

# Fear of Dementia among Middle-Aged and Older Adults in China: Lived Experiences, Coping, and Support Needs

P3-14

Huohuo Dai, Anke Versluis, Rujie Xu, Wilco Achterberg, Hongxia Shen, Niels H. Chavannes, Jiska J. Aardoom

KEY TAKEAWAY: Fear of dementia was closely linked to autonomy, dignity, identity, and fear of burdening family. Support should be practical, trustworthy, culturally sensitive, and accessible, including low-burden digital options.

| INTRODUCTION                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | METHODS                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   | RESULTS                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           | CONCLUSIONS                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           | REFERENCES                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Fear of dementia (FoD) is increasingly recognized as an important psychological concern in ageing populations.</p> <p>FoD may reduce well-being and discourage preventive help-seeking.</p> <p>Little is known about how FoD is experienced and managed in China, or what support people want.</p> <div><div></div><div>Study aim: to explore lived experiences, coping strategies, and support needs among Chinese adults aged 45 years and older.</div></div>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | <div><div><div> Participants (N=20, age ≥45)</div><div>↓</div><div> Semi-structured interviews</div><div>↓</div><div> Vignette: "Auntie Li"</div><div>↓</div><div> Framework analysis</div><div>↓</div><div> TDF-informed interpretation</div></div><div><ul style="list-style-type: none"><li>Urban and suburban communities across China</li><li>Online and offline interviews</li><li>Mean age: 59.0 years</li><li>Focus: experiences, coping, and intervention needs</li><li>Theoretical Domains Framework (TDF) used to structure analysis</li></ul></div></div> <tr><td><div><div>1. Meanings of Fear</div><div><ul style="list-style-type: none"><li>FoD was socially embedded and future-oriented</li><li>Shaped by dementia knowledge and prior exposure</li><li>Main concerns: autonomy, dignity, identity, and becoming a burden to family</li></ul><div><p>“If I really develop dementia in the future, I'll become a burden to my family...”</p></div></div></div><div><div>2. Coping Responses</div><div><div> Proactive<ul style="list-style-type: none"><li>Memory exercises</li><li>Physical activity</li><li>Lifestyle adjustment</li><li>Information seeking</li></ul></div><div> Avoidant / emotion-focused<ul style="list-style-type: none"><li>Distraction</li><li>Suppressing worries</li><li>Postponing consultation</li><li>'Deal with it later'</li></ul></div></div></div><div><div>3. Support Needs &amp; Preferences</div><div><ul style="list-style-type: none"><li>Clear, actionable information</li><li>Professional guidance and reassurance</li><li>Family and peer support</li><li>Large fonts, simple steps, low burden</li><li>Digital delivery acceptable when usability, trust, and digital literacy are addressed</li></ul><div><p>“Don't just talk about how scary dementia is. You need to tell me what I can actually do.”</p></div></div></div><div><div> Overall, engagement with support depended on perceived usefulness, ease of use, and trust.</div></div></td><td><div><div> Main conclusion<ul style="list-style-type: none"><li>FoD reflects broader concerns about ageing, dependency, and social roles.</li><li>Person-centered and culturally sensitive support may promote well-being and healthy ageing behaviors.</li><li>Digital approaches are promising, but engagement depends on usability, trust, and equitable access.