

# Dementia-friendly initiatives within the context of COVID-19 pandemic: Challenges and strategies perceived by service professional stakeholders from the USA and China

Dementia

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Fei Sun, Fredrika A Opur, Ha-Neul Kim<sup>ID</sup> and Lucas R Prieto

School of Social Work, Michigan State University, East Lansing, MI, USA

Christian Conyers

School of Social Work, University of Michigan, Ann Arbor, MI, USA

## Abstract

**Purposes:** Dementia-friendly initiatives (DFI) are community-based movements aimed to address stigma, exclusion, and discrimination associated with dementia. This study examined the challenges faced and strategies used by DFI prior to and during the COVID-19 pandemic from the perspectives of stakeholders in the USA and China.

**Methods:** Qualitative interviews with 17 stakeholders involved in DFI from the United States and mainland China were conducted via the Zoom platform. Semi-structured interview questions focused on DFI challenges and strategies prior to and during the pandemic. Thematic analysis was used to analyze the data.

**Results:** Three major challenges prior to the COVID-19 pandemic included low participation of persons with dementia, difficulties in building community collaborations, and limited funding and resources needed to sustain DFI. During the COVID-19 pandemic, challenges included exacerbated difficulties of involving persons with dementia and reduced policy support for DFI. Strategies implemented prior to COVID-19 included partnerships with community organizations to outreach and engage persons with dementia, and coordination of resources and diversification of funding sources to sustain DFI. Strategies during the COVID-19 pandemic centered on the implementation of person-centered technology to support persons with dementia and family caregivers, and the development of new programs that integrated efforts to address the impact of COVID-19.

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## Corresponding author:

Ha-Neul Kim, School of Social Work, Michigan State University, 655 Auditorium Road, East Lansing, MI 48824, USA.

Email: [kimha15@msu.edu](mailto:kimha15@msu.edu)

**Implications:** DFI in the USA and mainland China shared similar challenges for DFI prior to and during COVID-19. During the COVID-19 pandemic, DFI in both countries showed resourcefulness through reliance on technology, community collaboration, and COVID-19–related resources to provide support and services. While it remains critical to advocate to the central government to fund DFI, DFI in both societies need to be open to other funding sources, hire persons with dementia as key staff members of DFI, and demonstrate its effectiveness through rigorous evaluation.

## Keywords

dementia-friendly initiative, dementia-friendly community, mainland China, USA, COVID-19

The novel coronavirus (COVID-19) pandemic has led to an unprecedented global public health crisis, posing high risks for persons with dementia. Evidence suggests that compared to those without dementia, persons with dementia were twice as likely to be affected by COVID-19 (Wang, Davis, Gurney, & Xu, 2021), more likely to experience severe virus effects (Numbers & Brodaty, 2021), and higher mortality rates (Cipriani & Fiorino, 2020). At the country level, the dementia population was positively associated with the number of COVID-19 cases (Azarpazhooh et al., 2020).

About one-third of the world's 50 million dementia population live in the USA and mainland China (Alzheimer's Disease International, 2020a). Over six million persons with dementia live in the USA (Alzheimer's Association, 2021) and about 10 million persons with dementia live in mainland China (Jia et al., 2020). Both countries issued safeguarding policies and procedures, such as shelter-in-place guidelines, social distancing, and social restrictions, to curtail the spread of COVID-19. However, such necessary measures may lead to social isolation, which is known to increase the risk for depression and anxiety among older adults (Gerst-Emerson & Jayawardhana, 2015; Santini et al., 2020), particularly for persons with dementia (Numbers & Brodaty, 2021). People in the early stages of dementia may feel overwhelmed by the complex nature of the virus, as they attempt to sort through information on social media or to follow social distancing rules. Persons at the moderate or late dementia stages are largely dependent on care from others and may experience disrupted access to services or support (e.g. hospital admission, family visits, and community services) (Alzheimer's Disease International, 2020b; Jiang et al., 2020).

The impact of COVID-19 pandemic on persons with dementia brings challenges to dementia-friendly initiatives (DFI), community-based movements charged to reduce social isolation and promote inclusion among persons with dementia and family caregivers. DFI occur at regional, state, or national levels and exist in about 46 countries (Alzheimer's Disease International, 2017). One goal outlined in the World Health Organization's (2017) global action plan on the public health response to dementia is to have half of its 194 member states to develop at least one DFI by 2025. Unlike earlier age friendly community initiatives of World Health Organization (WHO) that have a well-established framework for its development and evaluation (World Health Organization, 2007), DFI first started around 2005 in Japan (Hayashi, 2017) and did not have global guidelines until August 2021, when World Health Organization (2021) released a global toolkit, which reads more descriptive than prescriptive.

In line with the WHO global toolkit and existing literature of DFI (Hebert & Scales, 2019; Shannon, Bail & Neville, 2019), we contend DFI encompasses three essential principles; (1) centering on the needs of persons with dementia, (2) multi-sector collaboration, and (3) physical and

social environment modifications (e.g. public spaces, businesses, and services) to be more inclusive and friendly for persons with dementia.

DFI often use a person-centered approach as it pertains to persons with dementia. This concept was initially applied to dementia care by [Kitwood and Bredin \(1992\)](#). It suggests that persons with dementia should not be considered of less value because of their cognitive decline, but rather their lived experiences, identity, and humanity should be respected in the treatment and care relationship. Systematic reviews of existing DFI ([Hebert & Scales, 2019](#); [Shannon, Bail & Neville, 2019](#)) suggest this is a shared principle by DFI. Additionally, there are five commonly used approaches in DFI which include Education (e.g. providing dementia information), Advocacy (e.g. changing policy/practice), Support (e.g. linkage to care/services), Training (e.g. skills building), and Transforming environment otherwise known as EAST ([Hayashi, 2017](#); [Sun, Zhang, & Li, 2019](#); [Turner & Morken, 2016](#)).

