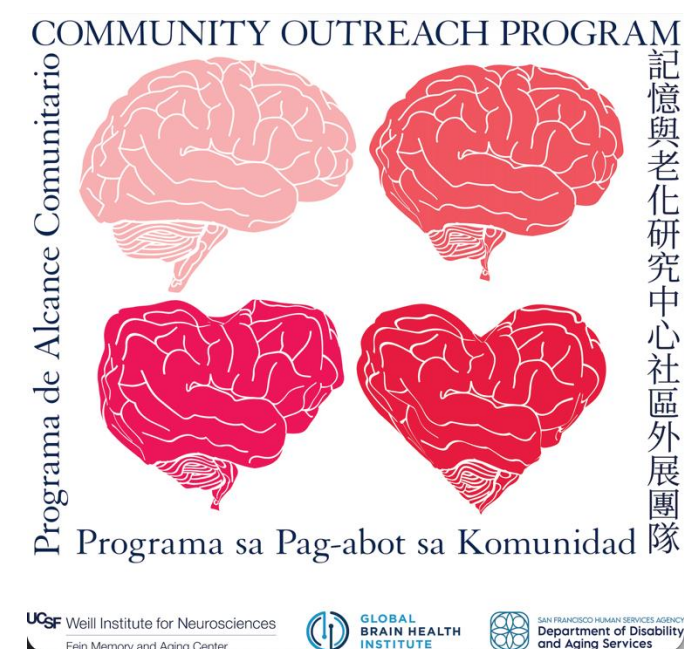




From Genomics to Care Partnership: Connecting Biological Discovery with Community Care



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Equity in research means ensuring everyone has the knowledge to make informed decisions.

Through a community-based genetics education program, we evaluated how tailored education improved understanding of genetics and informed engagement in neurodegenerative disease research.

Introduction

Genetic research offers important opportunities to improve health, but equitable participation requires informed understanding—not just recruitment. Many Spanish-speaking older adults are invited to participate without access to culturally and linguistically appropriate education about genetics, data use, and their role in neurodegenerative diseases. This creates an ethical gap, where individuals may be asked to contribute without fully understanding what participation entails. **Genes & Generations** was developed to address this gap by providing culturally tailored, Spanish-language genetics education to older adults, with the goal of improving genetic literacy, understanding of genetics and disease, building trust, and supporting informed engagement in research.

