


BMJ Open Exploring the social and cultural aspects of Chinese family caregivers' experience as they support loved ones with dementia transitioning into nursing homes: a qualitative study protocol

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ABSTRACT

Introduction Asian American caregivers supporting loved ones with dementia experience greater burden and more stress than other racial/ethnic groups, warranting the need for more culturally and linguistically appropriate formal support, such as in nursing homes. Transitioning loved ones into nursing homes with dementia care units is a complex process that can be impacted by a multitude of factors. Employing several established frameworks, including the socioecological model, this qualitative study will focus on the largest Asian American subgroup (people of Chinese descent) and explore the experience of family caregivers as they support the transition of their loved ones with dementia into nursing homes in the USA. Our focus will be on the nuanced influences of the Chinese language and culture and COVID-19-related social isolation and racial discrimination.

Methods and analysis Recruitment will take place starting in January 2024. Current or former Chinese caregivers for Chinese loved ones with dementia, able to communicate in Mandarin Chinese or English, and currently residing in the USA will be eligible. Key informants with intimate understanding and experience with this population will also be included. Data will be collected through 2024 using semistructured, in-depth interviews with each participant. Depending on participants' preferences, interviews will be conducted in either Mandarin Chinese or English and either in person, via Zoom or by phone. Interviews will be transcribed verbatim. Iterative thematic analysis will be employed. A coding structure will be developed based on interview questions and themes and patterns that are revealed through data immersion. Transcripts, prepared in their original language, will be dual-coded by bilingual researchers using NVivo 14. Consensus summaries of themes will be prepared. Relevant direct quotes for each thematic area will be identified (those in Chinese will be translated into English) and cited in reports and manuscripts.

Ethics and dissemination The study is approved by the UMass Chan Medical School Institutional Review Board (ID: STUDY00001376). Findings will be published in peer-review journals following the consolidated criteria for reporting qualitative research.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study dives deeply into the cultural nuances in the experiences of current and former caregivers to loved ones with dementia in Chinese families in the USA, the largest subgroup of Asian descent in the USA.
- ⇒ The bilingual team will conduct interviews in the caregivers' preferred language (English or Mandarin Chinese) in person, virtually or over the phone, eliciting a wider range of caregiver experiences and enhancing accessibility for the target population.
- ⇒ Recall bias cannot be ruled out when participants discuss past events related to caregiving and considerations of nursing home care.
- ⇒ Virtual/phone interviews are prone to missing non-verbal cues and diminished sense of engagement.
- ⇒ Experiences of caregivers of Chinese descent may not be representative of caregivers of other Asian groups.

BACKGROUND

Nearly 7 million older Americans above the age of 65 years are living with Alzheimer's dementia.¹ The burden of dementia in the USA is projected to reach 14 million by 2060, doubling the current rate, accounting for over 3% of the entire population.² Asian Americans represent 6.2% of the US population³ and about 4.6% of the US population aged 65 years and above. This percentage is projected to reach 8% by 2060.⁴ Data on the prevalence of dementia among Asian Americans and by specific Asian ethnic groups at the national level is scarce.⁵ The most recent estimate of dementia prevalence for older Asian Americans and Pacific Islanders combined was 8.4% in 2014.⁶ Given that Asian Americans are the fastest-growing racial minority group in the USA,⁷ this estimate may have shifted in the past decade. Despite having the



lowest documented age-adjusted incidence rate and prevalence of dementia compared with other race/ethnicity groups,^{6,8} dementia is frequently underdiagnosed in Asian Americans due to a multitude of factors, including the prevalent stigma around dementia, lack of access to culturally and linguistically competent care and shortages of bilingual providers for older adults who are less likely to be proficient in English.^{9–11} Consequently, care is often delayed until dementia symptoms are severe.¹²

In many Asian cultures, caring for the older population is generally expected and highly valued. This may partially explain why Asian Americans are more likely to assume family caregiving roles than the general population.¹³ Research has found that Asian American caregivers to people with dementia experience more associated burden and stress than other racial/ethnic groups, highlighting the need for more culturally and linguistically appropriate formal support.¹³

Nursing homes, especially those with special dementia care units, are one type of formal support for older adults with dementia in the USA.¹⁴ However, transitioning from home care into nursing home care is not easy and may involve several stages. Hainstock *et al*¹⁵ proposed a conceptual framework that depicted a 3-phase process of caregiver's experience transitioning their loved ones into residential care settings. Phase 1 includes recognising the need to transition due to the care recipients' declining health conditions and caregivers' burnout. Phase 2 focuses on preparing for the transition by assuming multiple roles in navigating through the healthcare system, and the final phase is finding a new balance through adjusting and adapting to new responsibilities post-transition.¹⁵ This process may not always be linear across time, as Caron *et al*¹⁶ noted in their model of the principal caregiver decision-making process. They contend that there is likely a feedback loop where the decision to move their loved ones into institutional care will be evaluated multiple times under various circumstances before the decision is finally reached.¹⁶

These studies demonstrated the complexity of caregivers' experiences transitioning their loved ones into institutional care. Yet several critical gaps remain. To begin with, limited work has been conducted in the context of nursing homes in the USA. Wide variation exists across long-term care settings and countries, including but not limited to the acuity of the residents, types of care provided and health insurance policies. Thus, the experience of caregivers with older loved ones with dementia in the USA may differ from experiences elsewhere.

Moreover, the extant literature is notably deficient in research that specifically addresses the nuanced experiences of caregivers of Asian descent, particularly by specific ethnic subgroups. Asian Americans encompass a diverse array of subpopulations. Analyses that indiscriminately group Asian American subpopulations overlook the important nuances in the ethnic, cultural and linguistic profiles that could contribute to the disparities of caregivers' experiences. This, coupled with the

variations in the incidence of dementia documented across different Asian subgroups,¹⁷ underscores the need to examine the specific Asian American subpopulations and their experiences.

This qualitative study will focus on caregivers of loved ones with dementia in families of Chinese descent in the USA. Individuals of Chinese descent represent the largest Asian American subgroup, comprising about a quarter of all Asian Americans.¹⁰ Within this population, the important cultural value of filial piety¹⁸ has particular relevance to family caregiving for older adults. Filial piety encompasses strongly held emotions, devotion and expectations related to responsibility, love and respect for parents and other older family members. When filial piety cannot be fulfilled, feelings of guilt and shame can emerge.¹³ With the fear of loved ones being isolated in nursing homes due to dementia, failing health, minority status and language barriers and the potential need to serve as the interpreter and advocate for their loved ones with limited English proficiency, caregivers of Chinese heritage may face additional challenges in providing care to their loved ones and supporting their transition into nursing home care. Qualitatively examining how cultural expectations and language challenges may influence caregivers' experiences with nursing home care will contribute to fundamental knowledge about the nature of these experiences, caregivers' needs for information and support and insight into how the care experience may be improved for this ethnic population, including culture-friendly and language-friendly care.

Last but not least, nursing homes have been particularly hard hit during the COVID-19 pandemic. According to the American Health Care Association and National Center for Assisted Living, total revenue loss in US nursing homes was over US\$11 billion nationwide.¹⁹ Approximately 15% of the entire nursing home workforce has been lost since the beginning of the pandemic.²⁰ As nursing homes may not fully recover from these losses anytime soon,²¹ formal care options for older adults with dementia could remain limited, making caregivers' decisions even more difficult. Simultaneously, social isolation in older adults, which has been linked to significantly higher risks of developing dementia,²² has worsened during the pandemic^{23,24} while discrimination against populations of Asian descent has increased.²⁵ The proposed study will be conducted post-COVID-19, which allows us to explore how the aftereffects of the pandemic may influence family caregivers' experiences and the experiences of their loved ones.