The principles and approaches of DFI reflect a mission toward a dementia inclusive and capable community ([Lin & Lewis, 2015](#)). However, DFI have also received some criticism from advocates of persons with dementia and scholars for its lack of input from persons with dementia in its design, the condescending language, and its primary focus on awareness raising rather than other actions ([Shakespeare, Zeilig, & Mittler, 2019](#); [Swaffer, 2014](#)). Moreover, the dearth of studies that use randomized controlled trials to evaluate the effectiveness of DFI on persons with dementia inclusion are lacking. But existing review articles of case studies of DFI around the world (most from Europe, Canada, Australia, and USA) have alluded to the positive effects of the features of DFI ([Hebert & Scales, 2019](#); [Shannon, Bail & Neville, 2019](#)). One positive feature is the above-mentioned principle—the placement of the needs of persons with dementia at the center. This person-centered practice is found to increase persons with dementia’s engagement and participation as persons with dementia, highlight their unique experiences, focus on their strengths, and make the appropriate accommodations. However, due to the COVID-19 pandemic and related policies to contain the spread of COVID-19, DFI have faced hurdles to engage, assess, and intervene with persons with dementia. Furthermore, persons with dementia in the community may have a limited capacity to understand the situation; disrupted access to healthcare; a lack of therapeutic, supportive, and social support programs; and experience more social isolation ([Wang et al., 2020](#)). Lockdown and social distancing policies restricted in-person outreach and contacts DFI would normally make.

The current study explored the challenges and strategies prior to and during the pandemic DFI (regardless how the agency labels themselves) faced through the perspectives of service professional stakeholders in the USA and mainland China. “Dementia friendly” is used in a broad sense to encompass the activities under other related but different terms such as dementia enabling, dementia capable, dementia inclusive, and dementia positive ([Lin & Lewis, 2015](#); [World Health Organization, 2021](#)).

USA and China were chosen as both have a large dementia population affected by COVID-19 pandemic. Additionally, both countries have DFI implemented with differential starting year, implementation levels, and policies. The first DFI in the USA started in Minnesota in 2011, and now expands to approximately 40 states ([Dementia Friendly America, 2021](#)). DFI in mainland China started around 2018 in Beijing and Shanghai communities ([Sun, Zhong, & Li, 2020](#)). The Shanghai government is the only local government that has taken steps and proposed regulations of Shanghai Municipality on Elderly Care Services to build dementia-friendly communities by allocating resources to agencies engaged in DFI ([Shanghai Municipal People’s Government, 2021](#)). At the national policy level, both countries have issued national dementia policies to address the impact of dementia. The National Alzheimer’s Project Act (NAPA) in the USA passed in 2011 created a national dementia plan ([U.S. Department of Health & Human Services, 2016](#)), with a goal to

enhance public awareness and engagement. This plan contributed to the rapid development of DFI in the USA. The Chinese government launched a national dementia policy in 2020 to promote dementia programs that focused on the person-centered approach and community education (Alzheimer's Disease International, 2020c; Zhang, 2020). However, no tangible support has been provided from the Chinese central government to DFI. The policy and practice differences related to dementia between the two socio-politically different countries that may affect DFI challenges and strategies within the context of COVID-19 pandemic are worthwhile to explore.

Given this background, this study aimed to examine the challenges and strategies of implementing and sustaining DFI from the perspective of service professional stakeholders in the USA and mainland China. Given most DFI are spearheaded by agencies, this study only included service professional stakeholders. This can be defined as those who are actively involved in designing, launching, implementing, and evaluating a DFI as administrators, service coordinators, program designers, advocates, or consultants. Specifically, the research question is to identify shared and distinctive challenges DFI's faced prior to and during COVID-19 pandemic in the USA and mainland China, as well as the adopted strategies to overcome these challenges.

## Methods

A qualitative research design based upon individual interviews of service professional stakeholders of DFI from the USA and mainland China was used. This study was approved by a University Institutional Review Board, and informed consent was obtained from each participant. Data collection took place between May and August 2020. Recruitment for individual interviewees were garnered through the referrals mainly from the principal investigators' network including Dementia Friendly America, Michigan Dementia Coalition, the dementia-friendly community toolkit development initiatives of WHO, the Amity Foundation in Nanjing, and the DFI networks in Shanghai.

### Participants

We identified nine stakeholders from six states (i.e. Illinois, Michigan, Massachusetts, Texas, Wyoming, and Virginia) in the USA and eight stakeholders from three cities (i.e. Shanghai, Beijing, and Nanjing) in mainland China. These states and cities were purposively selected because each has an active DFI in a different capacity. For example, Massachusetts has a statewide supported DFI, while Michigan has two local DFI. Shanghai, Beijing, and Nanjing are metropolitan areas where DFI are growing in mainland China. This study did not include the city of Wuhan in China, where COVID-19 pandemic started, because Wuhan does not have any DFI programs.

### Procedure

Individual interviews were conducted using semi-structured interviews through Zoom, an online video meeting platform. Interviews were conducted in English or Chinese mandarin, and the average interview length was one hour. Interviews were conducted and recorded by one trained graduate student and the principal investigator with the embedded camera on. Each participant received a US\$25 gift card as an incentive. Interview questions covered participant demographics and questions regarding challenges and strategies DFI faced and used. As most DFI are anchored within one primary organization that leads and coordinates the initiative, interviewees reported many challenges related to DFI faced by their organization or by the formed DFI partnership networks. Interviewees were asked the following; (1) "Thinking about the DFI you were involved, what are the

difficulties faced before the COVID-19 pandemic?"; (2) "What are the challenges faced during the pandemic?"; (3) "What are the strategies used before the pandemic?"; and (4) "What are the strategies used during the pandemic?"

