REASONS TO PARTICIPATE IN ALZHEIMER'S RESEARCH: VARYING PERSPECTIVES OF PARTICIPANTS FROM THE WISCONSIN REGISTRY FOR ALZHEIMER'S PREVENTION

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BACKGROUND

- Longitudinal studies are essential to developing effective Alzheimer's disease (AD) interventions, yet participation requires long-term commitment. Evidence from several longitudinal studies suggests varying reasons for participation in research, such as societal/altruistic reasons[1] and personal benefit.[2]
- By investigating motivation for particular subgroups, recruitment and retention strategies can be tailored more specifically to participant needs.[3,4]

OBJECTIVE

- To identify themes for participating in longitudinal research provided by people enrolled in the Wisconsin Registry for Alzheimer's Prevention (WRAP) using qualitative content analysis of speech sample narratives.
- To investigate whether themes varied across subgroups such as gender or AD family history status.

METHODS

Participants: The Wisconsin Registry for Alzheimer's Prevention (WRAP) is a longitudinal study of a cohort (n > 1500) enriched with positive family history of AD (FH+). We used multi-stage sampling to obtain a set of 32 speech samples that balanced representation across gender (16 male, 16 female), FH status (15 FH+, 17 FH-) and site (19 Madison, 13 La Crosse).

Materials: At the third and fourth wave visits, participants are asked, "Why is being involved in the WRAP study important to you?" Responses are digitally recorded.

Qualitative Analysis: Participant samples were transcribed and analyzed according to qualitative research methods[5,6]. Process notes were recorded during the analysis and 19 categories emerged, which fell into three broad themes: Personal, Family, and Societal. For each of the 32 speech samples, two independent coders assigned yes/no ratings to the 19 identified categories. Inter-rater reliability was calculated at 91% agreement (Cohen's κ = 0.60).

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2. Ejiogu N, Norbeck JH, Mason MA, Cromwell BC, Zonderman AB & Evans MK (2011). Recruitment and retention strategies for minority or poor clinical research participants: Lessons from the healthy aging in neighborhoods of diversity across the life span study. The Gerontologist , 51 (suppl 1), S33–S45.

3. Areán PA & Gallagher-Thompson D (1996). Issues and recommendations for the recruitment and retention of older ethnic minority adults into clinical research. Journal of Consulting and Clinical Psychology, 64, 5, 875-880.

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TABLES & FIGURES

FIGURE 1. Why Participate in Alzheimer's Research? Quotes from WRAP Participants

Personal Themes

"To have my memory monitored over time."

"To find a cure that may someday help me."

"The fifty bucks."

"The tests are fun."

"It feels like I am helping in my own small way."

Family Themes

"For my children and grandchildren."

"To find a way to prevent my kids from having to take care of me."

"In memory of my father."

"To provide moral support to my wife."

Societal Themes

"For scientific advancement."

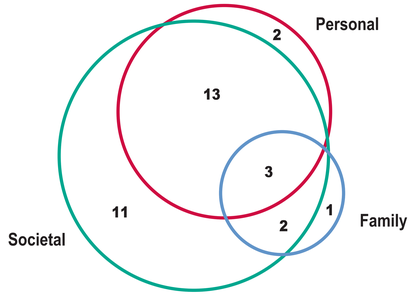
"It may do someone some good."

"Anything we can do to make it better, make it easier for people."

"As the Baby Boomers age, more people are getting Alzheimer's."

"To reduce the financial burden on society."

FIGURE 2. Frequency of Response Categories



The Venn diagram represents participants' response categories overall, scaled by frequency. Each speech sample is represented in one section of the diagram. The "centermost" blob (n=3) represents speech samples that cited at least one reason in each theme.

FIGURE 3. Most Common Response Categories, by Family History

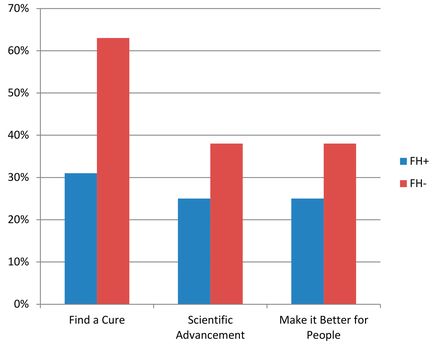
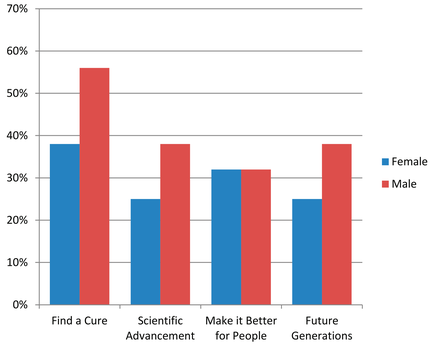


FIGURE 4. Most Common Response Categories, by Gender



RESULTS

19 content categories representing three broad themes emerged (**Figure 1**):

- Personal (9 Categories)
- Family (3 Categories)
- Societal (7 Categories)

The median sample listed 3 reasons (range: 1-8) representing 2 of the 3 broad themes. 56%, 19%, and 91%, respectively, cited at least one personal, family, and societal reason for participating (**Figure 2**).

We explored subgroup differences in reasons for participation. In this small sample, no differences were statistically significant, but we observed the following trends:

- FH+ participants were no more likely than their FH- counterparts to cite categories within the Family theme (20% vs.18%), and surprisingly, a higher percentage of FH- participants cited a desire to help their own children or grandchildren (18% vs 7%). A few specific categories within the Societal theme tended to show up more often in FH- responses, such as an enjoyment of volunteering in general (12% vs 0%) and the sense that "it feels like I am helping in my own way" (35% vs 13%) **(Figure 3)**.
- The most common responses for women and men are shown in **Figure 4**. More women listed at least one category within the Personal themes (69% vs 44%) and fewer listed a Societal reason (81% vs 100%). More women than men expressed desire to participate for their children or grandchildren (25% vs 0%).
- More Madison participants cited a desire to learn more about AD (21% vs 0%) or a sense that AD is becoming a big social problem (21% vs 0%). These site differences were not explained by education level.

CONCLUSIONS

Preliminary analyses indicate diverse reasons for participating in time-consuming longitudinal research studies, and that motivations vary based on participant characteristics. Providing educational information and feedback to address these diverse motivations may enhance recruitment and retention efforts. As samples representing minority groups will soon be available, content analysis of reasons to participate will be further explored and compared across groups and retention strategies may be further identified.

ACKNOWLEDGEMENTS & CONTACT

We would like to thank WRAP participants and WAI staff for their contributions to the WRAP study. Without their efforts this research would not be possible. WRAP is supported by NIA grant R01AG27161 (Wisconsin Registry for Alzheimer Prevention: Biomarkers of Preclinical AD), Helen Bader Foundation, Northwestern Mutual Foundation, Extendicare Foundation and State of Wisconsin. WRAP is also supported by the Clinical and Translational Science Award (CTSA) program, through the NIH National Center for Advancing Translational Sciences (NCATS), grant UL1TR000427. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

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