Study Protocol and Statistical Analysis Plan

Research Title: Developing a Culturally-sensitive Volunteering Intervention to Reduce Stress among Dementia Caregivers in Chinese American Communities

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Procedure and setting

Following the approach of community-based participatory research, we worked with a community agency, [blind for review], the largest organization serving dementia caregivers in New York City (NYC). Before designing the intervention, we conducted in-depth interviews with 30 caregivers and a survey with 168 caregivers to understand caregivers' needs, challenges, strengths and resources [Blind for review]. We also studied the utilization, effectiveness and limitations of existing services for these caregivers from a focus group with social work professionals [Blind for review]. Based on the empirical evidence, we concluded that a peer mentoring intervention may help reduce Chinese American caregiver reduce stress. We established a community advisory committee, including one social work professional, one administrator and three caregivers, and gathered their insights on the development of the intervention. We sent the first and second drafts of the intervention manual to committee members, collected their feedback from committee meetings, and revised the manual based on their feedback. After a pilot test, we presented the results in community events to dementia caregivers, professionals and administrators for their comments to improve the intervention for a larger-scale test.

We developed the intervention and conducted the pilot test in NYC, the metropolitan area with the largest Chinese American population in the United States. Based on 2017 census estimates, 893,697 Chinese live in NYC, and most Chinese older adults live in ethnic enclaves such as Chinatown (U.S. Census Bureau, 2017). In the past three decades, bilingual professionals in [blind for review] had provided various services, such as group training,

public lectures, mental health counseling, to support local Chinese older adults and their family caregivers. However, many Chinese caregivers in NYC have challenges accessing individually tailored support due to the shortage of bilingual and bicultural professionals.

Intervention

The PMP was a 3-month intervention that provides one-on-one mentoring support via phone calls to reduce the stress of Chinese dementia caregivers. Guided by the conceptual framework shown in Figure 1, the peer mentoring support covered the themes of cultural beliefs about dementia, culturally effective coping strategies, and culturally appropriate social support. The program recruited and trained Chinese American experienced caregivers to be volunteering mentors for dementia caregivers in the same ethnic community. Prior to mentoring caregivers, the mentors received training on knowledge about dementia, caregiving skills, social support, and problem-solving strategies. A social worker led the training workshop via lectures, discussions, and role-play practice, in which mentors could learn how to deliver knowledge and skills in a culturally competent way to their mentees. Due to the COVID-19 pandemic, the mentor training workshop was delivered in five synchronous online sessions and each session lasted for 4 hours with two 10-minute breaks. With technology support provided by the research assistants, mentors did not have any technology issues and appreciated the convenience of having the training via the internet.

Each mentor was paired with one to three caregivers based on their language preference and similar caregiving experiences (e.g., relationship with care recipient). During the 3-month intervention, each pair of mentor–mentee was expected to have one weekly phone call, which lasted for 30 to 60 minutes. After each call, the mentor was required to

document major issues and strategies covered in the call by filling the mentoring record form. A social worker supervised mentor's work by reviewing mentoring records and facilitated bi-weekly meetings with mentors to address questions or issues related to the intervention.

Sample

We recruited caregivers and mentors through referrals by [blind for review] and distributing flyers in community events as well as the agency's monthly letters to clients, senior centers, hospitals, geriatric clinics, and community agencies serving Chinese older adults in NYC. Trained research assistants conducted screening interviews with caregivers and mentors who expressed interest to the study. The eligibilities for being a participating caregiver were: (a) self-identify as Chinese; (b) 21 years old or older; (c) providing care to a family member with dementia for 10 hours or more a week; (d) interested in receiving supportive interventions; (e) having moderate to severe caregiver burden; and (f) able to access a telephone and communicate via phone call. The eligibility of being considered as a mentor were: (a) 50 years old or older; (b) self-identify as Chinese; (c) able to speak Mandarin or Cantonese Chinese; (d) having experience of providing care to a family member with dementia; (e) able to access a telephone and communicate via phone call; (f) able to attend mentor training via zoom; and (g) committed to volunteering with minimal financial compensation. Caregivers and volunteer mentors were excluded if they had cognitive impairment. We aimed to develop the intervention as a senior volunteer program, so mentors were limited to those aged 50 or older. We recruited 45 caregivers and 10 volunteers who expressed interests and participated in the screening interviews. Our final sample for this pilot study included 38 Chinese caregivers and 8 mentors who met the above criteria. The enrolled

caregivers were randomly assigned to the intervention group (n=19) and the control group (n=19). The intervention group received 3-month mentoring support and the control group received a package of educational materials on knowledge of dementia, caregiving skills, self-care and community resources. A caregiver participant received a $30 gift card after each assessment at baseline (T1), 3-month follow up (T2), 6-month follow up (T3). A volunteer mentor received a $100 gift card after completing the training and another $100 gift card after the 3-month mentoring service and assessments at T1 and T2.

Analysis

For the feasibility test, we calculated relevant percentages and means across the intervention study measurements. We also transcribed and coded the qualitative data from the open-ended questions to identify strengths and weakness of the intervention design and implementation. For the efficacy test, we conducted t-test to compare outcome variables across T1 to T3, and changes between time points (T2-T1, T3-T2, T3-T1) between the two groups. We also conducted difference in difference (DID) analysis using the *mixed* command in Stata. In multilevel (observations nested in caregivers) linear regression models, we first entered group, time and the interaction term of group and time and then entered covariates, such as sociodemographic, health, acculturation and caregiving variables, one by one due to the small sample size. None of the covariates changed the main findings, so we did not report those parameters in this paper. We missed three caregivers' data at T2 and T3. Two caregivers (one in the intervention group and the other in the control group) lost their care recipients during the intervention time and most measures (e.g., caregiving burden, caregiving competency) were not applicable to them. One caregiver in the control group

dropped off the study due to tight personal schedule. Given the purpose and sample size of this pilot study, we did not perform imputations or replications for missing data.