All interviews were video recorded and then transcribed for analyses. Most participants were female, in their 40s, had a master's degree, and were from the non-governmental community service sector. [Table 1](#) presents the detailed characteristics of stakeholder participants in the study.

### *Analytic approaches*

A qualitative descriptive analytic approach was used to summarize the key themes shared across participants. Specifically, we followed the steps of [Braun and Clark's \(2006\)](#) thematic analysis process that involves reading transcripts, developing codes, and refining themes. Four researchers divided into two work teams that coded interview transcripts. One team consists of two bilingual (English and Mandarin) researchers who coded eight Chinese transcripts, and the other team coded English transcripts ([See Appendix 1](#)). Open coding was used to identify any challenges or strategies reported by participants. Axial coding was then applied to compare and consolidate these categories. Four researchers compared their categories, and, with the bilingual principal investigator's input, reached the consensus about the finalized coding framework. Based upon the coding framework, themes were derived based upon participant responses from both countries. In the process of reaching a consensus about themes, all five researchers engaged in team meetings to discuss themes related to challenges and strategies of DFI.

## **Results**

### *Challenges prior to COVID-19 pandemic*

[Table 2](#) presents the themes related to challenges and strategies. Challenges prior to COVID-19 pandemic focused on the difficulties of involving persons with dementia, building collaborations among community organizations, and having adequate manpower and finances to sustain DFI implementation.

*Challenge 1: The low engagement and participation of persons with dementia.* Stakeholders reported the difficulties to involve persons with dementia in DFI programs prior to COVID-19. Stakeholders attributed the low visibility of persons with dementia in the community to dementia stigma and inadequate competency of the public interacting with persons with dementia. The stigmatizing belief that one loses the capacity or desire to engage in social participation right after their diagnosis led to little initiatives of family members to bring social participation opportunities to their care recipients. Participants reported that the public has low competency of communicating and interacting with persons with dementia. Neighbors and friends avoided visiting or talking to persons with dementia. Even service professionals like police officers failed to act appropriately when dealing with a person with dementia with behavioral problems. As one stakeholder in Michigan pointed out:

There can be possible confusion and confrontation with somebody living with dementia. For police officers who normally do not have such training, families were concerned that an officer could be called for something like domestic violence without a full picture of what's going on. The person may have dementia and may be acting out aggressively so that the response of the department may be inappropriate.

**Table 1.** Demographic characteristics of participants (N = 17).

	Mean/SD	Frequency (%)
Female		14 (82.4)
Age	47.0/10.7	
Sectors		
NGO/Community-based programs		11 (64.7)
Government-owned company		1 (5.9)
Hospital		2 (11.8)
University health care provider		1 (5.9)
Faith-based agency		2 (11.8)
Education level		
Bachelor		3 (17.6)
Master		12 (70.6)
PhD		2 (11.8)
Position		
Executive director		3 (17.6)
Program administrator		1 (5.9)
Program coordinator		8 (47.1)
Consultant		3 (17.6)
Educator		1 (5.9)
Community leader/advocate		1 (5.9)
Country		
Mainland China		
Nanjing		1 (5.9)
Beijing		2 (11.8)
Shanghai		5 (29.4)
USA		
Colorado		1 (5.9)
Illinois		1 (5.9)
Michigan		2 (11.8)
Texas		1 (5.9)
Wyoming		1 (5.9)
Massachusetts		2 (11.8)
Virginia		1 (5.9)

Such negative interactions with the outside world further deterred families from taking persons with dementia to DFI activities.

*Challenge 2: Difficulties to establish organization collaborations.* Stakeholders shared the difficulties of involving different organizations and sectors to support DFI and attributed this challenge mainly to agencies' low awareness of dementia. Local businesses and public services (e.g. banks and law enforcement) had little knowledge about dementia, resulting in low interest to participate in DFI activities. One stakeholder from Illinois reported the difficulties of collaboration:

I think that one of our biggest challenges is trying to get everybody together and to understand what it is, what's our next step, how we are going to work together. I think just getting people to understand that we all have a role to play is difficult.

**Table 2.** Summary of themes related challenges and strategies.

Pre-COVID-19		Post-COVID-19	
Challenges	Reasons	Challenges	Reasons
The low engagement and participation of persons with dementia	Dementia stigmatization Community lacks competency of interacting with persons with dementia	Exacerbated difficulties of involving persons with dementia	Social restrictions Limited access to technology services for some persons with dementia
Difficulties to establish organization collaborations	Lack of awareness about dementia among organizations	Reduced policy support to DFI	Government's focus on COVID-19 containment and emergency assistance to people affected by COVID-19 Other agencies' priority on COVID-19 prevention
Limited resources available to support the sustainability of DFI	Lack of leadership, shortage of manpower, and lack of financial resources		
Strategies	Outcomes	Strategies	Outcomes
Forming partnerships with community organizations and sectors to reach out and engage persons with dementia	Stay connected and increased DFI awareness	Using person-centered technology means to reach persons with dementia and family caregivers	Increased the outreach and engagement of persons with dementia and family caregivers in DFI programs
Coordinating resources and securing funding from diverse sources to sustain DFI	Funding and resources leveraged to support DFI	Integration of efforts to address the impact of COVID-19 into DFI activities	Addressed COVID-19 and dementia-related needs

Additionally, receiving funding amongst organizations that provide similar services to persons with dementia is competitive and can be a barrier to agency collaboration. For example, the regional chapters of Alzheimer's Association might feel threatened due to the funding competition with local aging service agency for DFI implementation. A founder of a community agency in Colorado suggested that each agency has a place to fill in and more communication and collaboration is needed. She mentioned:

We provide services [where there] were gaps previously existed. But the barrier is, how do we let people know that we exist in that? I think just continuing with or promoting collaboration in the community instead of competition... That is a challenge, even in the Denver area or dementia friendly America Initiative. I don't think we play well in the same box with Alzheimer Association. And I don't get that because I think we all have our place and I want to support Alzheimer's Association as much as they will support us.