</li></ul></div><div><div>Implications for intervention design</div><div><div> Practical<ul style="list-style-type: none"><li>Actionable daily strategies</li></ul></div><div> Culturally sensitive<ul style="list-style-type: none"><li>Address family roles, burden, and dignity</li></ul></div><div> Accessible<ul style="list-style-type: none"><li>Clear language, large fonts, simple structure</li></ul></div><div> Trusted digital support<ul style="list-style-type: none"><li>Usability, guidance, and credibility</li></ul></div></div><div><div> Research funded by China Scholarship Council and Leiden University Global Seed Fund 2026. Conference attendance supported by Alzheimer Nederland.</div></div></div></div></td><td><div><div>1. World Health Organization. Dementia. 2025.</div><div>2. Dai H, Sun C, Xu S, et al. <i>Aging &amp; Mental Health</i>. 2025;29(6):1144–1151.</div><div>3. Dai H, Shen H, Versluis A, et al. <i>Alzheimers Dement Behav Socioecon Aging</i>. 2025;1(2):e70020.</div><div>4. Gale NK, Heath G, Cameron E, et al. <i>BMC Med Res Methodol</i>. 2013;13:117.</div><div>5. Atkins L, Francis J, Islam R, et al. <i>Implement Sci</i>. 2017;12:77.</div><div><i>Selected references only.</i></div></div><div><div>CONTACT</div><div><div><div>Huohuo Dai</div><div>Leiden University Medical Center / NeLL / WeLL</div><div><a href="mailto:h.dai@lumc.nl">h.dai@lumc.nl</a></div></div></div><div><div>Scan to connect on LinkedIn</div><div><a href="http://www.nell.eu">www.nell.eu</a>   <a href="http://www.wearewell.net">www.wearewell.net</a></div></div></div></td></tr> | <div><div>1. Meanings of Fear</div><div><ul style="list-style-type: none"><li>FoD was socially embedded and future-oriented</li><li>Shaped by dementia knowledge and prior exposure</li><li>Main concerns: autonomy, dignity, identity, and becoming a burden to family</li></ul><div><p>“If I really develop dementia in the future, I'll become a burden to my family...”</p></div></div></div> <div><div>2. Coping Responses</div><div><div> Proactive<ul style="list-style-type: none"><li>Memory exercises</li><li>Physical activity</li><li>Lifestyle adjustment</li><li>Information seeking</li></ul></div><div> Avoidant / emotion-focused<ul style="list-style-type: none"><li>Distraction</li><li>Suppressing worries</li><li>Postponing consultation</li><li>'Deal with it later'</li></ul></div></div></div> <div><div>3. Support Needs &amp; Preferences</div><div><ul style="list-style-type: none"><li>Clear, actionable information</li><li>Professional guidance and reassurance</li><li>Family and peer support</li><li>Large fonts, simple steps, low burden</li><li>Digital delivery acceptable when usability, trust, and digital literacy are addressed</li></ul><div><p>“Don't just talk about how scary dementia is. You need to tell me what I can actually do.”</p></div></div></div> <div><div> Overall, engagement with support depended on perceived usefulness, ease of use, and trust.</div></div> | <div><div> Main conclusion<ul style="list-style-type: none"><li>FoD reflects broader concerns about ageing, dependency, and social roles.</li><li>Person-centered and culturally sensitive support may promote well-being and healthy ageing behaviors.</li><li>Digital approaches are promising, but engagement depends on usability, trust, and equitable access.</li></ul></div><div><div>Implications for intervention design</div><div><div> Practical<ul style="list-style-type: none"><li>Actionable daily strategies</li></ul></div><div> Culturally sensitive<ul style="list-style-type: none"><li>Address family roles, burden, and dignity</li></ul></div><div> Accessible<ul style="list-style-type: none"><li>Clear language, large fonts, simple structure</li></ul></div><div> Trusted digital support<ul style="list-style-type: none"><li>Usability, guidance, and credibility</li></ul></div></div><div><div> Research funded by China Scholarship Council and Leiden University Global Seed Fund 2026. Conference attendance supported by Alzheimer Nederland.</div></div></div></div> | <div><div>1. World Health Organization. Dementia. 2025.</div><div>2. Dai H, Sun C, Xu S, et al. <i>Aging &amp; Mental Health</i>. 2025;29(6):1144–1151.</div><div>3. Dai H, Shen H, Versluis A, et al. <i>Alzheimers Dement Behav Socioecon Aging</i>. 2025;1(2):e70020.</div><div>4. Gale NK, Heath G, Cameron E, et al. <i>BMC Med Res Methodol</i>. 2013;13:117.</div><div>5. Atkins L, Francis J, Islam R, et al. <i>Implement Sci</i>. 2017;12:77.</div><div><i>Selected references only.</i></div></div> <div><div>CONTACT</div><div><div><div>Huohuo Dai</div><div>Leiden University Medical Center / NeLL / WeLL</div><div><a href="mailto:h.dai@lumc.nl">h.dai@lumc.nl</a></div></div></div><div><div>Scan to connect on LinkedIn</div><div><a href="http://www.nell.eu">www.nell.eu</a>   <a href="http://www.wearewell.net">www.wearewell.net</a></div></div></div> |
