19 [21,31]. Studies have also shown that cognitive and functional decline as well as neuropsychiatric symptoms among adults with dementia have accelerated in the pandemic period [8]. While the pandemic has led to disturbances in social networks, healthcare delivery, and community support services for everyone, adults with dementia have been disproportionately affected due to their high level of reliance on these systems [4,15]. In addition, their mood, perceived stress levels, and physical health have worsened with isolation and decreased access to healthcare and social support services. [29] Likewise, dementia caregivers have reported experiencing great stress and burnout due to inadequate supports and unmet needs of their loved ones during the pandemic [1].

In a recent survey study, while a majority of this population reported adequate awareness of typical COVID-19 symptoms, they felt unprepared to recognize atypical manifestations, respond to emergencies and...
utilize the appropriate resources [23]. Bridging the knowledge and support gaps among people with dementia and their caregivers is essential to protecting this population during the pandemic. Education and support programs often utilize verbal instruction, handouts, brochures, or videos with text, and pictures. However, the best way to present information to this population for education or support purposes is unknown. Animation can simplify complex medical information and display it in an easy to understand format. Improved knowledge retention has resulted from medical education interventions that utilized animation-based methods [5,6]. As a patient education tool, animation has been shown to promote patient knowledge, engagement and compliance in the pre-operative, and hospital settings as well as in chronic disease management [11,25,30].

The aim of this mixed methods study was two-fold: (1) to identify challenges associated with caring for older adults with dementia during the pandemic; and (2) to develop an animated e-curriculum to address these challenges. To accomplish this aim, we performed a needs assessment in collaboration with dementia and caregiver educators and support staff at Alzheimer’s Association CT (AACT). Based on the results, we developed an animated pilot e-curriculum. Finally, we evaluated the content and delivery medium.

2. Materials and methods

2.1. Overview

Fig. 1 summarizes the workflow of tasks undertaken by the team during curriculum development. We conducted a needs assessment in September 2020; this included an initial focus group and a survey. The results of the needs assessment informed the processes of conceptualization, content and multimedia development, which took place between October 2020 and April 2021. The e-curriculum was evaluated via a second focus group and surveys in May 2021.

This study was conducted as part of the Connecticut Older Adult Collaboration for Health 4 M (COACH-4 M) project at Yale School of Medicine. It received an exemption from the Yale Institutional Review Board as a quality improvement initiative. Verbal and/or electronic consent was obtained from all participants at the time of the focus group(s) and/or survey(s), respectively, depending on their participation. All study participants who took part in the focus groups agreed to be anonymously audiotaped during the focus groups.

2.2. Study participants

Study participants included dementia and caregiver educators and support staff at AACT, which provides virtual and in-person education and support to a clientele of adults with dementia and/or their caregivers living in Connecticut. Within AACT, the study participants held various roles. One of these was to facilitate monthly educational and support sessions. These sessions not only provided a safe and supportive environment for the clients to form relationships with one another but were also a platform to learn about dementia complications, receive anticipatory guidance and discuss common issues in real time. Another one of the participants’ role was to provide individualized education and support to clients via phone or electronic means. While most of the participants were with the AACT as volunteers, many currently held or had held in the past, jobs as social workers, or homecare staff. In addition, some had personal experiences being caregivers for adults with dementia. The study participants held a unique position in the community, given their firsthand knowledge of local needs of the target population (adults with dementia and caregivers), as well as insight into existing educational and support materials. An invitation to participate in the study was emailed to AACT lead program coordinator who distributed this to the dementia educators and support staff. Participants could choose to participate in the focus group(s), survey(s), both or neither.

2.3. Needs assessment

In the focus group, participants were asked to identify new issues and challenges raised by clients who joined the educational and support sessions during the COVID-19 pandemic. The focus group was
conducted virtually via Zoom. The audio portion was recorded. Two separate members of the study team analyzed the narratives to identify themes.