*Challenge 3: Limited resources available to support the sustainability of DFI.* Implementing DFI requires resources and innovation in every aspect of the organization. The demand for continuous activities could be halted by the lack of leadership, shortage of manpower, and lack of financial resources as reported by participants.

Participants in both China and USA reported that the development of many DFI stemmed from personal experiences as the founders had a family member who had dementia. However, the founders often did not possess the appropriate skillsets to manage such an organization. Leadership problems, for example, affected those assigned to coordinate the organization and the rules of succession. A stakeholder from Virginia stated, “in some groups where they haven’t planned sustaining leadership, when the original leader has other priorities, transition in leadership affects the visibility of the organization DFI activities.”

Shortage of manpower and lack of financial resources are constraints to the sustainability of many DFI. Most organizations are nonprofits that rely on grants and donations which include volunteers to run their DFI activities. Funding agencies (e.g. governmental departments and foundations), particularly if dementia is not their focus interest, lack awareness of the importance of supporting and engaging in DFI programs. This financial challenge deters DFI from expanding activities or recruiting staff. A stakeholder from Wyoming said she wished she had more funding to recruit one additional staff member to conduct community outreach, and to meet with businesses and the state to stress the importance and validity of preventative programs for dementia.

### *Challenges during the COVID-19 pandemic*

Two common challenges during COVID-19 pandemic included the exacerbated difficulties of involving persons with dementia in DFI activities and reduced policy support to DFI.

*Challenge 1: Exacerbated difficulties of involving persons with dementia due to social restrictions.* COVID-19 pandemic presented heightened challenges to connect with persons with dementia who could not access services delivered via technology-based means. Many persons with dementia did not know how to use smartphones, computers, and social media platforms, such as Zoom, Facebook, WeChat, and DingTalk. With many DFI activities transitioning to virtual platforms due to the pandemic, persons with dementia and family caregivers who were less technologically savvy were left out of the adapted outreach activities. The social distancing guidelines led to the closure of many public service spaces, which further isolated persons with dementia from engaging in face-to-face DFI activities. A Shanghai stakeholder shared what challenges they thought persons with dementia faced during the pandemic, “Isolation, fear of not being able to get out. Not being able to come to attend activities in our center like they were before is probably the biggest challenge.” Similarly, a stakeholder in Illinois shared, “We considered doing that via Zoom. That is the biggest challenge. The people we need to reach are often not able to be reached via technology. The isolation is compounded.”

*Challenge 2: Reduced policy support to DFI due to the pressing need to contain COVID-19.* As the COVID-19 pandemic continued to impact the world, the government and funding organizations directed its attention toward combating the pandemic leaving DFI without the needed support. Many businesses that provided support to DFI activities were reducing their efforts because of their own financial struggles because of the pandemic. State and local public service and welfare programs were focused on providing emergency assistance to people affected by COVID-19. This shift in local and national initiatives reduced the momentum to support DFI activities. One stakeholder from Shanghai noted:



We have closed all in-person activities in the communities for persons with dementia and family caregivers. We know family caregivers stuck with persons with dementia at home [are] feeling distressed. As our program is contracted by the government, some of our staff were called upon to help the community implement virus prevention. Without policy approval, we cannot deliver any in-person support to persons with dementia.

### *Implemented strategies prior to COVID-19*

*Strategy 1: Forming partnerships with community organizations and sectors to reach out and engage persons with dementia.* Strategies prior to COVID-19 pandemic included partnerships with diverse organizations in or outside the community. The idea is to reach out to persons with dementia through the wide networks of all these organizations or agencies. A stakeholder from Illinois shared their strategies to accessing the Latino community:

We have had a terrible time getting members of [the] Latino community to notify us of needs. Partially language and culture are barriers. So, we partnered with the Alzheimer's Association, Evanston Community Foundation, Dementia Friendly Evanston, Northwestern University, Rush University, and the library to hold a Dementia Day and we advertised it widely to get members of community to come and say what they needed.

The importance of partnership was echoed by a stakeholder from Texas, who said, "we have stayed close to our partnerships. Through programs, we've stayed connected. We've worked together to spread what's going on in the community. Whether it's training, we share various contacts and listservs we have. Partnerships are key."

*Strategy 2: Coordinating resources and securing funding from diverse sources to sustain DFI.* The partnership strategy described above not only increased awareness of DFI in dementia communities, but also leveraged manpower and other resources to support DFI. In the USA, funding channels for DFI include the local government, foundations, local donors, and the public. In China, fundraising is highly regulated for NGOs, but one "new" way of seeking funds is through online platforms such as Tencent and Alibaba (Chinese multinational technologies that can be used for social networking and digital payments) during their annual charity days. Agencies also charge fees for services to expand revenue. A Shanghai stakeholder had the following to say about funding:

We are contracted by the Department of the Civil Affairs of Shanghai that is our major funding source, and so most services are free. However, for our cognitive training services, we charged a fee for families, as it opened a means of generating revenue and also encouraged families to participate actively because they paid.

### *Implemented strategies during COVID-19*

Strategies during the COVID-19 pandemic focused on the use of persons with dementia-centered technology to reach persons with dementia and to integrate program features that addressed the impact of COVID-19 in DFI programs.