| <div><div>1. Meanings of Fear</div><div><ul style="list-style-type: none"><li>FoD was socially embedded and future-oriented</li><li>Shaped by dementia knowledge and prior exposure</li><li>Main concerns: autonomy, dignity, identity, and becoming a burden to family</li></ul><div><p>“If I really develop dementia in the future, I'll become a burden to my family...”</p></div></div></div> <div><div>2. Coping Responses</div><div><div> Proactive<ul style="list-style-type: none"><li>Memory exercises</li><li>Physical activity</li><li>Lifestyle adjustment</li><li>Information seeking</li></ul></div><div> Avoidant / emotion-focused<ul style="list-style-type: none"><li>Distraction</li><li>Suppressing worries</li><li>Postponing consultation</li><li>'Deal with it later'</li></ul></div></div></div> <div><div>3. Support Needs &amp; Preferences</div><div><ul style="list-style-type: none"><li>Clear, actionable information</li><li>Professional guidance and reassurance</li><li>Family and peer support</li><li>Large fonts, simple steps, low burden</li><li>Digital delivery acceptable when usability, trust, and digital literacy are addressed</li></ul><div><p>“Don't just talk about how scary dementia is. You need to tell me what I can actually do.”</p></div></div></div> <div><div> Overall, engagement with support depended on perceived usefulness, ease of use, and trust.</div></div> | <div><div> Main conclusion<ul style="list-style-type: none"><li>FoD reflects broader concerns about ageing, dependency, and social roles.</li><li>Person-centered and culturally sensitive support may promote well-being and healthy ageing behaviors.</li><li>Digital approaches are promising, but engagement depends on usability, trust, and equitable access.</li></ul></div><div><div>Implications for intervention design</div><div><div> Practical<ul style="list-style-type: none"><li>Actionable daily strategies</li></ul></div><div> Culturally sensitive<ul style="list-style-type: none"><li>Address family roles, burden, and dignity</li></ul></div><div> Accessible<ul style="list-style-type: none"><li>Clear language, large fonts, simple structure</li></ul></div><div> Trusted digital support<ul style="list-style-type: none"><li>Usability, guidance, and credibility</li></ul></div></div><div><div> Research funded by China Scholarship Council and Leiden University Global Seed Fund 2026. Conference attendance supported by Alzheimer Nederland.</div></div></div></div>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     | <div><div>1. World Health Organization. Dementia. 2025.</div><div>2. Dai H, Sun C, Xu S, et al. <i>Aging &amp; Mental Health</i>. 2025;29(6):1144–1151.</div><div>3. Dai H, Shen H, Versluis A, et al. <i>Alzheimers Dement Behav Socioecon Aging</i>. 2025;1(2):e70020.</div><div>4. Gale NK, Heath G, Cameron E, et al. <i>BMC Med Res Methodol</i>. 2013;13:117.</div><div>5. Atkins L, Francis J, Islam R, et al. <i>Implement Sci</i>. 2017;12:77.</div><div><i>Selected references only.</i></div></div> <div><div>CONTACT</div><div><div><div>Huohuo Dai</div><div>Leiden University Medical Center / NeLL / WeLL</div><div><a href="mailto:h.dai@lumc.nl">h.dai@lumc.nl</a></div></div></div><div><div>Scan to connect on LinkedIn</div><div><a href="http://www.nell.eu">www.nell.eu</a>   <a href="http://www.wearewell.net">www.wearewell.net</a></div></div></div>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |