

**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.**  
**Supplemental Material 2**

**Caregiver Interview Protocol**

**Title:** *CARING*: Exploring the social aspects of Chinese family caregivers' experience as they support loved ones with dementia transitioning into nursing homes

**Procedure:**

We will structure the interviews around the timeline of planning for nursing home care. Interviews may be conducted in person, by phone, or via Zoom conference call, depending on participants' preference.

**Materials:**

For all participants: Mail and/or Email to Participant Ahead of Time

- Fact Sheet

In-Person interviews	Phone or Zoom interviews
<ul style="list-style-type: none"> <li>• Refreshments</li> <li>• Recorders/Computers (2) – charged/backup batteries</li> <li>• Mics (2) – backup batteries</li> <li>• Materials packet for facilitator</li> <li>• Researcher's business cards</li> <li>• Sign for Door – “Interview in Progress”</li> <li>• Tape</li> <li>• Observer Notes</li> <li>• Gift card</li> <li>• Participant Packet (pre-marked with participant ID)               <ul style="list-style-type: none"> <li>○ Pen &amp; paper</li> <li>○ Fact Sheet</li> <li>○ Background Survey</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Phone recorder – charged/backup batteries</li> <li>• Materials packet for facilitator</li> <li>• Sign for Office Door – “Interview in Progress”</li> <li>• Tape</li> <li>• Observer Notes</li> </ul>

## **Interviewer's script (English):**

### **I. Introduction**

Thank you so much for taking the time to meet with me today. As you know, this is a research project being conducted by the UMass Chan Medical School, funded by the National Institute on Aging. We are interested in **your experiences as a current or past caregiver to your loved one dementia, as you transition the family member to nursing homes, with particular focus on the impact from Chinese culture and language as well as from the COVID-19 pandemic**. This interview will last about an hour to an hour and a half, no longer than two hours. This interview will be recorded. There will be a background questionnaire for you to complete at the end of the interview.

We'll learn from this interview and others by studying your ideas and the overall themes that will emerge over different in-depth individual interviews. Your responses may be shared verbatim or in summary along with the other interviews anonymously. There are no right or wrong answers to anything I am asking today. Both positive and negative comments are valuable to the discussion.

To ensure your confidentiality, I'd like to refer to you by your first name. (Clarify preferred first name.) You can call me [first name].

You indicated in the *Screening Questionnaire* that the loved one that you have been providing care to is your [loved one]. Can I confirm if this is correct?

***FOR ALL INTERVIEWS*** - Throughout the interview, we will replace "loved one" with whoever that may be for this interviewee, like "dad" or "husband" or "sister" etc.

Another important thing to remember is to protect the confidentiality of your doctors, family members, etc. So, please refrain from using real names or other specifics that might identify other people. Please speak in general, say, "My family doctor – or My oldest sister – or my neighbor..." – something like that. If you do begin to speak about a person/situation in a way that might identify them, I will ask you to rephrase. If we accidentally record someone's real name, we will remove names from the transcript and replace them with a general reference, like doctor or sister or neighbor, and so forth. Also, the audio files will be destroyed three years after the project is over.

### **II. Begin Recording & Review Fact Sheet**

Are you ready? If so, let's begin. I am now turning on the recorders.

**\*\* TURN RECORDERS ON \*\***

One last bit of business, I do need to begin by going over the *Fact Sheet* to ensure you still want to participate. May I ask if you get a chance to review the *Fact Sheet* sent earlier?

**\*\* REVIEW FACT SHEET \*\* (Use Screen Sharing for Zoom interviews)**

I want to emphasize that your participation is voluntary, that you can decide not to participate with no penalty, and that you can withdraw at any time. Any questions? (**STOP** if participant withdraws consent)

### III. Begin the Interview

Now we are going to start the interview. First, I would like to ask you a few questions to get a bit more information **about the care you have provided to your [loved one]**.

	Interviewer takes notes:
<b>How long have you been providing care/assistance to your [loved one] with dementia?</b>	<input type="checkbox"/> years
<b>What is the primary language you use now to communicate with your loved one? Mandarin, Cantonese, other dialects? English?</b>	
<b>What is the primary language your [loved one] use <i>now</i> to communicate with healthcare providers?</b>	
<b>What other family members or friends have provided significant help or assistance to your [loved one]?</b>	<input type="checkbox"/> Your child or children <input type="checkbox"/> Your spouse <input type="checkbox"/> Others (please describe): <input type="checkbox"/> <input type="checkbox"/> No one else <input type="checkbox"/> Prefer not to answer
<b>Have you ever been involved (currently or in the past) in any community organizations/support groups for caregivers to people with dementia?</b>	<i>(Choose only one)</i> <input type="checkbox"/> Yes. Please describe: <input type="checkbox"/> <input type="checkbox"/> No <input type="checkbox"/> Prefer not to answer
<b>Has your [loved one] with dementia ever received care and/or support from community organizations/support groups for people with dementia?</b>	<i>(Choose only one)</i> <input type="checkbox"/> Yes. Please describe: <input type="checkbox"/> <input type="checkbox"/> No <input type="checkbox"/> Prefer not to answer

