



Caregivers' Perceptions of Neuroimaging Biomarkers in Early Age-of-Onset Alzheimer's Disease



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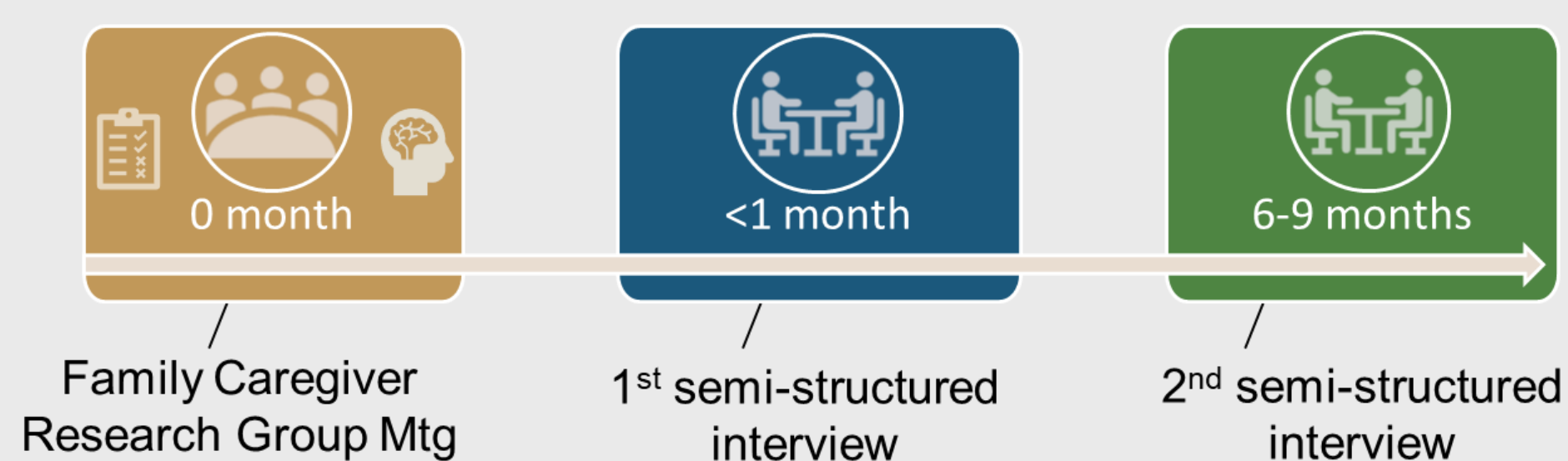
BACKGROUND

- Caregivers and patients with early onset (prior to age 65) often struggle with significant legal, financial, and social decision-making.
- Caregivers and patients often have limited understanding of dementia diagnosis and desire more information.
- Neuroimaging can help individuals with AD and caregivers to better understand a dementia diagnosis.