*Strategy 1: Using person-centered technology means to reach persons with dementia and family caregivers.* DFI attempted to adapt the format of already established services of online platforms due to the COVID-19 pandemic. Online platforms, such as Zoom and WeChat, were utilized to deliver DFI

programs. A DFI stakeholder from Texas described the benefits of the virtual transition as “more people who weren’t able to attend things in person are now able to attend memory care or bible study.”

In response to the challenges for persons with dementia or families who have no access to online technology or have limited technology competency, a stakeholder from Nanjing had the following to say, “for an older lady who’s 92, she wouldn’t even want to use or she doesn’t have the internet.” To accommodate this, DFI used technology that met the needs of persons with dementia, for example, phone calls or radio. A Minnesota stakeholder noted, “there’s been an uptick for friendly visiting phone calls. We want to engage people in a way that they feel comfortable and safe, but also addresses their social isolation which can be exacerbated with dementia or being a caregiver.” Mailing, a traditional outreach means, has been increasingly used to connect with persons with dementia who have limited technology access. In places, such as Wyoming and Illinois, DFI sent personalized check-in cards and health information sheets via mail to persons with dementia and their families. Describing her knowledge and experience with the DFI, a stakeholder from Wyoming stated, “The Mission of Dementia Friendly Wyoming is building an informed inclusive community where persons living with dementia and their care partners are valued and supported.”

A stakeholder from Illinois also stated that “One of the biggest goals is to reduce isolation due to risk associated with it. Another is to find more effective ways to get communication to people in the community. The third is to bridge digital divide.”

*Strategy 2: Integration of efforts to address the impact of COVID-19 into DFI activities.* Since COVID-19 posed an epidemic crisis, local, state, and national aids were available for organizations working in the communities to help people deal with the effects of the pandemic, and more grants are made available for this purpose. Thus, communities began to tap into COVID-19 related resources to fulfill unmet needs of persons with dementia that DFI previously did not address. For example, most DFI would not provide food delivery service for persons with dementia before COVID-19. During the pandemic, organizations developed a check-in system, which included delivering meals, groceries, and personal protection equipment (PPE) to persons with dementia, and staying in touch via phone calls to maintain engagement of persons with dementia. This check-in system was created as part of DFI programs to maintain communication with their clients.

With the existent funding suspended for in-person activities and new funding purposed for COVID-19-related challenges, agencies were able to use these financial resources to develop new services or collaborations, such as home activity packages for persons with dementia, online training and support for family caregivers, phone counseling, and assistance via a collaborator agency. A stakeholder from Illinois reported:

We have trained 3-1-1 staff on dementia friendly initiative and what we can offer now. So, if someone calls about a home activity packet, they can do that. We have a social worker at the library who is available to help people access resources they need by the phone.

### *Differences in challenges and strategies between USA and mainland China*

Some cultural differences were noted between USA and mainland China in challenges and strategies prior to and during COVID-19. Regarding the difficulties to reach persons with dementia, stakeholders from the USA highlighted the obstacles to involve ethnic minorities, such as Latinos and Native Americans. However, in mainland China, stakeholders reported participation of persons with dementia and family caregivers was more affected by education and socioeconomic status (SES). One stakeholder from Beijing reported:

Low SES groups needed more mobilization to attend DFI activities in the beginning, but gradually they were more likely to participate; for those with higher SES were more likely to attend DFI activities in the beginning but needed continuous encouragement to maintain participation. I think the higher SES groups had higher expectations of DFI and more likely to hide their internalized stigma, and programs should address their respective needs.

Reflecting on strategies used by DFI to improve persons with dementia outreach, stakeholders from mainland China emphasized the use of social media and celebrities to improve persons with dementia outreach, but those in the USA stressed the adoption of culturally competent practices and peer advocates of persons with dementia. Regarding the source of external funding, agencies in the USA tended not to express funding from the government as their major source but rather have diverse funding sources; but those in China considered the support from Bureau of Civil Affairs of the local government as the major funding source.

## Discussion

We first placed the discussion of challenges and strategies in line with the three core principles of DFI; (1) persons with dementia needs centered perspective; (2) multi-sector collaboration; and (3) transforming social and physical environment (Hebert & Scales, 2019; Jiang et al., 2020). Challenges prior to and during COVID-19 revolved around how to place persons with dementia as the centered focus. The leverage of person-centered care/service remains a challenge to providing quality dementia care in both societies (Chen et al., 2017; Maslow, 2013). Internal challenges came from the lack of organizational leadership and competent staff, and external challenges were related to community partnership building and resource availability. Strategies adopted before and during COVID-19 focused on the realization of the second principle of DFI—the form of-multi-sector collaborations. This strategy is used to help community outreach, service coordination, awareness raising, leveraging resources, and securing new funding. Challenges and strategies reported focused more on social environment (e.g. individual or group dementia awareness and attitude) than physical environment (e.g. modifications of public space) changes.

The common challenges prior to and during the COVID-19 pandemic described above appear to apply to programs that serve non-dementia populations, but the next discussion explains how COVID-19 has exacerbated challenges for DFI to outreach and serve persons with dementia and their families, and new strategies adopted by DFI to address these challenges.

### *Challenges exacerbated for DFI*

Prior to COVID-19, DFI service professional stakeholders reported that stigma and inadequate training for interacting with persons with dementia resulted in low participation of DFI activities. This finding was not surprising as these barriers, as well as others (e.g. transportation), have been cited among other DFI (Shannon, Bail & Neville, 2019). Unfortunately, due to the COVID-19 pandemic, low participation from persons with dementia in DFI activities was an exacerbated challenge in two different ways. First, it increased outreach difficulties. COVID-19 lockdown policies that were implemented made it challenging for organizations to deliver in-person educational activities. Originally, door-to-door visits or in-person gatherings, which would have been the most effective means to reach out to this excluded population seems no longer viable since lock down and social distancing became the norm during the pandemic. In general, communication among persons with dementia is particularly important, as engagement in interpersonal

communication allows the persons with dementia to maintain a connection to their environment (Ward, Vass, Aggarwal, Garfield, & Cybyk, 2008). Furthermore, effective communication not only benefits the persons with dementia but also enhances the ability for providers to improve their dementia care (Jootun & McGhee, 2011; Windle et al., 2020).