Got it. Just a few more questions to get a better idea of **when various things happened as you prepare(d) to transition your [loved one] to nursing home care**, and then we will move to hear about your experience. May I ask about what month and year did:

	Interviewer takes notes:	Assign the participant to group...	Instructions
<b>Your [loved one] started having early signs of dementia.</b>	Month: [    ] Year: [    ]		
<b>You started thinking about nursing home care.</b>	Month: [    ] Year: [    ]	A	
<b>You started looking at different nursing home options.</b>	Month: [    ] Year: [    ]	B	Skip to next part if “not yet”

	<input type="checkbox"/> Not yet		
<b>You selected the nursing home.</b>	Month: [     ] Year: [     ]	C	Skip to next part if “not yet”
	<input type="checkbox"/> Not yet		
<b>You admitted your [loved one] to nursing home.</b>	Month: [     ] Year: [     ]	D	Skip to next part if “not yet”
	<input type="checkbox"/> Not yet		

Thank you very much. Now, let’s start from the beginning.

Participant Group				Open-Ended Question				
A	B	C	D	1. <i>Tell me about your thinking and your experiences when you first started thinking about nursing home care.</i>				
A	B	C	D	<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 50%;">Follow-up Questions</th> <th style="width: 50%;">Probes</th> </tr> </thead> <tbody> <tr> <td style="vertical-align: top;">           a. <b>What was going on</b> that made you consider nursing home care as an option? What were your initial thoughts about it?           <ul style="list-style-type: none"> <li>• How was your [loved one]’s <b>health</b> at the time that made you consider nursing home?</li> <li>• What was your [loved one]’s <b>and living situation</b>? Were they socially isolated?</li> <li>• What <b>hopes</b> did you have for nursing home care?</li> <li>• What <b>feelings</b> (e.g., worries, concerns, fears, etc.) did you have at that time?</li> </ul>           b. <b>Who else</b> (e.g., the other caregivers noted earlier) <b>was involved in this discussion</b>?           c. <b>Was your [loved one] involved in this discussion</b>?           <ul style="list-style-type: none"> <li>• If so, what were <b>their thoughts and feelings</b>?</li> </ul> </td> <td style="vertical-align: top;">           1. What is <b>your role</b> in care taking?            2. Has anyone else (e.g. friends, family, doctors, other professionals) advised you? What helped? What got in the way?            3. Where did you look for resources (e.g., community organizations, caregiver support groups)? What helped? What got in the way?            4. When thinking about nursing home care, did you consider <b>how to maintain social connections</b> with your [loved one]?            5. When you initially thought about nursing home care, do you think your <b>Chinese heritage</b> affected your thinking process? If so, in what ways?            6. Did you think <b>COVID</b> has impacted this discussion at all?   <i>Anything else?</i> </td> </tr> </tbody> </table>	Follow-up Questions	Probes	a. <b>What was going on</b> that made you consider nursing home care as an option? What were your initial thoughts about it? <ul style="list-style-type: none"> <li>• How was your [loved one]’s <b>health</b> at the time that made you consider nursing home?</li> <li>• What was your [loved one]’s <b>and living situation</b>? Were they socially isolated?</li> <li>• What <b>hopes</b> did you have for nursing home care?</li> <li>• What <b>feelings</b> (e.g., worries, concerns, fears, etc.) did you have at that time?</li> </ul> b. <b>Who else</b> (e.g., the other caregivers noted earlier) <b>was involved in this discussion</b> ?           c. <b>Was your [loved one] involved in this discussion</b> ? <ul style="list-style-type: none"> <li>• If so, what were <b>their thoughts and feelings</b>?</li> </ul>	1. What is <b>your role</b> in care taking? 2. Has anyone else (e.g. friends, family, doctors, other professionals) advised you? What helped? What got in the way? 3. Where did you look for resources (e.g., community organizations, caregiver support groups)? What helped? What got in the way? 4. When thinking about nursing home care, did you consider <b>how to maintain social connections</b> with your [loved one]? 5. When you initially thought about nursing home care, do you think your <b>Chinese heritage</b> affected your thinking process? If so, in what ways? 6. Did you think <b>COVID</b> has impacted this discussion at all?  <i>Anything else?</i>
Follow-up Questions	Probes							
a. <b>What was going on</b> that made you consider nursing home care as an option? What were your initial thoughts about it? <ul style="list-style-type: none"> <li>• How was your [loved one]’s <b>health</b> at the time that made you consider nursing home?</li> <li>• What was your [loved one]’s <b>and living situation</b>? Were they socially isolated?</li> <li>• What <b>hopes</b> did you have for nursing home care?</li> <li>• What <b>feelings</b> (e.g., worries, concerns, fears, etc.) did you have at that time?</li> </ul> b. <b>Who else</b> (e.g., the other caregivers noted earlier) <b>was involved in this discussion</b> ?           c. <b>Was your [loved one] involved in this discussion</b> ? <ul style="list-style-type: none"> <li>• If so, what were <b>their thoughts and feelings</b>?</li> </ul>	1. What is <b>your role</b> in care taking? 2. Has anyone else (e.g. friends, family, doctors, other professionals) advised you? What helped? What got in the way? 3. Where did you look for resources (e.g., community organizations, caregiver support groups)? What helped? What got in the way? 4. When thinking about nursing home care, did you consider <b>how to maintain social connections</b> with your [loved one]? 5. When you initially thought about nursing home care, do you think your <b>Chinese heritage</b> affected your thinking process? If so, in what ways? 6. Did you think <b>COVID</b> has impacted this discussion at all?  <i>Anything else?</i>							
A	B	C	D	2. <i>Now let’s talk about how you went/are going about looking for and choosing suitable nursing homes for your [loved one]. What was/is important for your decision?</i>				
A	B	C	D	<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 50%;">Follow-up Questions</th> <th style="width: 50%;">Probes</th> </tr> </thead> <tbody> <tr> <td style="vertical-align: top;">           a. Describe the <b>IDEAL NURSING HOME</b> for your [loved one].            b. What factors are your <b>TOP PRIORITIES</b> during decision-making? What is the most important factor to you?         </td> <td style="vertical-align: top;">           1. <b>Where did you get information</b> about the facilities? From their website, Nursing Home Compare, speak to other caregivers, seek out information from your community, or         </td> </tr> </tbody> </table>	Follow-up Questions	Probes	a. Describe the <b>IDEAL NURSING HOME</b> for your [loved one]. b. What factors are your <b>TOP PRIORITIES</b> during decision-making? What is the most important factor to you?	1. <b>Where did you get information</b> about the facilities? From their website, Nursing Home Compare, speak to other caregivers, seek out information from your community, or
Follow-up Questions	Probes							
a. Describe the <b>IDEAL NURSING HOME</b> for your [loved one]. b. What factors are your <b>TOP PRIORITIES</b> during decision-making? What is the most important factor to you?	1. <b>Where did you get information</b> about the facilities? From their website, Nursing Home Compare, speak to other caregivers, seek out information from your community, or							