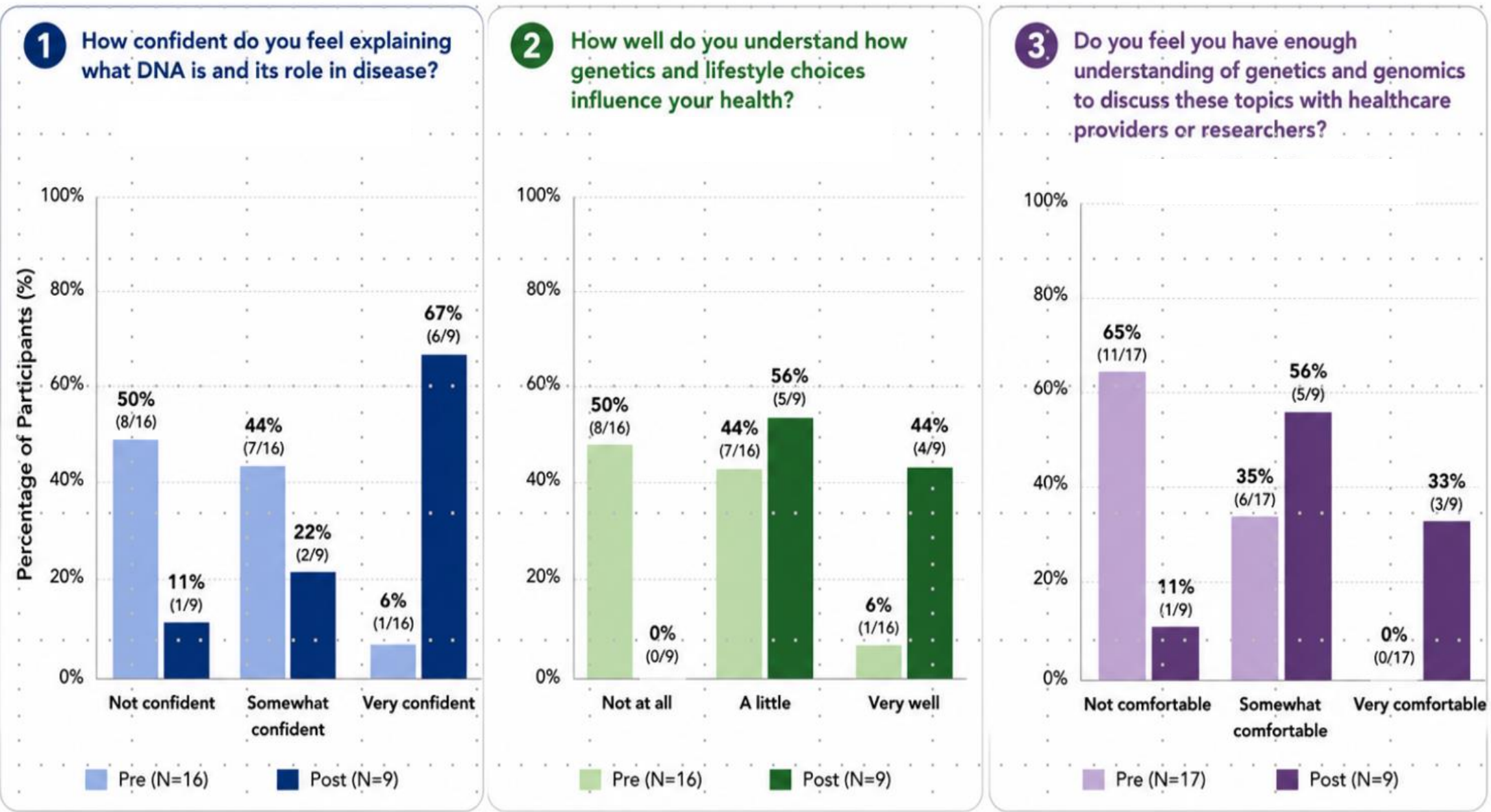
Methods

We conducted a 12-session, Spanish-language genetics education program for older adults at a community center. Sessions were two hours and included presentations, discussions, and hands-on activities. Outcomes were evaluated using pre/post surveys, DNA drawing assessments, attendance tracking, and group feedback.

Results

Participant Characteristics:
An average of 17 participants attended each session. The program included a core group of 11 individuals who attended ≥10 sessions. Participants had a mean age of 68 years and an average of 9 years of formal education.

Knowledge and Confidence Outcomes: Pre and Post Survey Results:



Learning Journey

Participants demonstrated progression from abstract perceptions of DNA to more accurate and meaningful understanding.



Participant's feedback



- “I had never done a science experiment before. It was great!”
- “The only thing I didn't like was learning this so late in life.”
- “I feel like I don't remember everything, but my notes help me not feel lost.”
- “It felt like going back to junior high, but learning something completely new.”
- “Building my family tree helped me connect with my family and reflect on the diseases we may be inheriting and passing on.”

Student-Partner Reflections

“The collaboration that exists with UCSF is wonderful, particularly this class with Dr. Piña. This class helped our participants to see how connected we are to the generations before us. Learning about genes made us realize that many traits and even some health conditions come from our families, which gave us a deeper sense of where we come from. At the same time, they learned that genes don't define everything. Our choices and environment still matter, and we have the ability to shape our own future. It also made us more understanding of others, knowing that not everything about a person is within their control. Overall, this class wasn't just about science—it helped us better understand ourselves and the people around us.”

Joana Mattero, MNC Inspiring Success Associate Director

“The collaboration with MNC Inspiring Success created a welcoming environment that fostered meaningful learning, where I was able both to teach and to learn from senior participants. The partner organization was highly supportive of the workshop, providing dedicated staff to ensure that the technology was fully prepared and that participants were present and engaged. As a student, this was a challenging yet rewarding experience that allowed me to share research knowledge with senior participants who are part of our research projects, creating a more horizontal and collaborative dynamic.”

Stefanie Piña Escudero, UCSF PhD Candidate

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