Appendix 1

The Supplementary Appendix should be paginated, with a table of contents, followed by the list of investigators (if there are any), text (such as methods), figures, tables, and then references. The supplementary appendix should not be included in the article's reference list.

The Appendix must be submitted in a Word file. The Appendix will not be edited for style. It will be presented online as additional information provided by the authors.

The published article will contain a statement that supplementary material exists online and will provide the reader with a URL and/or link. Refer to the following example for how to reference the supplementary appendix in the text of the article: "Many more regressions were run than can be included in the article. The interested reader can find them in a supplementary appendix online."

Perspective of the lived experience

To provide a real-world experience, co-author and patient advocate, Tina Aswani Omprakash (T.A.O.), shares how various cultural considerations affected her while living with multiple gastrointestinal (GI) conditions, ranging from perianal fistulizing Crohn's disease requiring ostomy surgery, irritable bowel syndrome (IBS), gastroparesis, small intestinal bacterial overgrowth (SIBO), gastroesophageal reflux disease (GERD), pelvic floor dysfunction, and autoimmune hepatitis.

Being of South Asian descent and having grown up in poverty, T.A.O. began to experience GI symptoms without access to health insurance (prior to the Affordable Care Act). As she was naïve to the healthcare system, she was not aware that many of her conditions could be better managed by sub-specialists and did not have the experience to understand how to navigate the system to effectively share her needs and advocate for herself. On top of the societal taboos of having GI conditions and symptoms which affect the bowels, motility, urgency, and even sexual performance and reproductive ability, there was cultural stigma to navigate as well. She had to make this personal decision around when and to whom to disclose as these decisions may affect a broad range of outcomes and dynamics including marriageability as a young person living with a lifelong, uncurable GI condition. In this vein, she recognized that certain features of the condition and treatment, including fistulae and ostomy surgery, only compounded concerns around reproductive viability and fitness to perform as a spouse or family member. T.A.O. comes from a religious family and upbringing and belief in karma added shame and guilt to her disease journey as she was told repeatedly that she must have done something 'bad' in previous lifetimes to deserve her plight.

At a time when her culture and faith and community could have been protective and helpful, T.A.O. often felt she could not participate in cultural or religious activities or be open with the people around her. Sitting cross-legged on the floor in prayer for hours caused her significant discomfort, eating cherished and nostalgic foods upset her stomach. It was difficult enough to make these decisions and making it harder were questions from the family or community around why she was not joining in the festivals or why she was so thin. These comments made her feel even more isolated and othered instead of feeling supported and aided.

T.A.O.'s experiences in healthcare settings were equally troubling. Her case was objectively complicated as she was told by her tertiary, top-tier IBD provider that they "have never seen such an aggressive phenotype of IBD in a person of South Asian decent" and yet was told she "looked good" while she had sepsis from a large abscess, multiple fistulae, and was struggling with suicidal ideation stemming from medical trauma. She felt as though she was not being listened to, properly educated, or supported. When it became clear that surgery was necessary, her family pushed for her to avoid an ostomy due to concerns around marriageability. Despite T.A.O. being an adult and the patient with an opinion about her options, the surgeon opted to agree with her family and told T.A.O. to, "consider a j-pouch as she was still young." When T.A.O. described her dietary needs as a lacto-vegetarian, this was ignored and healthcare providers often encouraged her to, "eat egg at the very least. Where will you get your protein?" When she was hospitalized, staff, despite being aware of her preferences, proceeded to bring her egg and meat dishes which she could not consume, and which were against her religious beliefs. This left her feeling disrespected and with close to nothing to eat, severely harming her recovery.

Unfortunately, T.A.O. had many trials and failures as she navigated her own changing health, the GI and healthcare systems, her culture and how she participates in it, and her own personal identity. She did not meet with providers who embraced the idea and philosophies of cultural humility, and she felt as though no one had been in her shoes before her. Many of these experiences led her to take on the work of patient advocacy to fill these unmet gaps and empower patients to educate HCPs and become partners in their own care.

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