			<p>c. How did you <b>start</b> looking for nursing homes that might suit your needs?</p> <p>d. How would you <b>find</b> facilities? What resources helped you? What resources you would like to have access to?</p> <p>e. How did you <b>evaluate</b> nursing homes?</p> <ul style="list-style-type: none"> <li>• Were you able to visit the homes? Who helped you?</li> <li>• What would make you rule out a nursing home?</li> </ul> <p>f. What kind of <b>support or resources</b> would you expect the nursing homes to provide to help you and your [loved one]?</p> <p>g. Is there any <b>difficulty</b> you have encountered already and/or you would foresee? How did you or will you overcome them?</p>	<p>visit facilities? (<i>Note: Nursing Home Compare is a website maintained by the Centers for Medicare &amp; Medicaid. It provides information about nursing homes such as their star ratings, which can be used as a reference in the selection of nursing homes.</i>)</p> <ol style="list-style-type: none"> <li>2. Who do you think has been <b>most helpful so far</b>? Your [loved one]'s healthcare provider? The staff (nurses, social workers, etc.) at potential nursing homes? Community organizations? Someone else?</li> <li>3. What would be your <b>main concern</b> in picking a nursing home? Proximity/location of the nursing homes, the facility being culturally/linguistically friendly, responsive staff, cost of care, etc.?</li> <li>4. Were you concerned about your [loved one] becoming <b>socially isolated</b> in the nursing home?</li> <li>5. How has being of Chinese descent affected your decision? <ul style="list-style-type: none"> <li>• Is the <b>Chinese-speaking environment</b> an essential factor for your decision?</li> <li>• Do you think cultural factors such as <b>filial piety</b> (In Chinese 孝顺, the traditional Chinese virtue of respect for one's parents, elders, and ancestors) would influence your experience? In what ways?</li> <li>• Did any of these potential nursing homes provide <b>culturally appropriate care</b>? (for example, celebrate holidays of different cultures, availability of food of different cultures, signs in different languages, respectful of cultural traditions, etc.)</li> </ul> </li> <li>6. Did the COVID pandemic affect your decision/consideration in any way?</li> </ol> <p><i>Anything else?</i></p>
	C	D	<p><b>Participant HAS selected a home or homes --</b></p> <p>3. <i>When you did choose a nursing home (or homes) – what about the nursing home(s) made you choose it/them?</i></p>	
	C	D	<p><b>Follow-up Questions</b></p> <p>a. What <b>factors made you choose this particular nursing home</b>?</p> <ul style="list-style-type: none"> <li>• What was the <b>TOP PRIORITY</b> for your decision?</li> <li>• What were the <b>BEST features</b>?</li> <li>• Were there any <b>trade-offs</b>?</li> </ul>	<p><b>Probes</b></p> <ol style="list-style-type: none"> <li>1. Who do you think has been <b>most helpful in choosing this nursing home</b>? Your [loved one]'s healthcare provider? The staff (nurses, social workers, etc.) at potential nursing homes? Community organizations? Someone else?</li> </ol>

