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

Kimberly Diggle Mueller, MS CCC-SLP, Rebecca L. Koscik, PhD, Asenath La Rue, PhD, Erin M. Jonaitis, PhD, Sarah K. Riedeman, Bruce P. Hermann, PhD & Mark A. Sager, MD

University of Wisconsin School of Medicine and Public Health, Madison, WI, USA

RESULTS

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 and personal benefits.

By investigating motivation for particular subgroups, recruitment and retention strategies can be tailored more specifically to participant needs. By investigating motivation for particular subgroups, recruitment and retention strategies can be tailored more specifically to participant needs.

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 diverse sample of speech samples representing representative demographics (16 males, 16 females, FH+ status, site (19 Madison, 13 La Crosse).

Materials: All the third and fourth wave visits, participants were 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. 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.

RESULTS

The most common motivations for participation were "to help myself" (20%), "to help my family" (20%), and "to help others" (20%). These site differences were not explained by education level.

The most common 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 personal 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 on the personal 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 2).

- The most common responses for women and men are shown in Figure 3. 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

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 and Clinical End Points) and NIA grants R01AG42846, R01AG38636, R01AG17613, U01AG06786, and P30AG10161. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Acknowledgements: 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 and Clinical End Points) and NIA grants R01AG42846, R01AG38636, R01AG17613, U01AG06786, and P30AG10161. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.