In the online survey, participants were asked to comment on their use of existing material for COVID-19 related education and discussion facilitation. They were also asked to rate their level of interest in obtaining new educational material and report their preferred medium for delivery of this information. Answers were captured using Qualtrics →, a HIPAA compliant survey capture system. Results were tabulated using Microsoft Excel.

2.4. Development of the E-curriculum: content and animation

Results from the needs assessment were used to develop the goals for the e-curriculum, which was delivered through two videos and incorporated both character animation and digital chalk talks, as well as the objectives of each video [6,22]. The length of the two videos (18 and 15 min, respectively) was informed by the needs assessment results as well as team consensus. The goals for the e-curriculum were for learners to be able to perform the following: 1) Enhance communication with loved ones while remaining socially distanced, 2) Adopt effective strategies and skills, and know the community resources for battling caregiver fatigue, 3) Protect themselves and loved ones through understanding why older adults and those with dementia are at higher risk of complications from COVID-19 and making informed choices regarding COVID-19 testing and vaccination, 4) Develop strategies to mitigate risks while navigating the healthcare system in the home, outpatient, inpatient and nursing home settings. As this was a pilot e-curriculum, we chose to focus our videos to achieve two of the four goals: safety concerns (goal #3 above) and difficulties with navigating the changing healthcare system (goal #4 above). These two were chosen due to their relevance and specificity to the pandemic period, as well as team consensus that the topics would be most suitable for the animation medium. Addressing safety concerns was particularly a priority, as the needs assessment revealed majority interest in obtaining new educational resources regarding the impacts and complications of COVID-19 in older adults and those with chronic medical conditions and dementia. Specific learning objectives for each video were the following:

**Video 1 (The Biology of COVID-19):**

1. Describe how COVID-19 infects the body
2. Explain why older adults are at higher risk
3. Recognize the manifestations of COVID-19 in older adults and those with dementia
4. Compare and contrast the different types of COVID-19 tests and vaccines
5. Learn to protect yourself and your loved ones

**Video 2 (Navigation of the Healthcare Scene During COVID-19):**

1. Describe how COVID-19 impacted different care settings including home care
2. Explain how delirium is prevented in the hospital
3. Describe how someone can communicate with the family while in the hospital
4. Describe why someone should go to rehabilitation after the hospital
5. Describe how someone can communicate with their family while in rehabilitation

An interdisciplinary team that included trainees (residents and fellows from internal medicine, neurology, geriatrics and medical education,) faculty members, and research support staff worked together on shared documents via comments and tracked changes to develop the scripts for the videos.

Once script writing was complete, concept and character art were developed to illustrate the virus, pandemic, older adults and chronic diseases. Team members sketched each video shot in conjunction with the completed script during the Storyboard stage (Fig. 2a). These sketches were organized into a shot list which was used to create more formal artwork. Software Pen and Camtasia were used for whiteboard-style visuals including the digital chalk talks, while SynfigStudio was used for vector animation. The clips from this artwork were then composited into full-length videos before dissemination to caregiver support session facilitators.

The first video was titled “The Biology of COVID-19,” and featured “Corona,” an animated character who “surreptitiously infected nearby cells and spread disease” (Fig. 2b). The video began by illustrating the biology of the virus and pathophysiology behind the COVID-19 infection, including the natural history and time course of symptom development. Different types of tests for COVID-19 were described along with their interpretations and implications, and reasons why an individual would be tested, including a description of typical and atypical symptoms. Next, we explained the premise behind vaccination through illustrating the immune response. In addition to 2-D animation, infographics from the Centers of Disease Control and Prevention were used to depict the increased proportion of COVID-19 deaths and hospitalizations among older adults and those with specific conditions as well as geriatric syndromes such as multimorbidity, frailty and dementia [20]. (Supplemental Video 1).

The second video titled “Navigation of the Healthcare Scene During COVID-19” featured Betty, an older woman with dementia, and Jane, her neighbor and caregiver, as they received medical care in different settings (home (Fig. 2c), outpatient, urgent care and inpatient). Strategies to remain safe while receiving necessary medical care, such as using telehealth, prior-to-visit symptom screens and appropriate personal protective equipment, were explored. Appropriate monitoring of one’s social and psychological well-being was encouraged and different avenues for seeking help were offered. In terms of inpatient care (hospital and rehabilitation stays), viewers watched Jane advocate for Betty and use multiple channels of communication to stay connected, despite in-person visitation restrictions. (Supplemental Video 2).