				<p>b. Anything you wish were better?</p> <p>c. Did you encounter any <b>difficulty</b> along the way? How did you overcome them?</p>	<p>2. <b>Did you have any concerns with this nursing home?</b> (e.g., proximity/location of the nursing homes, responsive staff, the facility being culturally/linguistically friendly, cost of care, etc.)</p> <p>3. Were there other factors that made the decision more difficult? (e.g., financial management, doing relevant paperwork, lack of advance care planning, difficulties in communicating with staff, long waiting list, limited [knowledge of] resources and services available, etc.)</p> <p>4. <b>Was language a consideration?</b></p> <ul style="list-style-type: none"> <li>• Were Chinese interpreters available in your chosen nursing home?</li> </ul> <p>5. Were there any <b>cultural factors</b> that influenced your decision?</p> <ul style="list-style-type: none"> <li>• Was the chosen nursing home racially/ethnically diverse?</li> <li>• What is the proportion of the residents that were of Chinese heritage?</li> <li>• Was the nursing home culturally inclusive?</li> <li>• Were staff trained to provide culturally appropriate care? (for example, celebrate holidays of different cultures, availability of food of different cultures, signs in different languages, respectful of cultural traditions, etc.)</li> </ul> <p>6. COVID-19 has made social isolation worse in older adults, particularly for those living in nursing homes, as did discrimination against populations of Asian descent. <b>Did your chosen nursing home prepare any social activities to engage your loved one?</b></p> <p><i>Anything else?</i></p>
<b>A</b>	<b>B</b>	<b>C</b>	<b>D</b>	<p><b>Expectations for transition to Nursing Home Care</b></p> <p>4. <i>Let's move on to what you EXPECT when making the transition from home to nursing homes for your [loved one]. What did (do) you think transition to the nursing home would (will) be like for you and your [loved one]?</i></p>	
<b>A</b>	<b>B</b>	<b>C</b>	<b>D</b>	<p><b>Follow-up Questions</b></p> <p>a. How would you expect <b>your</b> life to change after transitioning your [loved one] into a nursing home? What are the main challenges and adjustments you would foresee for <b>you</b>?</p> <p>b. How would you expect <b>your [loved one]'s</b> life to change after transitioning into a nursing home? What are the main challenges and adjustments you would foresee for them?</p>	<p><b>Probes</b></p> <p>1. How might <b>language and/or culture</b> be/have been a challenge for your [loved one] in making the transition to nursing home care?</p> <p>2. Did/do you expect <b>additional challenges</b> regarding social interactions due to COVID-19?</p>