Second, the lack of specific policy support for persons with dementia during the pandemic was a salient challenge. Due to COVID-19 social distancing rules, extra resources are required to deliver in-home support for persons with dementia and their families. These new demands are related to access to information on COVID-19, access to food and PPE for persons with dementia that are isolated at home, risk prevention efforts of the virus, and social isolation due to the lockdown policy. Moreover, the priorities of DFI during the pandemic have moved from raising dementia awareness to COVID-19 virus prevention. Agencies need to be equipped with knowledge about COVID-19 and safety strategies for preventing the spread of the infectious disease and disseminate such information to their service population. Surprisingly, the availability of volunteers to deliver services has improved during the pandemic in general. Many DFI have reported that volunteers were available to help persons with dementia by services such as delivering food at home, writing and delivering letters to persons with dementia, and responding to helplines for persons with dementia and family members.

### *New strategies showing resourcefulness and resilience of DFI*

While strategies prior to COVID-19 included close partnerships with sectors that engaged with persons with dementia, during COVID-19, innovative programs in terms of service delivery methods and program features were adopted to reach and serve persons with dementia. These strategies used by DFI exhibited agencies' resourcefulness and resilience. One strategy is the shift of in-person DFI activities to technology-based programs. Online platforms in the USA (e.g. Zoom and Facebook) and mainland China (e.g. WeChat and DingTalk) have been widely used to meet more people and organize events that allowed interaction with families and persons with dementia in a virtual world. One recent study that used a randomized control trial design found that a telehealth program for dementia caregivers and care recipient dyads had similar effectiveness on psychological outcomes as the program delivered in-person but yielded favorable outcomes in accessibility (Laver et al., 2020). This increased accessibility through online technology may explain the increased persons with dementia and family attendees at online sessions. Besides expanded enrollment, these online platforms have provided a viable avenue for persons with dementia to stay connected, keep informed of COVID-19 progress, and receive continual support.

Innovation in program features was also observed. As a strategy, organizations have reallocated part of the budget to meet pressing needs of persons with dementia, such as food and PPE. Some states have provided more resources for organizations in the form of grants. DFI agencies were able to apply and obtain such grants to deliver programs that integrated DFI features with COVID-19 preventive efforts. DFI organizations partnered with local businesses and other agencies to fulfill the needs of persons with dementia emerged due to COVID-19. Both innovation in program contents and delivery showed agencies managed to be resourceful and resilient to meet their mission to provide an inclusive environment for persons with dementia and family members.

### *Differences between DFI in two societies*

A few subtle differences between the two countries are worth noting. One difference between the two countries was related to factors that affect persons with dementia participation. In the USA,

systematic racial/ethnic disparities contributed to the low participation of persons with dementia from ethnic minority groups, while in Chinese society, participation was affected by socioeconomic status (SES). Possible explanations may be that the USA sample had a more ethnically diverse sample or that there is a culture difference in terms of principles between each country. In both countries, findings in relation to SES and ethnic minority status suggest that dementia care among underprivileged groups deserves more attention.

Another point worth considering is the cultural differences that shaped the role of government and affected community awareness. The limited funding from the federal or the central government to support DFI is a common issue in both societies. However, DFI in the USA tend to have more funding resources and agency partners across health, social care, academics, business, education, transportation, and housing than those in mainland China. DFI in mainland China tend to rely on funding from the local government and have limited community partners that come from health and social care sectors. The level of participation from other agencies and sectors is influenced by the level of dementia awareness of the local Chinese government who has the authority for resource allocation. Educating and advocating the local government on the benefits of DFI is essential for Chinese DFI to gain sustainability. There are cultural differences of dementia awareness among the public between the two countries. Given the established DFI network under Dementia Friendly America, championed by the National Association of Area Agencies on Aging ([Dementia Friendly America, 2021](#)), this suggests a nationwide DFI network in the USA does not exist in mainland China. In the case of mainland China, public awareness of dementia is low. As cognitive impairment is associated with the beginning stages of dementia, it is often mistakenly seen as a normal process of aging, while dementia symptoms at moderate and later stages are considered psychosis ([Chen et al., 2017](#); [Liu et al., 2019](#)). No concerted efforts between DFI agencies across cities have been made.

Several limitations of this study should be noted. This study embraces the idea that DFI aim to promote community-based support for persons with dementia and their caregivers in a large sense, which acknowledges that DFI connotation and practice are not universally agreed upon. Despite the seemingly positive meaning of the word “dementia friendly,” it can be considered “patronizing and inappropriate” ([Shakespeare, Zeilig, & Mittler, 2019](#), p. 1081). Thus, future research needs to consider the perspectives of persons with dementia and family care partners, who may have different insight than DFI. Secondly, the findings of this study may have limited generalizability beyond DFI service professional stakeholders recruited from the two countries. We acknowledge DFI stakeholders involve persons living with dementia and their family caregivers, who were not recruited in this study, but their perspectives need to be examined in future studies of DFI. DFI in mainland China are currently available in several large and economically developed metropolitan areas where municipal governments recognized aging and dementia as pressing social issue. Thus, the challenges for DFI in the Chinese metropolitan communities may not encompass the enormous hurdles for DFI implementation in rural China, which features low dementia awareness and limited resources. Finally, the lack of data that specified challenges and strategies at different stages of the COVID-19 pandemic is another limitation. As the time span covered in this study was until August 2020, there could be other challenges or strategies that have since developed given the rapidly changing situation regarding COVID-19, like the development of COVID-19 vaccination.

