IGA NEPHROPATHY FOUNDATION
Dedicated to finding a cure.

Understanding the Cultural Influences and Care Barriers Impacting Asian Americans and Pacific Islanders Living with IgA Nephropathy

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Background

IgA Nephropathy (IgAN) disproportionately affects people of Asian descent. Studies suggest Asians:

» **Account for up to one-third of new diagnoses** [1]
» Face a significantly **higher risk of progression to kidney failure** [2,3]

Despite this elevated prevalence and disease burden, there remains limited awareness of the lived experiences and unmet needs of these populations. Cultural, linguistic and social factors may further influence how AAPI individuals experience, seek care for and manage IgAN. To date, few studies have assessed the perceptions, gaps, and challenges voiced by AAPI individuals to help ensure care and education are culturally sensitive and accessible.

Methods

The IgA Nephropathy Foundation conducted a series of focus groups with 19 people.

Patient recruitment (Columbia University Medical Center, Stanford Health Care, Tufts Medical Center)

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Conduct virtual focus groups *Sept-Oct 2024*, semi-structured approach/guiding questions, supplemental survey

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Analysis of insights, perceptions

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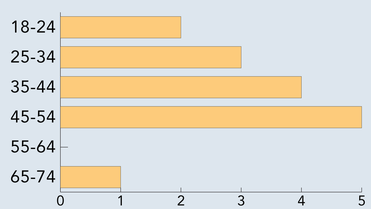
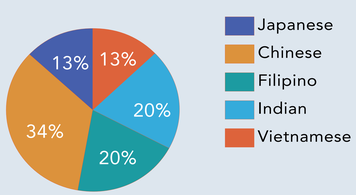
Identify key themes, gaps, unmet needs, opportunities

Key Inclusion Criteria:
» Self-Identify as Asian American
» U.S. Resident
» Proficient in English
» Confirmed IgAN Diagnosis

Participant Age



Participant Ethnicity



Results

Participants described challenges commonly reported by people living with IgAN, as well as distinct barriers and concerns shaped by cultural, linguistic, structural, and social factors.

Common IgAN Struggles

» Delays in diagnosis, limited disease awareness
» Difficulty maintaining kidney-friendly lifestyle
» Isolation, emotional burden of living with "invisible" lifelong disease
» Importance of self-advocacy and support systems
» Need for clear, reliable information and resources

Unique AAPI Challenges

» Reticence to disclose illness (privacy, shame, stigma tied to chronic illness)
» Tension between Eastern and Western medicine
» Challenges with obtaining cultural foods that are not high in sodium
» Language and communication barriers
» Few culturally competent providers
» Despite having insurance, many struggle to find specialists who understand these cultural challenges

Limitations

» English-proficient patients
» Participants had established access to care at major academic medical centers
» Small sample size

Conclusions

Asian Americans living with IgAN face distinct cultural and structural barriers that affect early detection, treatment and outcomes. Addressing these disparities requires:

» Culturally competent care and training for both nephrology and primary care providers
» Early detection and screening to promote more timely diagnosis of kidney disease in at-risk populations
» Tailored, multilingual education and outreach delivered through trusted community-based organizations, places of worship, messengers, social media channels, etc
» Partnerships with AAPI health and advocacy organizations
» Greater representation of AAPI voices in nephrology care, advocacy, and research

Together, these efforts can foster trust, earlier diagnosis, connection with resources, and more equitable kidney health outcomes.

Future Research - Next Steps

» Conduct community listening sessions with organizations that provide direct care, services to Asian populations to improve health outcomes
» Leverage the Foundation's new IgANHOPE Patient Registry to identify AAPI specific trends
» Assess impact of culturally tailored education/resources

References

Scan to review

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