			c. How would you <b>maintain your relationship</b> with your [loved one] after the transition?	3. Were/are you aware of any support systems or resources available to facilitate family involvement in nursing homes?  <i>Anything else?</i>
			<b>D</b> <b>Experience with transition to Nursing Home Care</b> 5. <i>Now consider what actually happened during the transition from home to the nursing home – What was that experience like for you and your [loved one]?</i>	
			<b>D</b> <b>Follow-up Questions</b>  a. How did your <b>[loved one] adjust to the new environment?</b> Did they experience any challenges in the new environment? b. How have you been adjusting? c. What kind of support/care did you and your [loved one] receive during the transition? d. Do/did you think being of Chinese heritage impacted your [loved one]'s social experience during the transition to the nursing home? e. Did the COVID-19 pandemic affect this transition in any way?	<b>Probes</b>  1. Was the transition what you expected? • What went well? • What could have been improved? 2. Were there any barriers to your loved-one's adjustment to the nursing home? • Did they miss home? • Did they feel confusion with this new environment? • Did they experience any social isolation in this new environment? 3. What helped your [loved one] adjust? • What kind of support or resources did you seek or utilize to ensure a smooth transition for you and your [loved one]? • Were there any community resources/advocate available?  <i>Anything else?</i>
			<b>D</b> <b>Experience with Nursing Home Care</b> 6. <i>Finally, let's talk about your experiences with nursing home care. – What has nursing home care been like for your [loved one]?</i>	
			<b>D</b> <b>Follow-up Questions</b>  a. What about the <b>medical care</b> your [loved one] is receiving are you pleased with? What could be improved? b. What about <b>social care</b> ? What are you pleased with? What could be improved? c. Did you experience <b>any difficulty in communicating</b> with the nursing home staff? d. Did <b>culture and language</b> impact your [loved one]'s social experience in the nursing home (e.g., preferences for social activities, interactions with others, feelings of prejudice)?	<b>Probes</b>  1. How do you <b>maintain your relationship</b> with your [loved one] in the nursing home? 2. Have you and your [loved one] experienced any additional challenges regarding social interactions, dementia care during the COVID-19 pandemic? • How did the nursing homes do to mitigate these issues (eg. activities with social distancing, use of technologies to connect with loved one, designated staff assigned to the family, staff spending more time with the loved ones, etc.) Are they resolved now?

				e. COVID-19 has exacerbated social isolation in older adults, particularly for those living in nursing homes, as well as discrimination against populations of Asian descent. In your opinion, does these COVID-19 related incidence influence your [loved one]'s experience in the nursing home?	3. Are you aware of any support systems or resources available to facilitate family involvement in the nursing home?  <i>Anything else?</i>
<b>A</b>	<b>B</b>	<b>C</b>	<b>D</b>	7. <i>What advice would you give to others who are going through the same experience with their loved ones?</i>	
<b>A</b>	<b>B</b>	<b>C</b>	<b>D</b>	8. <i>Is there anything else you would like to add? Anything I didn't ask you about?</i>	

#### IV. Closing the Interview

**\*\* TWO-MINUTE WARNING (if needed, let the participant know when you are running low on time.) \*\***

We are nearing the end of our interview time. Do you have anything else you would like to add?  
I am now going to turn off the recorders.

**\*\*TURN OFF RECORDER\*\***

The last thing we need from you is the short survey called Background Questionnaire, collecting a few additional items on your and your loved ones' sociodemographic characteristics. May I ask how you would like to complete this questionnaire? We could do it verbally, (for Zoom interviews only) online, (for in-person interviews only) on this laptop, or on paper.

**\*\* PARTICIPANT COMPLETE BACKGROUND QUESTIONNAIRE \*\***

I want to thank you for your participation in this interview. I have learned a lot from you! As I mentioned before, this interview will be transcribed and then analyzed with all our other data. Once we have the transcription, we will remove your name/pseudonym and replace it with a participant number to further protect your confidentiality.

Thank you again for contributing your insight.



## 访谈提纲（中文版）

### I. 介绍

非常感谢您今天抽出时间与我见面。正如您所知，本研究项目由麻省大学医学院组织，由美国国立卫生研究院资助。我们对您作为现任或曾经的家庭看护者将亲人转入养老院的经历非常感兴趣，特别是文化和语言以及新冠疫情对您经历的影响。本次访谈将持续一到一个半小时，最多不超过两小时。对本次访谈，我将进行音频录音。访谈结束后，会有一份背景问卷供您填写。

通过分析与您以及其他访谈参与者的深度访谈内容，我们将提炼出一系列整体主题。您与其他参与者的回答将以原文逐字或摘要形式出现。我今天提出的问题，回答没有正确或错误。正面或负面的评论都非常有价值。

为了确保您的保密性，我想用您的名字称呼您。（确认参与者偏好的名字）您可以称呼我[名字]。

在筛选问卷中您提到，一直以来您所照顾的患有失智症的亲人是您的[关系]，是这样吗？

*对于通所有访谈访谈*：访谈中将替换[关系]为具体亲人，例如父亲、丈夫、姐姐等。

还有一件重要的事情需要记住，就是保护您医生、家庭成员等人的隐私。所以，请不要使用真实姓名，或其他可能被识别出来的具体信息。请尽量使用笼统的说法，比如“我的家庭医生，或者我大姐，或者我的邻居……”之类的。如果您开始以可能识别他们的方式谈论某个人的情况，我会要求您重新表述。如果我们不小心录到某个人的真实姓名，我们将从文本中删除姓名，并用类似医生、姐姐或邻居等的泛称替代。在项目结束三年后，音频文件将被销毁。