2.5. Evaluation of the E-curriculum

The videos were available via a secure website on our institutional network and the link was disseminated to the study participants by e-mail. All participants were instructed to watch the videos as many times as they wished and use them with their clients for means of education and support if they wished. There was no comparator group that did not receive the intervention. One month after dissemination, we conducted a second focus group and surveys to collect qualitative and quantitative feedback on the material content, the media platform and the e-curriculum. As part of these post-curriculum development surveys, participants were asked to self-report the improvement in their ability to perform the curriculum objectives. Data collection and analysis were performed using the same methods as described under the needs assessment section.

3. Results

3.1. Needs assessment

Thirty-four individuals received an invitation email to participate in the study. There were twelve participants in the needs assessment focus group, and eighteen survey respondents. The qualitative analysis of the focus groups identified the following four themes dominating the educational and support sessions: 1) social isolation, 2) caregiver fatigue, 3) safety issues, and 4) difficulty navigating the healthcare system (Table 1A).

With respect to social isolation, participants reported their clientele’s frustrations about connecting with family members with dementia due to social distancing restrictions and barriers posed by electronic
communication. These barriers included the family member with dementia having limited access to Wi-Fi and internet, lack of ability to navigate the electronic system as well difficulty with recognizing their family members or engaging with them on the screen.

Examples of caregiver fatigue included reduced privacy and need for respite from around-the-clock caregiving, lack of control over the current situation, anxiety about the future, and frustration about the accelerated decline during the pandemic.

In terms of safety issues, stopping home care services despite a continued need for fear of COVID-19 exposure, was a major topic. Similarly, distancing and isolating from family members who were at risk of exposure to the virus through their work or in the community contributed to social isolation and created barriers to having needs met (i.e., another family member doing shopping or paying bills).

Regarding navigating the healthcare system, study participants shared that many dementia caregivers had questions related to their role as health advocates. Challenges arose due to visitor restrictions in advocating and caring optimally for those with dementia during inpatient and outpatient medical encounters.

Focus group participants also commented on their evolving role as group leaders and facilitators during the pandemic, noting that they were more often having to provide reassurance, caregiver empowerment, particularly with respect to the role of healthcare advocate, safety reinforcement regarding masking and quarantining guidelines, and encouragement of caregiver respite.

58% of participants felt their current educational resources were not adequate to address the pandemic-related needs of their clients. Over 70% were interested in obtaining new educational resources regarding the impacts and complications of COVID-19 in older adults and those with chronic medical conditions and dementia. Educational material provided in the format of online videos or live zoom sessions had the highest likelihood of use (Table 1B).

### 3.2. Evaluation of the E-curriculum

There were six participants in the evaluation focus group, and twelve survey respondents. All participants rated the quality of “Biology of COVID-19” video to be very good or excellent. Ratings were similar for the “Navigation of the Healthcare Scene” video other than one participant whose rating was “good.” After watching the videos, over 60% of participants noted “a great deal” or “considerable” improvement in their self-reported ability to perform the curriculum objectives (Fig. 3). No participants felt that the duration of the videos were too long.

Focus group participants commented that videos were “easy to understand,” “at the right level,” “great at explaining the information,” and “accessible.” The animation was described as “refreshing,” as it “kept the video interesting,” “gave a playful element to the discussion of dementia…conveyed both concern and kindness” and prevented the viewer from “drifting during the course.” In regards to the characters in the Navigation of the Healthcare Scene video, one participant appreciated the “racial diversity” and the “friend component.” The main downside of the e-curriculum was that “it came too late.” Many participants echoed the sentiment that the e-curriculum would have been more useful at the start of the pandemic.