This exploratory qualitative study will address the gaps and further our understanding of Chinese family caregivers' experience as they support loved ones with dementia transitioning into nursing homes. To guide our inquiry, this study will use the social-ecological model,²⁶ incorporating the conceptual framework by Hainstock *et al*¹⁵ on the transition from home care into residential care and principles of structural racism²⁷ (figure 1). Individual, relationship, community and society-level factors will be explored at each stage of transition from home to

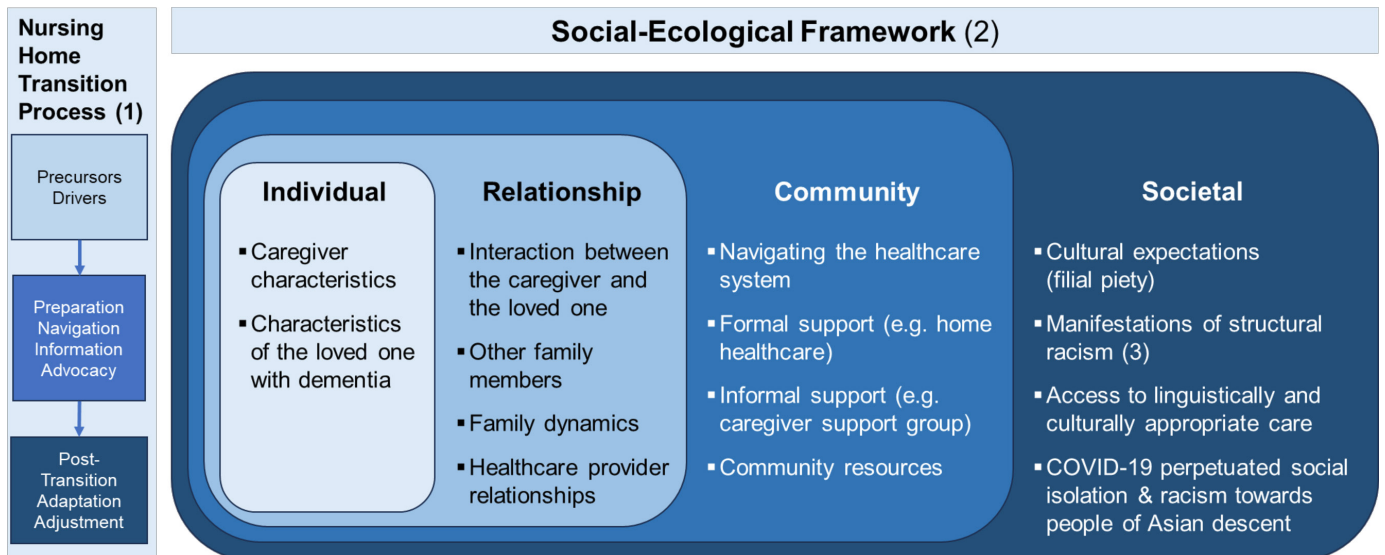


Figure 1 Exploring the social and cultural aspects of Chinese family Caregivers' experience as they support loved ones with dementia transitioning into nursing homes: conceptual framework.

nursing home care. At the individual level of the social-ecological model, we will explore factors including the increasing care needs, caregivers' physical, mental and practical capacity to provide care and the interactions between the caregivers and their loved ones. The relationship level will include family dynamics and interpersonal communications with healthcare providers who may identify suitable nursing homes for their loved ones. On the community level, we will investigate disparities in access to resources such as formal support through adult daycare programmes, informal support from caregiver support groups and social support such as language services. The impact of societal level factors such as Chinese cultural expectations (filial piety), limited access to linguistically and culturally appropriate quality care as a manifestation of structural racism and the social isolation and racism towards Asians/Asian Americans exacerbated by the COVID-19 pandemic will also be explored. Guided by this conceptual framework, through in-depth, semistructured interviews with Mandarin Chinese and/or English-speaking, current or former caregivers, we attempt to answer the following research questions:

1. What factors influence the decision to transition a loved one with dementia into a nursing home?
2. What are the facilitators and barriers to communication with healthcare and social service providers during this transition?
3. What resources are available or lacking for family caregivers during this process?
4. What challenges have caregivers faced due to COVID-19-related social isolation and racial discrimination?
5. What has been the experience of those who have transitioned to nursing home care, and how has this affected the caregivers and their loved ones?
6. How have Chinese culture and language influenced the experiences of caregivers and their loved ones?