### *Implications for policy and practice*

Our findings have some policy implications to improve the implementation of national dementia strategy plans of U.S. and Chinese governments ([U.S. Department of Health and Human Services, 2012](#); [Alzheimer’s Disease International, 2020c](#)). In both countries, there has been limited funding

allocated from the central or federal governments to support DFI in the community. In the USA, services offered through the Older Americans Act have expanded to people with early on-set dementia under the age of 60 in 2020 (Alzheimer's Association, 2020). As the U.S. government is piloting projects to establish dementia capable health and social service systems, it is equally important to direct funding to support DFI. In China, most funding support is from district or municipal governments. Overall, more funding directly from the federal or central level to support the modifications of the environment to involve persons with dementia participation is needed.

At the same time, DFI need to be open to funding resources from other initiatives that are relevant for persons with dementia. During COVID-19 pandemic, new initiatives are available to provide resources and funding to address the psychological impact of COVID-19 on the community (e.g. anxiety and depression of residents) (Dong & Bouey, 2020). DFI can take advantage of these initiatives and direct funding and resources to the specific needs of persons with dementia and their family members. In addition to COVID-19 initiatives, other initiatives targeting the aging population, people with other disabilities, and behavioral health can be another avenue to support DFI work.

DFI need to find ways to document the effectiveness of respective programs developed to engage, support, and empower persons with dementia. Though DFI have raised dementia awareness, made physical and social environmental changes adapted to needs of persons with dementia, there lacks evidence from evaluation studies using rigorously designed methodology.

Furthermore, many DFI failed to include persons with dementia as key staff members, which could help strengthen the design and delivery of DFI programs from the perspectives of persons with dementia. One study (Phillipson et al., 2019) in Australia reported the positive effects of using persons with dementia as spokespersons in DFI programs to promote dementia awareness and positive attitude. The perception of dementia as a disability that prevents persons with dementia at early stages from performing a productive role may exist in agencies that run DFI. In line with the suggestions from Swaffer (2014), an international dementia advocate, DFI agencies need to break down these barriers by hiring people with dementia in different capacities. Given an unprecedented public health crisis, it is essential to have persons with dementia voice their lived experiences during COVID-19 and participate in DFI program design. DFI agencies should lead by example and challenge dementia stigma that suggests persons with dementia are incapable of becoming staff members or collaborators.

This study presents a narrative of challenges and strategies used by DFI service professional stakeholders in USA and mainland China prior to and during COVID-19 pandemic. Despite differences in levels of persons with dementia participation and major funding source, DFI in both countries went through similar challenges and used alike strategies before and during COVID-19 pandemic. Challenges prior to COVID-19 focused on the involvement of persons with dementia in DFI activities, partnerships with other agencies and sectors, and resources to sustain DFI; and those challenges were worsened because of COVID-19 due to social restrictions and policy priority shift. The strategies prior to COVID-19 were mainly about collaborating with community organizations and leveraging diversified resources to increase persons with dementia engagement and sustain DFI. On the other hand, COVID-19 has compelled DFI to be resourceful by using person-centered technology in outreach and service delivery, and developing new program features that addressed COVID-19-related needs for persons with dementia. The COVID-19 pandemic presented challenges as well as opportunities for DFI to grow its competency to serve persons with dementia and their family caregivers in the USA and mainland China. While it remains critical to advocate to the central or federal government to fund DFI, DFI in both societies need to be open to other funding sources, involve persons with dementia as key staff members of DFI, and demonstrate the

effectiveness of DFI through rigorous evaluation. The findings are not intended to be generalizable, but rather offer some glimpses into the experiences of DFI in two countries with large populations of persons with dementia. Acknowledging the practice of DFI is involving and diverse, there is evidence to support a shared DFI framework that outlines shared features and approaches, and leaves latitude for cultural and local adaptations to fit the needs of the community. As DFI are implemented in 46 countries around the world, some may resonate with and benefit from the experiences described in this study.

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### ORCID iD

Ha-Neul Kim  <https://orcid.org/0000-0002-1234-8296>

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**Fei Sun**, PhD, MSW, is a professor at the School of Social Work (SSW) at Michigan State University (MSU). He is a fellow of The Gerontological Society of America, and was a Hartford Geriatric Social Work Scholar (2009–2011). Awarded as a Health and Aging Policy Fellow (2017–2018), he has been working with the Department of Mental Health and Substance Abuse of World Health Organization (WHO) on developing a global toolkit for dementia-friendly communities. His overall research area is aging and mental health with a focus on addressing the impact of Alzheimer's disease and related disorders in the Chinese American community.

**Fredrika A Opur** is a Master candidate in the School of Social Work (SSW) at Michigan State University (MSU). She has a passion on issues of victimization, mental health and particularly, domestic violence against vulnerable population such as women and older adults. She is committed to supporting and mitigating the challenge among these populations across the globe at large and particularly, in developing country context.

**Ha-Neul Kim** is a PhD student in the School of Social Work (SSW) at Michigan State University (MSU). She has a passion for creating change in society and promoting a better world for older adults. Her research interests are in the fields of gerontology, dementia, family caregiving, aging and technology, community care, and welfare policies supporting the dignity of older adults. She also focuses on the use of data analysis and text mining methodology in social work research.

**Lucas R Prieto** is a PhD candidate in the School of Social Work (SSW) at Michigan State University (MSU). His research focuses on the sexual health and wellbeing of older adults who identify as a sexual or gender minority. He is affiliated with MSU’s Consortium for Sexual and Gender Minority Health and the University of Michigan’s Sexuality, Relationships, and Gender Research Collective.