### II. 开始录音，重温项目说明

您准备好了吗？如果准备好了，我们就开始吧。我现在要打开录音设备了。

**\*\*打开录音设备\*\***

我需要先重温一下项目说明，以确保您依旧愿意参与。请问您之前有看过项目说明吗？

**\*\*重温项目说明\*\***

我想强调一下，您的参与是完全自愿的，您可以决定不再参与，不会有任何后果，您可以随时选择退出。请问您有任何问题吗？（若参与者撤回同意，请停止录音）

### III. 开始访谈

现在我们要开始访谈了。首先，我想问您几个关于您对您[亲人]的看护情况的问题。

请问您已经护理或帮助您患有失智症的[亲人]多久了？	<input type="checkbox"/> 年
您与您患有失智症的[亲人]交流时，主要使用的是哪种语言？普通话、粤语、其他方言？还是英语？	<input type="checkbox"/>
您的[亲人]与医护人员交流时，主要使用的是哪种语言？	<input type="checkbox"/>
请问有其他家庭成员或朋友为您的[亲人]提供重要帮助吗？	<input type="checkbox"/> 您的子女 <input type="checkbox"/> 您的配偶 <input type="checkbox"/> 其他，请详述 <input type="checkbox"/> 没有他人帮助 <input type="checkbox"/> 不希望回答
请问您是否参与过任何失智症看护者的社群组织或互助小组？	<i>(请只选择一项)</i> <input type="checkbox"/> 参与过，请简要介绍：_____ <input type="checkbox"/> 没参与过 <input type="checkbox"/> 不希望回答
请问您患有失智症的[亲人]收到过来自针对失智症患者的社区组织或互助小组的帮助和支持吗？	<i>(请只选择一项)</i> <input type="checkbox"/> 参与过，请简要介绍 <input type="checkbox"/> 没参与过 <input type="checkbox"/> 不希望回答

好的，接下来我想了解一下在您准备将您的[亲人]转移到养老院照顾期间，各种事情发生的大致时间。请问大概是何时：

	研究员记录：	将参与者分组至：	指示：
您的[亲人]最初开始出现的失智迹象	<input type="checkbox"/> 年 <input type="checkbox"/> 月		

您开始考虑养老院的护理	[ ]年[ ]月	A	
您开始寻找不同的养老院	[ ]年[ ]月 [ ]尚未开始寻找养老院	B	若尚未开始寻找养老院，则跳过余下问题
您选定了一家养老院	[ ]年[ ]月 [ ]尚未选定养老院	C	若尚未定养老院，则跳过余下问题
您将[亲人]送入了养老院	[ ]年[ ]月 [ ]尚未送入养老院	D	若尚未送入养老院，则跳过余下问题

好的。那我们开始吧。

参与者组别				开放性问题 –	
A	B	C	D	1. 请告诉我，当您最初开始考虑养老院护理时，您的想法和经历是怎样的。	
A	B	C	D	<b>后续问题</b> a. 是什么让您开始考虑养老院的护理呢？您最初对此有什么想法？ <ul style="list-style-type: none"> <li>• 当您考虑养老院护理的时候，您[亲人]的身体状况如何？</li> <li>• 生活状况如何？他们是否社交孤立？</li> <li>• 您对养老院护理有什么期望？</li> <li>• 当时您有什么感受（担忧、关注、恐惧等）？</li> </ul> b. 在做出这个决定时，还有其他人参与吗？ c. 您的[亲人]参与了关于此事的讨论吗？ <ul style="list-style-type: none"> <li>• 如果参与了，他们有什么想法和感受？</li> </ul>	<b>深入提示</b> 1. 您在照顾[亲人]上扮演怎样的角色？ 2. 有朋友、家人、医生或其他专业人士给您提供过建议吗？哪些是有帮助的？有哪些阻碍？ 3. 您在哪里寻找资源呢？哪些是有帮助的？有哪些阻碍？ 4. 在考虑养老院护理时，您是否考虑过如何与您的[亲人]保持社交联系？ 5. 作为华人，当您开始考虑养老院的护理时，文化传统对您有什么影响吗？ 6. 您是否考虑过 COVID-19 的因素？  有什么需要补充吗？
A	B	C	D	2. 现在，我们来谈谈您是如何寻找和选择适合您的[亲人]的养老院的。对您的决策来说，有什么重要的因素？	
A	B	C	D	<b>后续问题</b>	<b>深入提示</b>

