

Understanding How Asian Indian Families Navigate Memory Loss And Care Options



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INTRODUCTION	METHODS	RESULTS	CONCLUSIONS	REFERENCES																																																																																												
Background - Asian Indian American families often provide care for relatives experiencing memory loss or dementia. - Cultural values, including family responsibility, respect for elders, privacy, and intergenerational support, may strengthen caregiving commitment. - Families may also face: - Dementia-related stigma; Uncertainty about memory symptoms; Limited familiarity with dementia services; Healthcare-system mistrust; Transportation difficulties; and Financial concerns. These challenges may affect whether families: - Discuss memory changes; Seek cognitive evaluation; Accept specialist referrals; Use community-based services; or Delay care until symptoms worsen. - Understanding how affiliate stigma intersects with practical barriers is essential for improving timely and equitable dementia care. Purpose - Identify barriers, examine sociodemographic factors, subjective norms(Affiliate Stigma, filial piety) and healthcare access barriers (Cognitive, structural and financial), influence dementia treatment seeking behavior among Asian Indian dementia family caregivers living in the US Theoretical Framework - Theory of planned behavior - Health care access Barrier Model - This study integrates the Theory of Planned Behavior and the Health Care Access Barriers Model to examine how individual beliefs and structural barriers influence healthcare-seeking behavior.	Study Design - Cross sectional study - Expedited/ Exempt Rutgers IRB approval obtained - Caregivers self reported, 18 year and older, Asian Indian origin, caregivers of family member with dementia, living in the US 254 participants completed anonymous online survey - Electronic informed consent was obtained before survey participation Sampling Method and Recruitment Plan - Convenience and snowball sampling - Community outreach, Social media, personal and professional networks, National Association of Indian Nurses, collaboration with healthcare providers, Ayurvedic and Homeopathic clinics, community events. Measurement/ Variables Sociodemographic factors, Affiliate Stigma Scale, Contemporary Filial Piety Scale, Dementia Knowledge Assessment scale and health care access barrier (Financial, Structural and Cognitive) questionnaire with outcome variables Data Analysis - Data were analyzed using IBM SPSS statistics, version 31. - Descriptive statistics summarized participant and response data. - Univariate bivariate and regression analysis were conducted	Characteristics of Study Sample (N=254) <table><tr><th>Variable</th><th>Category</th><th>N</th><th>Valid %</th></tr><tr><td>Age in years</td><td>Mean (SD)</td><td>38.6 (11.7)</td><td>100%</td></tr><tr><td>Sex</td><td>Male</td><td>135</td><td>53%</td></tr><tr><td></td><td>Female</td><td>119</td><td>47%</td></tr><tr><td>Marital status</td><td>Single (never married)</td><td>54</td><td>21%</td></tr><tr><td></td><td>Married/domestic partnership</td><td>185</td><td>73%</td></tr><tr><td></td><td>Widowed/Divorced / Separated</td><td>15</td><td>6%</td></tr><tr><td>Education level</td><td>High School, Trade School, or Less</td><td>28</td><td>11%</td></tr><tr><td></td><td>Associate degree</td><td>45</td><td>18%</td></tr><tr><td></td><td>Bachelor's degree</td><td>135</td><td>53%</td></tr><tr><td></td><td>Graduate degree</td><td>46</td><td>18%</td></tr><tr><td>Years lived in the U.S.</td><td>10 or less</td><td>48</td><td>18.9%</td></tr><tr><td></td><td>11 – 20</td><td>88</td><td>34.6%</td></tr><tr><td></td><td>More than 20</td><td>61</td><td>24.0%</td></tr><tr><td></td><td>Born in the United States</td><td>57</td><td>22.4%</td></tr><tr><td>Relationship to Person with dementia</td><td>Adult children and in laws</td><td>154</td><td>60.7%</td></tr><tr><td></td><td>Spouse</td><td>35</td><td>13.8%</td></tr><tr><td></td><td>Grandchild</td><td>43</td><td>16.9%</td></tr><tr><td></td><td>Niece or nephew</td><td>21</td><td>8.3%</td></tr><tr><td>Living arrangement of family member with dementia</td><td>Lives with you</td><td>144</td><td>56.7%</td></tr><tr><td></td><td>Lives in nursing home</td><td>55</td><td>21.7%</td></tr><tr><td></td><td>Lives with someone else</td><td>46</td><td>18.1%</td></tr><tr><td></td><td>Lives alone</td><td>9</td><td>3.5%</td></tr></table> Significant Findings - Higher affiliate stigma was associated with greater odds of transportation difficulty, OR = 1.11, 95% CI [1.07, 1.15], and healthcare-system mistrust, OR = 1.07, 95% CI [1.04, 1.11]. - Higher affiliate stigma was also associated with greater odds of delaying or avoiding care because of cost, OR = 1.11, 95% CI [1.06, 1.15], highlighting stigma as both a psychosocial and healthcare-access concern. - Affiliate stigma was not associated with dementia knowledge and awareness Culturally adapted and validated Contemporary Filial Piety Scale, and Dementia Knowledge Assessment Scale to short version-18 item scale	Variable	Category	N	Valid %	Age in years	Mean (SD)	38.6 (11.7)	100%	Sex	Male	135	53%		Female	119	47%	Marital status	Single (never married)	54	21%		Married/domestic partnership	185	73%		Widowed/Divorced / Separated	15	6%	Education level	High School, Trade School, or Less	28	11%		Associate degree	45	18%		Bachelor's degree	135	53%		Graduate degree	46	18%	Years lived in the U.S.	10 or less	48	18.9%		11 – 20	88	34.6%		More than 20	61	24.0%		Born in the United States	57	22.4%	Relationship to Person with dementia	Adult children and in laws	154	60.7%		Spouse	35	13.8%		Grandchild	43	16.9%		Niece or nephew	21	8.3%	Living arrangement of family member with dementia	Lives with you	144	56.7%		Lives in nursing home	55	21.7%		Lives with someone else	46	18.1%		Lives alone	9	3.5%	Conclusions - Higher affiliate stigma linked to transportation difficulties, healthcare-system mistrust, and delayed or avoided care because of cost. - Affiliate stigma should be addressed as both a psychosocial concern and an important marker of healthcare access challenges among Asian Indian American dementia caregivers. - Affiliate stigma was not associated with dementia knowledge, but it was consistently associated with practical barriers to dementia care. Limitations - Cross-sectional design limits causal interpretation. - Self-reported data may introduce recall or social-desirability bias. - English-language and digital recruitment may limit generalizability. - Unmeasured socioeconomic, immigration, and caregiving factors may affect findings. Future Implications - Address stigma alongside transportation, cost, navigation, and trust. - Screen caregivers for stigma and access barriers. - Partner with trusted Asian Indian community and faith organizations. - Use longitudinal and qualitative studies to examine delayed care. - Recruit more linguistically, economically, and geographically diverse caregivers.	- Baghirathan S, Cheston R, Hui R, Chacon A, Shears P, Currie K. A grounded theory analysis of the experiences of carers for people living with dementia from three BAME communities: Balancing the need for support against fears of being diminished. Dementia (London). 2020;19(5):1672-1691. - Choi J, Ta Park V, Nguyen E, Jung A, Tsoh J. 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