### 4. Discussion and conclusions

#### 4.1. Discussion

We conducted a local needs assessment of caregiver educators and
Movie S1. Clip from educational video titled “The Biology of COVID-19,” features Corona, an animated character representing the SARS-CoV-2 virus, and introduces the pathophysiology and clinical course of COVID-19 infection. A video clip is available online. Supplementary material related to this article can be found online at doi:10.1016/j.pec.2022.10.346.

Movie S2. Clip from educational video titled “Navigation of the Healthcare Scene During COVID-19” showcasing Betty, an older woman with dementia, and Jane, her neighbor and caregiver, as the former receives home care. A video clip is available online. Supplementary material related to this article can be found online at doi:10.1016/j.pec.2022.10.346.
“Everyone is so isolated and missing human contact. It’s been devastating and folks are seeing definite declines in their person with dementia.”

“… how to have meaningful conversations. Individuals with dementia are not used to seeing their loved ones on tablets… some family members are not even sure what to say anymore. It’s frustrating for families because they feel like they are not connecting with someone that has dementia.”

“… harder for some our members to get on Zoom, and have an hour or to talk to people about Alzheimer’s when their spouse [with Alzheimer’s] is right there.” “There is a lot more stress and anxiety on them [caregivers]… One person told me ‘I’m just watching her die… I think I just need to move her ‘cause [sic] I can’t just sit and watch this everyday… they’re just stuck in the house, it makes it really hard.’”

“… couple questions on the vaccine, when that might happen… but also questions on the flu shot and when school is starting. Family members have been worried about their kids, going to school, not going to school. From the perspective of their loved one’s safety…”

“We had a case where it has been unavoidable that they had to have their loved one in a nursing facility and they had to weigh the safety of the loved one against the policy of visitation… and we had to know where you can visit outside.”

“Another [caregiver] said when her husband needed emergency abdominal surgery, ‘they said either you stay now, stay the whole time or you leave now and you can see him when he gets discharged… that was a huge stress for the family.’

“At the beginning of COVID, we had 30% of people drop home care… because they did not want people in their home.”

“Someone recently asked me, her husband is homebound, totally homebound… how to get him a flu shot. These questions have been coming up a lot… a lot of the flu clinics have been suspended for the year.”

Table 1

**Needs Assessment.** A) Focus Group Themes and Narratives B) Survey Findings.

**A)**

| Social Isolation |
|------------------|
| “Everyone is so isolated and missing human contact. It’s been devastating and folks are seeing definite declines in their person with dementia.” |
| “… how to have meaningful conversations. Individuals with dementia are not used to seeing their loved ones on tablets… some family members are not even sure what to say anymore. It’s frustrating for families because they feel like they are not connecting with someone that has dementia.” |

**Caregiver Fatigue**

“… harder for some our members to get on Zoom, and have an hour or to talk to people about Alzheimer’s when their spouse [with Alzheimer’s] is right there.”

“… couple questions on the vaccine, when that might happen… but also questions on the flu shot and when school is starting. Family members have been worried about their kids, going to school, not going to school. From the perspective of their loved one’s safety…”

“We had a case where it has been unavoidable that they had to have their loved one in a nursing facility and they had to weigh the safety of the loved one against the policy of visitation… and we had to know where you can visit outside.”

**Safety Concerns**

“… couple questions on the vaccine, when that might happen… but also questions on the flu shot and when school is starting. Family members have been worried about their kids, going to school, not going to school. From the perspective of their loved one’s safety…”

“We had a case where it has been unavoidable that they had to have their loved one in a nursing facility and they had to weigh the safety of the loved one against the policy of visitation… and we had to know where you can visit outside.”

“Another [caregiver] said when her husband needed emergency abdominal surgery, ‘they said either you stay now, stay the whole time or you leave now and you can see him when he gets discharged… that was a huge stress for the family.’

“At the beginning of COVID, we had 30% of people drop home care… because they did not want people in their home.”

“Someone recently asked me, her husband is homebound, totally homebound… how to get him a flu shot. These questions have been coming up a lot… a lot of the flu clinics have been suspended for the year.”