			<p>a. 描述一下您心目中理想的、适合您[亲人]的养老院。</p> <p>b. 在做决策时，您最关注哪些因素？对您来说最重要的是什么？</p> <p>c. 您是如何开始寻找可能适合您需求的养老院的？</p> <p>d. 您如何找到这些机构？有哪些资源对您有帮助？您希望能够获得哪些资源？</p> <p>e. 您是如何评估养老院的？</p> <ul style="list-style-type: none"> <li>• 您去参观过这些养老院吗？有人帮助您了吗？</li> <li>• 有哪些因素会让您排除一家养老院？</li> </ul> <p>f. 您遇到过或可能预见到的困难有哪些？您是如何克服它们的，或将如何克服它们呢？</p>	<p>1. 您是从哪里获得关于养老院的信息呢？是从他们的网站，Nursing Home Compare，与其他看护者交谈，从社区获取信息，还是亲自访问养老院？（注：Nursing Home Compare 是一个由联邦医疗保险和医疗补助服务中心（CMS）维护的网站，提供养老院的星级评定等其他信息，可作为选择养老院的参考）</p> <p>2. 您认为到目前为止，谁提供的帮助最多？是您[亲人]的医护人员，养老院的工作人员（护士、社工等），社群组织，还是其他人？</p> <p>3. 在选择养老院时，您最关心的是什么？例如，养老院的距离，养老院提供对文化和语言友好的环境，养老院工作人员沟通方便，护理费用等等。</p> <p>4. 您是否担心您的[亲人]在养老院会变得社交孤立？</p> <p>5. 作为华人对您的选择有什么影响吗？</p> <ul style="list-style-type: none"> <li>• 中文环境对您的决定是否至关重要？</li> <li>• 您是否认为文化因素，如孝顺（孝顺在中国传统中是尊重父母、长辈和祖先的美德），会影响您的经历？以何种方式呢？</li> </ul> <p>6. 您期望养老院提供什么样的支持或资源来帮助您和您的[亲人]？</p> <p><i>有什么需要补充吗？</i></p>
	C	D	<p><b>参与者已选择了一个或多个养老院 -</b></p> <p>3. <i>当您选择了养老院，有哪些原因促使您选择这个/这些养老院？</i></p>	
	C	D	<p><b>后续问题</b></p> <p>a. 是什么因素使您选择了目前的养老院？</p> <ul style="list-style-type: none"> <li>• 您决策的首要考虑因素是什么？</li> <li>• 这家养老院最突出的地方是什么？您是否需要做出任何权衡？</li> </ul> <p>b. 有任何您希望能够改善的方面吗？</p> <p>c. 您在决策过程中遇到困难了吗？您是如何克服这些困难的？</p>	<p><b>深入提示</b></p> <p>1. 在选择养老院方面，您认为谁提供的帮助最多？是您[亲人]的医护人员，养老院的工作人员（护士、社工等），社群组织，还是其他人？</p> <p>2. 在选择养老院时，您的主要关注点是什么？（例如：养老院的距离/地点，养老院符合文化和语言要求，养老院工作人员沟通方便，护理费用等等。）</p>

					<p>3. 有没有其他因素使决策变得更加困难？（例如：财务问题，文件处理，没有提前做好护理规划，与工作人员沟通困难，长时间的等待名单，有限的资源和服务等等。）</p> <p>4. 语言是否在您的考虑之内？</p> <ul style="list-style-type: none"> <li>• 您选择的养老院是否提供中文翻译服务？</li> </ul> <p>5. 是否有任何文化因素影响了您的决策？</p> <ul style="list-style-type: none"> <li>• 您选择的养老院是否有来自不同族裔的人群？</li> <li>• 华人占了多少比例？</li> <li>• 是否具有文化包容性？</li> <li>• 员工是否接受了提供符合文化需求的培训？（例如，庆祝不同文化的节日，提供不同文化的食物，提供不同语言的标识，尊重文化传统等等。）</li> </ul> <p>6. 新冠疫情加剧了老年人的社交孤立问题，尤其是居住在养老院的人，还有针对亚洲族裔人群的歧视问题。新冠疫情是否影响了您在选择养老院时的整体决策？您选择的养老院有没有准备任何社交活动让您的[亲人]参与？</p> <p>有什么需要补充吗？</p>
A	B	C	D	<p><b>对于转移到养老院护理的期望：</b></p> <p>4. <b>想到将您的[亲人]从家里移到养老院这个过程，您的期望是什么？您认为这对于您们来说会是怎样的经历？</b></p>	
A	B	C	D	<p><b>后续问题</b></p> <p>a. 在将您的[亲人]转移到养老院后，您预期自己的生活会有什么变化？您预见到的主要挑战和调整是什么？</p> <p>b. 在将[亲人]转移到养老院后，您预期他们的生活会发生什么变化？您预见到的主要挑战和调整是什么？</p> <p>c. 在过渡期后，您将如何与您的[亲人]保持关系？</p> <p><b>深入提示</b></p> <p>1. 在[亲人]转移到养老院护理中心时，语言或文化可能会/已经成为了什么样的挑战？</p> <p>2. 您是否预期由于新冠疫情，您[亲人]的社交互动方面会出现额外的挑战？</p> <p>3. 您是否了解有关支持系统或资源，能帮助家庭更好地参与到养老院的活动？</p> <p>有什么需要补充吗？</p>	
			D	<p><b>关于转移到养老院护理中心的经历：</b></p> <p>5. <b>现在回想一下从家里养老院的过渡过程 - 对于您和您的[亲人]来说，那段经历是怎样的？</b></p>	