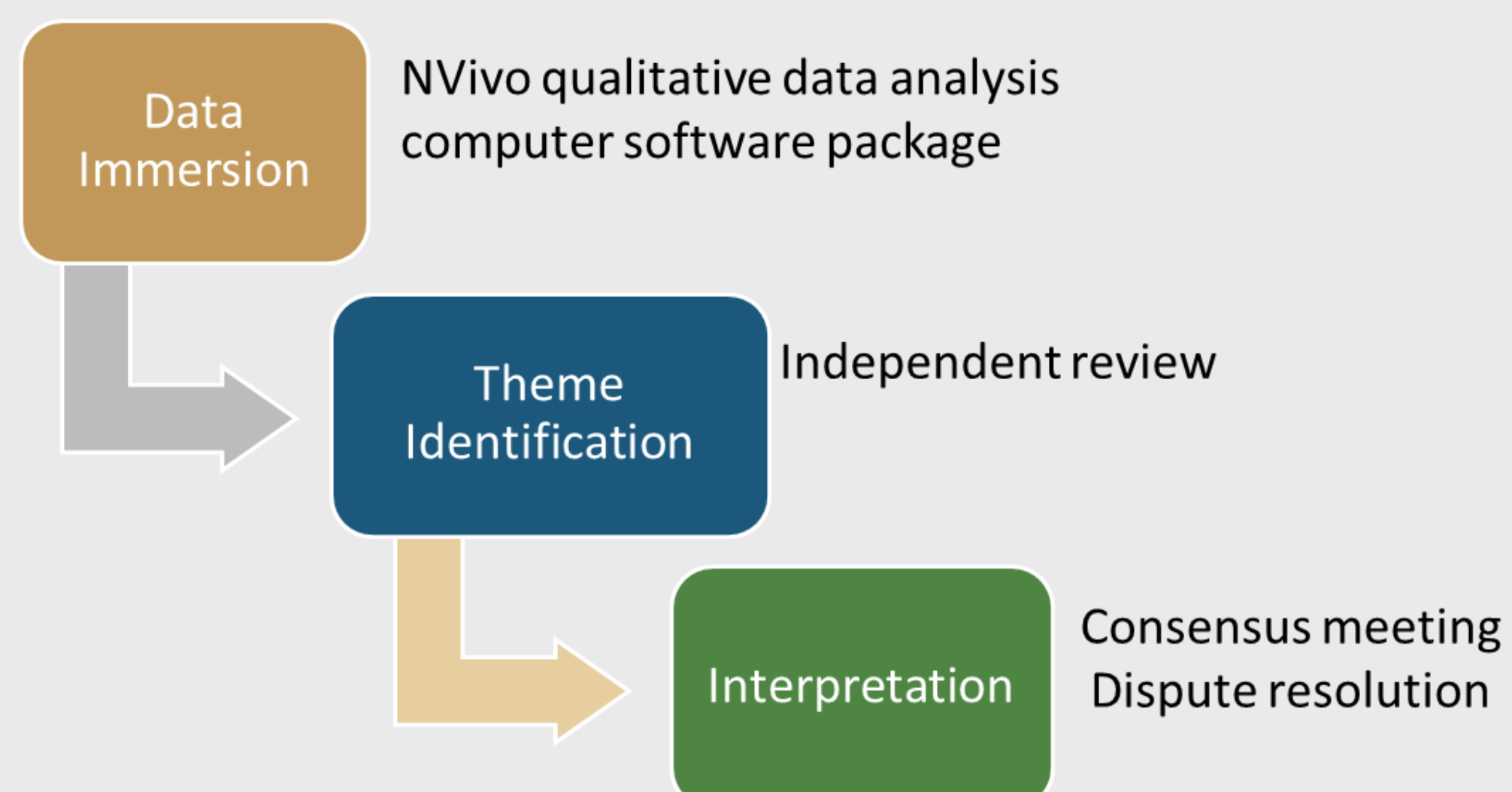
OBJECTIVE

- Explore how neuroimaging can **improve understanding of EOAD diagnosis** among caregivers.

METHODS



Methodology: Adjusted Grounded Theory



13 CAREGIVERS OF PATIENTS WITH EOAD	N
Age	60.5
Gender (M:F)	7 : 6
Education (years)	16.2
Race (n=41)	
▫ White	11
▫ Asian	1
▫ Native Hawaiian/Pacific Islander	1
Ethnicity	
▫ Latinx	2
▫ Non-Latinx	11
Study Partner Relationship	
▫ Spouse	11
▫ Sibling	2
Employed at time of interview (Y/N)	10 : 13
Reason for unemployment	
▫ Left early due to patient's diagnosis	1
▫ Retired	2

RESULTS

In what ways has neuroimaging...

helped with convincing caregivers about a patient's diagnosis?

- Overarching theme: Belief that neuroimaging confirmed EOAD diagnosis**
 - "... to have two scans of her brain that were about five years apart, and it was evident from the scans that there were some changes in her brain structure that would lead one to believe that there might be something going on." (69 M, husband)
 - "They put his scans up there, to see it turn positive was-- to see it come through that he had the red, the proteins, ... Dr. X said **it turns positive if you seen the red**. If there wasn't any red, then maybe there was hope it was something else that it could've been. But when we seen that i was ... like okay **you do 100% have it.**" (58 F, wife)
 - "...to see the differences was, again, **pretty blatantly obvious**. And it was disturbing... I would say **a picture is worth 1,000 words**. I think the PETs and the MRI spoke loudly... would call a normal brain at that age and then seeing K.'s exam and seeing the differences. That was pretty stark." (57 M, brother)

better understand the diagnosis?

- Overarching theme: Illness outlook**
 - "**understanding that this is a progressive situation** ... we have a number of things to consider ... looking at some of the ramifications for us in terms of personal finance management and property ... it's still a progressive disease, that **there isn't really any treatment for other than possibly slowing the progression**. And so it's a difficult thing to accept." (69 M, husband)
 - "It's **more clear now how dire things are**. And back then I believe I still thought that there was some hope, and now it looks like we pretty much just have to live **for the moment and enjoy what we have.**" (55 M, husband)

made communication easier?

- Overarching theme: Reducing caregiver-patient conflict**
 - "He wants to drive and with no license, and **he thinks I took it away from him**. But I said, **'No. It didn't come from me.'**" (58 F, wife)

improved living with a person with dementia?

- Overarching theme: Reducing caregiver burnout**
 - "I have to **figure out a way to make it work**... There's a lot of decisions that are tough and it feels like I'm involved in just everything that goes on throughout the day ... **I'm learning that now that she's going to need freedom**. She needs to walk the dog around the block by herself. We've lived here 26, 27 years. And I'm scared to go to the store, and I shouldn't be because it's language that is her problem. Her motor skills are fine. And right now, and this has only been a few days, but right now **I'm realizing the freedom that she's been talking about is much more important than her danger**. She's not dangerous to herself yet. (54 M, husband)

affected stigmatizing beliefs?

- Overarching theme: Reaction to final diagnosis**
 - "I would say the people that love her or love us, unconditionally have loved us, will continue on. **Alzheimer's has a stigma**. People don't know what to do, how to help, or to react to people with Alzheimer's. Most of them know Alzheimer's as being a stage that **we can't even see.**" (57 M, husband)
 - "It's a **terrible stigma** about Alzheimer's. **People don't understand it**, they're afraid of it. And that's worldwide, the way that people with Alzheimer's are treated and misunderstood. And sometimes that may not even be the diagnosis. ... I think it was a reflection of their own biases." (72 M, husband)

CONCLUSION

- These narrative descriptions suggest neuroimaging biomarkers can **enhance caregivers' understanding of an AD diagnosis** and help overcome some of the challenges of caring for patients with EAOD.
- Quantitative studies are needed to verify these findings among **diverse communities**, so everyone benefits from advances in Alzheimer's science.