**B)**

| Current Educational and Support Resources (n = 18) |
|-----------------------------------------------|
| Very or Somewhat Inadequate                    |
| Very or Somewhat Adequate                     |
| Interest in Obtaining Educational Resources Regarding the Following (n = 18) |
| Medical impacts and complications of COVID-19 in older adults with chronic medical conditions | 13 (72) |
| Behavioral strategies for people with dementia during social distancing and isolation | 13 (72) |
| Community resources for people with dementia within social distancing limitations | 13 (72) |
| Emotional support resources for caregivers during social distancing and isolation | 13 (72) |

| Likelihood of Using Educational Material in the Following Format (n = 17) |
|-------------------------------------------------------------------------|
| Audio Podcast                                                          |
| Online Video                                                           |
| Live Zoom Seminar                                                     |
| Written Pamphlet/Infographic                                          |
| 14                                                                     |
| 16                                                                     |
| 14                                                                     |
| 14                                                                     |

Fig. 3. Participants’ self-rating of the improvement in their ability to perform the curriculum objectives. A) Video titled Biology of COVID-19 (n = 10) B) Video titled Navigation of the Healthcare Scene (n = 13).

surveyed reported high role overload [26]. Another qualitative study assessing for the impact of COVID-19 in Pennsylvania demonstrated the challenges of social isolation, caregiver fatigue, and safety concerns, i.e., “fear and risk mitigation” during their interviews with dementia caregivers [24].

While these challenges existed prior to the pandemic, they were likely exacerbated by infection prevention efforts. Our e-curriculum addressed these by recommending potential strategies. One such strategy was telemedicine, which has been shown to improve health outcomes in the older adult population and can reach those in rural or underserved areas with limited access to care [2,19]. Now that there is widespread implementation of telehealth with the pandemic, more research is needed to evaluate telehealth’s effectiveness in managing dementia complications beyond screening and diagnosis [10,13].

Additionally, engaging older adults with digital communication practices may help to curb social isolation by offering them a means to communicate with friends, family and other supports. Virtual education and counseling can increase social supports and equip caregivers with skills needed to care for their loved ones [5,28]. Alzheimer’s Association, for example, had virtual caregiver support sessions alongside in-person sessions in the community during the pandemic.

The animation medium may have played a role in both the success of the educational aspect and positive reception of these videos. First, pictures and videos have been shown to improve comprehension of health information [3]. Meta-analyses have shown that when it comes to dynamic phenomena such as biological processes, animation has a positive effect in learning when compared to static images [14]. Animation has the potential to mitigate cognitive load in education and has previously been implemented in patient- and caregiver-facing education and shown benefits over print resources [16-18,27]. The effects are even greater among populations with reduced health literacy, such as our identified the key themes of social isolation, caregiver fatigue, safety issues, and difficulty navigating the healthcare system as barriers to providing dementia care during the COVID-19 pandemic. Information from the initial survey was used to develop an animated educational series to help inform adults with dementia and their caregivers about the current health crisis. Study participants, who interface regularly with adults with dementia and their caregivers in their roles as educators, reviewed the animated curriculum positively, with the majority self-reporting improvement in their understanding of the biology of COVID-19 and the pandemic’s impact on navigating the healthcare system. Four major themes dominated the sphere of dementia caregiving during the COVID-19 pandemic: social isolation, caregiver fatigue, safety concerns, and difficulty navigating the changing healthcare system. Our needs assessment findings were consistent with other recent studies among adults with dementia and caregivers. In a Virginia study during the stay-at-home phase of the pandemic, nearly half of caregivers...
target population with dementia [12]. Finally, a recent study that compared vector animation in medical education to digital chalk talk style of animation concluded that while the former enhanced learner experience, blended learning that employs combination of the two types, as used in our e-curriculum, produced the most successful didactic experience [7].