**Christian Conyers** is a current MSW student at the University of Michigan in Ann Arbor. She has an interest in policy and research pertaining to older adults, specifically surrounding health outcomes and quality of care in long-term and healthcare settings. She is also a 2021 National Academy of Social Insurance Somers Intern. Christian has a bachelor of science in psychology from Howard University.

## Appendix I

### Coding process and map

	Researcher I	Researcher II
First-level coding		
Challenges before COVID-19	<p>Inexperience of a beginner</p> <p>How to get people living with dementia together</p> <p>Language and cultural barriers</p> <p>Lack of resources</p> <p>Lack of awareness</p> <p>Lack of awareness exacerbated for communities where English is not the first language</p> <p>Communities of color, communities that have less resources have not had as much opportunity to start initiatives and find resources</p> <p>Fear of bandwidth and not have enough space and time to manage and increase interest of organization</p> <p>Challenges to drive interest of organizations, but with the implication of the council on aging, interest of other organizations skyrocketed</p>	<p>Challenge to make people understand what dementia is like and how it can affect</p> <p>Challenge to face the perception of somebody who does not understand that dementia is an invisible disability</p> <p>Financial challenge: Ensure the services are free and sustainable</p> <p>Marketing challenge to get known</p> <p>Misunderstanding of other association that we are not duplicating what they are doing</p> <p>Shortage of staff member</p> <p>Shortage of funding to support more staff member</p>

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	Researcher I	Researcher II
Challenges during COVID-19	<p>Less socialization</p> <p>Less engagement</p> <p>Isolation causes deterioration of people</p> <p>Isolation exacerbates dementia symptoms</p> <p>Age and dementia activities pushed in the background due to the pandemic</p> <p>Entities running initiatives are more constrained about resources</p> <p>Challenges for technology transition for staff and community transition</p> <p>Grants reallocated for food security, instead of designing activities</p> <p>Increase stress level of caregivers</p> <p>Shutdown of services that are dementia friendly (restaurant, art, etc.)</p> <p>Exacerbation of social isolation</p> <p>Technology and internet access constraint to join virtual activities</p>	<p>Increase in caregiver's stress</p> <p>Loss of adult daycare and respite services for persons with dementia</p> <p>Increase in calls related to stress, ask for help and assistance as result of COVID-19</p> <p>Closure of adult daycare center</p> <p>Adult foster care and nursing facility closed for the public</p> <p>Outreach program shutdown completely</p> <p>Person living with dementia could not get diagnosed because there was not emergency in going to doctors in hospitals</p> <p>Challenges to implement the physical activities in another way</p> <p>Isolation</p> <p>Fear</p> <p>Not being able to get out into community</p> <p>Getting information needed in timely manner</p> <p>Doctor visit for PWD</p> <p>Cancellation of all in-person programs</p>
Strategies before COVID-19	<p>Being consistent</p> <p>Meeting consistently and work through problems</p> <p>Talk to Dementia Friendly America on a regular basis</p> <p>Learn from other communities</p>	<p>Building partnerships in community</p> <p>Do a lot of training</p> <p>Provide counseling for volunteers to go through the transition phase</p>
Strategies during COVID-19	<p>Train a social worker at the library to help people access resources they need via phone</p> <p>Dementia resource center available in library</p> <p>Evanston Cares Network is a single portal where all resources available to anyone in Evanston, including those who are older or those with dementia</p> <p>Our multiple partners allow many people to join our services</p> <p>A choir of people living with dementia</p> <p>The services help them to stay connected to their environment</p> <p>Help initiatives that are starting with some administrative forms, guide them in how to walk through the first steps of their initiatives</p>	<p>Work closely with Alzheimer's Association, the office on aging, the four Call Symphony, Bisharp Arts Engagement</p> <p>Utilize technology low tech to reach people with dementia</p> <p>Facebook and monthly newsletters to educate people</p> <p>Choir for people living with dementia</p> <p>Memory café in bilingual format</p>
Axial coding		

(continued)

(continued)

	Researcher I	Researcher II
Challenges before COVID-19	Increase visibility of DFI activities in the community Language barrier Integrate dementia and age friendly activities Access to fund and its sustainability Increase in engagement	Outreach Dementia awareness Funding Community engagement
Challenges during COVID-19	Exacerbation of isolation Decrease in social engagement Dementia services shut down, and limit access to technology for virtual activities Decrease of attention toward dementia activities	Isolation Outreach
Strategies before COVID-19	Partnership Learn from experience of other institutions Resource mobilization	Local partnerships Grants
Strategies during COVID-19	Moving activities to virtual Increase phone calls Local partnership and grants Deliver food	Increase virtual presence writing/phone calls Local partnerships
Resolved and finalized coding		
Challenges before COVID-19	Challenge 1: Engagement of PWD in DFI Challenge 2: Access to funding for DFI Challenge 3: Difficulties to access groups with language barriers; difficulties to involve organizations with low dementia awareness Challenge 4: Visibilities of DFI activities in the community Challenge 5: Sustainability of DFI activities	
Challenges during COVID-19	Challenge 1: Exacerbated isolation of PWD due to COVID-19 and the limited available services Challenge 2: Difficulties of outreaching to PWD due to COVID-19 (technology literacy, access) Challenge 3: Priorities of local and national policy and practice efforts changed to COVID-19	
Strategies before COVID-19	Strategy 1: By forming partnership with different organizations and sectors to reach out and engage PWD and the public Strategy 2: Securing and coordinating resources and funding from different sources to sustain DFI	
Strategies during COVID-19	Strategy 1: Delivering program activities using online tools Strategy 2: Using phone calls/ letters (traditional media) to promote outreach Strategy 3: Partnering with other agencies to address the basic (e.g., food) and other needs of PWD families due to COVID-19	