7. What resources and advice could improve the transition process for others?

METHODS AND ANALYSES

Study design

This study will use an exploratory qualitative research design with in-depth, semistructured interviews. Participant enrolment commenced in January 2024, and the data collection will occur throughout the year. The study protocol and all relevant materials have been approved by the UMass Chan Medical School Institutional Review Board (study ID: 00001376). The findings will be reported according to the consolidated criteria for reporting qualitative research (COREQ).²⁸

Setting and participants

The study will be conducted with caregivers of older adults with dementia in families of Chinese descent (see eligibility criteria).

Convenience sampling will be used. In initial efforts to recruit eligible participants, the research team will contact Massachusetts-based community organisations, churches and caregiver support groups primarily serving the Chinese/Chinese American population, and recruitment materials will be distributed (eg, flyers). Recruitment materials will also be disseminated via local newspapers, social media sites (eg, WeChat (a communication tool widely used in Chinese populations)), Facebook/Instagram, X (formerly known as Twitter, Next Door, etc) and groups/forums designated for caregivers of people with dementia. The research team will reach out to local, Massachusetts-based nursing homes, home care agencies and clinics that predominantly serve the population of Chinese descent to help disseminate the recruitment information. Snowball sampling will also be used, with



recruited participants asked to assist in disseminating the recruitment materials to other potential participants.

Initial recruitment will focus on Massachusetts-based organisations, given the location of the research team. If the recruitment is not satisfactory, other regions in the USA with a larger population of people of Chinese descent (eg, California, New York, etc) will be considered. All recruitment materials contain a *hyperlink* and *QR code* generated using the hyperlink. Potential participants are invited to use the link or scan the code to determine their eligibility for the study, which will take them to the *screening questionnaire* hosted in the Research Electronic Data Capture (REDCap).²⁹ The *screening questionnaire* includes eligibility questions, caregiver demographics, contact information and information about their stage of decision-making (see online supplemental material 1).

Once the potential participant is deemed eligible, the research team will contact them by letter and email and will provide consent information using the project *fact sheet*. All files will be provided in English and Chinese (simplified and traditional). After 1 week, the research team will contact the potential participants via phone in their preferred language (English or Mandarin Chinese). During the phone call, the *fact sheet* (elements of consent) will be verbally reviewed with the caregiver, and then the caregiver will be asked for verbal consent. If verbal consent is voluntarily confirmed, the caregiver will be enrolled and may be scheduled for an interview. On completion of the interview, the participant will receive a US\$50 gift card as a token to thank them for their time and effort.

Eligibility criteria

To be eligible for the in-depth interviews, the participants must be:

- ▶ Aged 18 years or older.
- ▶ Residing in the USA.
- ▶ Chinese or of Chinese descent.
- ▶ Mandarin Chinese-speaking or English-speaking.
- ▶ Currently providing care or have provided care in the past 5 years to older loved one(s) (aged 65 years and above; Chinese or of Chinese descent) with dementia.
- ▶ Have transitioned their loved ones with dementia to a US nursing home or have actively considered doing so.
- ▶ Willing to talk about their experiences and be audio-recorded.
- ▶ Willing to appear on camera (for Zoom interviews) and be recorded.

We will exclude the individuals who:

- ▶ Lack the capacity to provide consent.
- ▶ Are unable to participate in a 60–90 min interview.
- ▶ Do not pass the additional validity to ensure participants are genuine (see below).

To ensure the validity of the study and screen out potential imposter participants,³⁰ once a *Screening Questionnaire* is completed with the potential participant meeting all eligibility criteria, we will further check for the following

‘red flags’.^{31 32} If at least three ‘red flags’ are identified, the participant will be excluded.

1. Large volume of *Screening Questionnaires* sign-ups received in a short period of time.
2. Timing of email receipt.
3. Similar email address format to others responding (eg, firstnamelastname #####@gmail.com).
4. Out-of-service or Google Voice phone numbers.
5. Similarity in the email message contents.
6. Rapidity of response when followed up to confirm certain information and schedule the interviews.
7. Incorrect or inconsistent responses.
8. Invalid postal addresses.