			<b>D</b>	<p><b>后续问题</b></p> <p>a. 您的[亲人]是如何适应的？他们在新环境中是否遇到了社交参与方面的挑战？</p> <p>b. 您是如何适应的？</p> <p>c. 在过渡期间，您的[亲人]收到了哪些护理、支持？</p> <p>d. 您认为华人背景对您的[亲人]在转移到养老院的过程中的社交经历产生了影响吗？</p> <p>e. 新冠疫情是否在某些方面影响了转移到养老院的过渡过程？</p>	<p><b>深入提示</b></p> <p>1. 这段过渡是否符合您的预期？</p> <ul style="list-style-type: none"> <li>• 哪些方面十分顺利？</li> <li>• 有哪些可以改进的地方？</li> </ul> <p>2. 您的[亲人]在适应养老院的护理过程中遇到过哪些障碍？</p> <ul style="list-style-type: none"> <li>• 您的[亲人]想家吗？</li> <li>• 新环境有没有造成什么困扰？</li> <li>• 在这个新环境中，有没有经历社交孤立？</li> </ul> <p>3. 哪些因素帮助您的[亲人]适应了新环境？</p> <ul style="list-style-type: none"> <li>• 为了确保顺利过渡，您寻求或利用了哪些支持或资源？</li> <li>• 是否有社区资源或倡导者提供帮助？</li> </ul> <p>有什么需要补充吗？</p>
			<b>D</b>	<p><b>关于养老院护理的经历：</b></p> <p><b>6. 最后，让我们谈谈关于养老院护理的经历- 对于您的[亲人]来说，养老院护理是怎样的？</b></p>	
			<b>D</b>	<p><b>后续问题</b></p> <p>a. 在您[亲人]接受的医疗护理上，您对哪些方面感到满意？有哪些可以改进的地方？</p> <p>b. 在社交护理方面，您对哪些方面感到满意？有哪些可以改进的地方？</p> <p>c. 在与养老院工作人员沟通方面，您是否遇到任何困难？</p> <p>d. 文化和语言是否影响您[亲人]在养老院的社交经历呢（例如，对某些社交活动的倾向，与他人的互动，对偏见的感受）？</p> <p>e. 新冠疫情加剧了老年人的社交孤立问题，尤其是居住在养老院的人，还有针对亚洲裔人群的歧视问题。在您看来，这些与新冠疫情相关的事件是否影响到了您[亲人]在养老院的经历？</p>	<p><b>深入提示</b></p> <p>1. 您是如何与您在养老院的[亲人]维持关系的？</p> <p>2. 在新冠疫情期间，您和您的[亲人]在社交互动和失智症护理方面是否遇到了额外的挑战？</p> <ul style="list-style-type: none"> <li>• 养老院为缓解这些问题采取了哪些措施（例如，保持社交距离的活动，利用信息技术与亲人联系，指派专门的工作人员为家庭提供支持，增加工作人员与[亲人]的互动时间等）？这些问题现在得到了解决吗？</li> </ul> <p>3. 您是否知道有哪些支持系统或资源可以促进家庭在养老院中的参与？</p> <p>有什么需要补充吗？</p>
<b>A</b>	<b>B</b>	<b>C</b>	<b>D</b>	<p><b>7. 对于其他正在经历类似情况的人，您有什么建议？</b></p>	

A	B	C	D	8. 您有什么需要补充的内容吗？有哪些我没有问到？
---	---	---	---	---------------------------

#### IV. 结束访谈

**\*\* 两分钟提示：提前告知参与者访谈即将结束。**

我们的访谈到这里就要结束了。请问您有什么想补充的吗？

**那么，现在我要关闭录音设备了。**

**\*\*关闭录音设备\*\***

我们还需要您完成最后一件事，就是一份简短的背景问卷，采集一些关于您和您[亲人]的基本信息。请问您倾向如何完成这份问卷呢？我们可以通过口头进行，您也可以（只针对 Zoom 访谈）在网上完成，（只针对面对面访谈）在这台笔记本电脑上完成，或直接填写。

**\*\*参与者填写问卷\*\***

非常感谢您参与本次访谈。我从中学到了很多。就像我之前提到的，这次访谈将被转录成文字稿、翻译成英文，然后我们会对所有访谈进行分析。在生成文字稿之后，我们会把您的名字或代称替换成参与者号码，以更好地保护您的隐私。

再次感谢您贡献您的见解。