The processes used to develop the e-curriculum were found to be accessible to clinicians and researchers. None of the study authors had formal training in film, animation, or related skills, yet were able to create an animated series through an evidence-based, stepwise approach. While our overall workflow is listed in Fig. 1, the steps of multimedia development are further delineated by Brown et al in their “toolkit” for aspiring clinician-animators [6]. The process was collaborative and resulted in an impactful final product that summarized key COVID-19 and dementia-related topics in an interesting and relatable manner. The engagement and interest bolstered by animation was noted by the focus group participants in their e-curriculum evaluation. We hope that this curricular design process serves as a useful guideline for clinicians and other educators looking to address similar public health crises and/or incorporate animation into their education efforts for the aging population.

This study had some limitations. Firstly, participants in the local needs assessment were dementia caregiver educators, rather than the intended audience for the COVID-19 e-curriculum: adults with dementia and their caregivers. While we felt the use of educators in this study was a strength due to their close ties to the dementia community and role in dissemination of the COVID-19 e-curriculum following our study, they served as a proxy for our target audience. Follow-up research should focus on feasibility and effectiveness of using this e-curriculum for education and support of adults with dementia and their caregivers. Secondly, we did not have a comparator group. We did not assess the participants pre and post videos for objective knowledge, but instead asked them to self-report the perceived improvement in their ability to perform the curriculum objectives. Another limitation raised by study participants regarded the timeliness of our education intervention. The prolonged duration of the COVID-19 pandemic was not anticipated and persists as of Winter 2022. This draw-out health crisis challenged our video series and other COVID-19 curricula to remain up-to-date despite the changing landscape of both the virus and infection prevention efforts. Our animated curriculum, for example, did not discuss new SARS-CoV-2 variants, evidence on waning immunity after vaccination, and booster vaccinations. Finally, this e-curriculum was a pilot, it addressed only two of the four major themes identified. Future COVID-19 education efforts should continue to address these limitations as well as identify appropriate methods of dissemination.

4.2. Conclusion

An animated video e-curriculum was a successful method of educating dementia caregivers in the community about pandemic-related issues. Several features of this project are worth special mention. We harnessed the knowledge and experience of local dementia and caregiver educators and support staff to identify major pandemic challenges and build an e-curriculum geared towards adults with dementia and their caregivers. An interdisciplinary team of medical trainees, faculty members, and research support staff followed a step-wise process to develop the content outline, script writing, storyboarding, and video production. The feedback revealed the impact of the animation medium in keeping the content memorable, accessible and interesting.

4.3. Practice implications

Given the unprecedented levels of isolation, disruption to daily routines and supports as well as barriers to essential needs including healthcare access during the pandemic, educating adults with dementia and caregivers around these pandemic challenges is critical to protecting them. Our e-curriculum was successful in meeting its goal of addressing two major pandemic challenges: safety and healthcare system navigation. The other challenges we identified, namely social isolation and caregiver burden, are not unique to the pandemic period; as such, this content may facilitate important discussions and development of resources that last beyond the pandemic period.

Secondly, the animation medium kept the videos interesting, relatable and accessible; this may be critical in providing effective education to this particular population. The step-wise process we outlined here of developing an educational animated video series by clinicians and researchers without formal training in film or animation, can be adapted by others to integrate animation, a powerful tool, to enhance the learning of their audiences.

CRediT authorship contribution statement

Oyeyemi, DM: educational session design and delivery, overall study concept and design, interpretation of data and preparation of manuscript; Omer, ZB: educational session design and delivery, overall study concept and design, data management, interpretation of data and preparation of manuscript; Brown, B: educational session design and delivery, overall study concept and design, interpretation of data and preparation of manuscript; Freimund, J: educational session design and delivery, overall study concept and design, interpretation of data and preparation of manuscript; Gummerson, C: educational session design and delivery, overall study concept and design, interpretation of data and preparation of manuscript; Rink, A: educational session design and delivery, overall study concept and design, acquisition of subjects, interpretation of data and preparation of manuscript; Gallant, N: educational session design and delivery, overall study concept and design, data management, interpretation of data and preparation of manuscript; Marrotti, RM: educational session design and delivery, overall study concept and design, acquisition of subjects, interpretation of data and preparation of manuscript, funding acquisition.

Declarations of Competing Interests

None.

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