Data collection procedure

Interviews will last 60–90 min with an overall time commitment of approximately 2 hours. To prepare for in-depth interviews, enrolled caregiver participant characteristics (gender and the stage in transitioning a loved one with dementia into nursing homes) will be determined from the *screening questionnaire*. Interviews will be conducted following the *interview protocol* (see online supplemental material 2) in the participant’s preferred speaking language (English or Mandarin Chinese) and mode (in-person, via Zoom or phone) by trained bilingual interviewers (YY, EL, SX and SQ). Two research team members will join the interview, with one being the interviewer and the other being an observer taking notes. At the beginning of the interview, the participant will be asked to provide estimates of when they started thinking about nursing home care; started looking at different nursing home options; selected the nursing home and if and when they admitted their loved one to a nursing home.

Using standard qualitative research procedures, the interview incorporates a semistructured and open-ended approach.

Data to be collected during the interviews include:

1. Dual audio recordings of interviews (to be transcribed and translated).
2. *Background questionnaire* with additional sociodemographic characteristics (see online supplemental material 3). The *background questionnaire* will be collected at the end of the interview verbally, online, on the research laptop, or on paper, depending on the participant’s preference in the participants’ indicated language (English; simplified Chinese and traditional Chinese). Data will be stored using REDCap.
3. Observer’s notes.

After each interview, the interviewer and the observer will discuss their initial impressions. When necessary, the team will further refine the interview protocol based on insights from concurrent interviews to better address the research questions. The interview protocol will be adjusted as needed through team collaboration.

Data analysis

This is an exploratory qualitative study, and thus, power analysis requirements do not apply. We anticipate that 20 interview participants will be sufficient to reach saturation, which will be determined by consensus of the research team. If saturation is not achieved after 20 interviews, additional interviews will be conducted as needed.

For interviews conducted in English, the recordings will be first transcribed verbatim by NVivo Transcription, which is fully compliant with the Health Insurance Portability and Accountability Act of 1996 requirements for medical transcriptionists. Each transcript will be proofread by two research team members and finalised by the respective original interviewers. During this process, participant names will be replaced by participant numbers (namely, P1, P2, etc.), and any other identifiers will be redacted and replaced with generic role identifiers when appropriate (eg, sister, doctor, etc). The research team lead will conduct quality control procedures by reviewing all transcripts to ensure accuracy. For interviews conducted in Mandarin Chinese, the same transcription process will apply as NVivo Transcription supports transcription in Chinese.

A random subset of the interviews in both languages will be selected to develop the coding structure in English. Once the initial coding structure is developed by the research team, transcript texts will then be subjected to line-by-line coding in NVivo 14. Additional codes will be added as needed. Iterative data analysis employing thematic analysis will be conducted, and all transcripts will be subjected to line-by-line coding by two bilingual researchers in the original language of the interview. Any discrepancies will be discussed and resolved between the team members. Discrepancies that cannot be resolved by the two team members will be presented to the research group for a final resolution. The codebook will be modified by team consensus as new codes are identified. Code reports for each code will be generated and used to (1) facilitate further team analysis discussions, (2) develop links between themes, (3) finalise data interpretation and (4) identify supporting quotations. Searches for alternative interpretations will be conducted and discussed before final decisions are made about how to report the study findings. Consensus theme summaries and representative quotations from the in-depth interviews will then be used to finalise the findings.

Reflective practices

Throughout the study design, data collection through interviews and data analysis, the research team will actively reflect on and address their biases, ensuring they do not influence the research questions and the data being collected and analysed.

Patient and public involvement

None.

Ethics and dissemination

The study has been approved by the UMass Chan Medical School Institutional Review Board (ID: STUDY00001376). Findings will be published in peer-reviewed journals following the COREQ.

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Contributors All authors have critically reviewed the manuscript, approved the final manuscript as submitted and agreed to be accountable for all aspects of the work. YY is the guarantor and accepts full responsibility for the finished work and/or the conduct of the study, has access to the data and controls the decision to publish. YY, CED and KLL conceptualised and designed the study. YY drafted the protocol. CED, SX, EL, SQ, EMP and KLL made important background and methodological contributions and revised the protocol.

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Competing interests None declared.

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