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Background

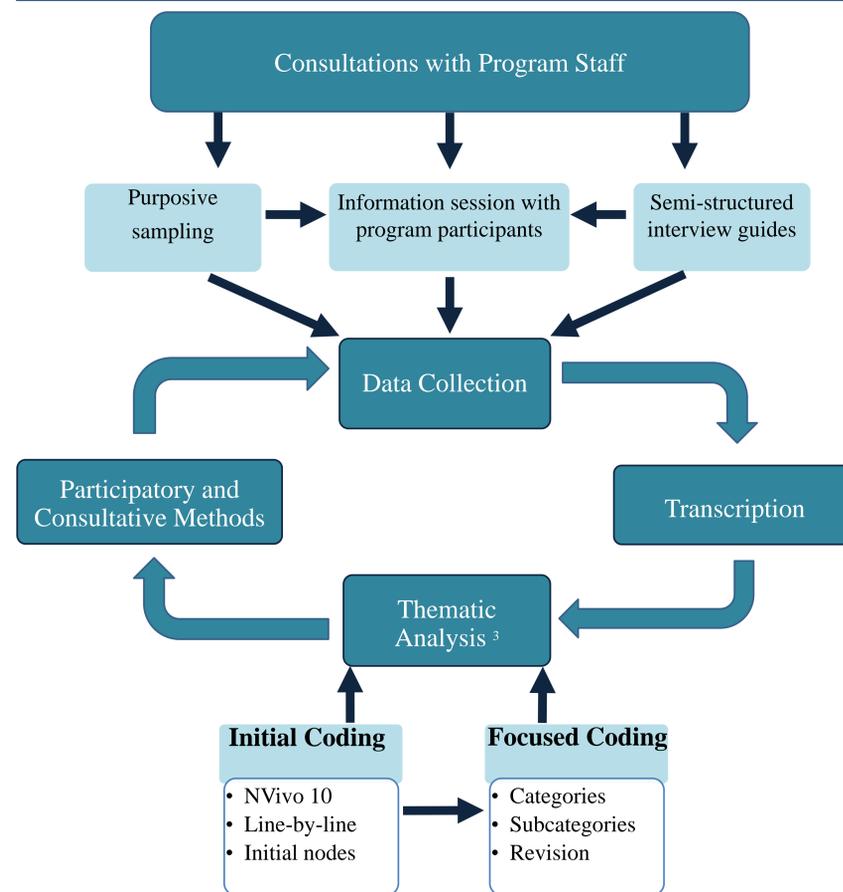
Purpose: To understand the role and potential benefits of young onset dementia (YOD) day programs, and how they might be improved to better serve the needs of younger (<65) persons with dementia

- ❖ Includes those who are diagnosed with dementia before the age of 65¹
- ❖ Some unique characteristics of YOD can include:
 - Working at time of diagnosis^{1,2}
 - Physically fit^{1,2}
 - Difficulty accepting loss of skill¹
 - Lack of appropriate services^{1,2}

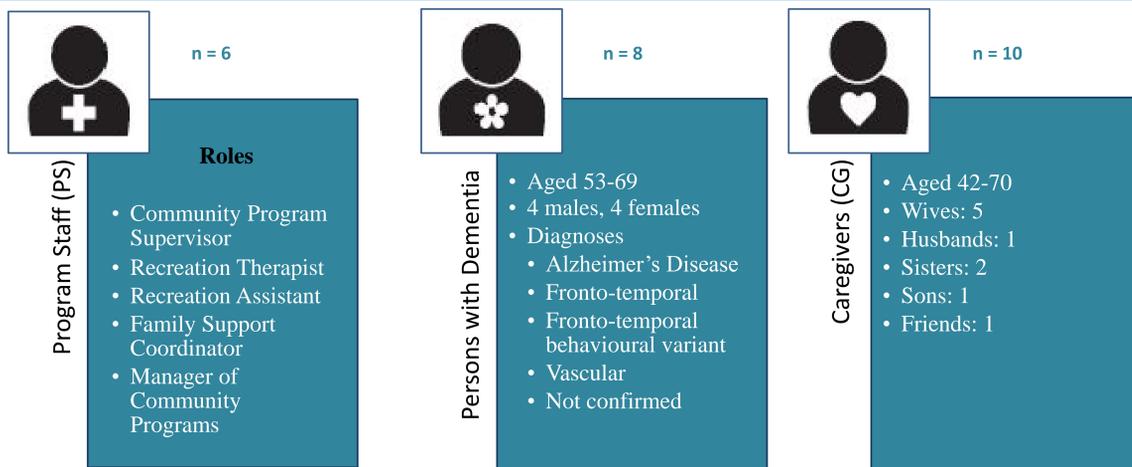
- YODA and the Wednesday Night Joes**
- ❖ Newly developed day programs for individuals with YOD
 - ❖ Operate in the Waterloo- Wellington Region and are of only a few known in Canada
 - ❖ Developed to address the unique needs of those living with YOD



Methods



Sample Description



A Selection of Themes

Diagnosis

Andy (participant): "It took 2 years to get it diagnosed... Yeah I went to my - I went to my doctor and he said it was depression. A lot of people make mistakes like that."

Henry (participant): "That's the whole thing with Alzheimer's is you slowly... have things taken away from you. You're memory, you're ability to do certain things... it never gives you an add, it's always a take."

Need for Age Appropriate Program

Diana (staff): "I think there's that younger group, um, there's been an ongoing issue with them finding - them fitting in our traditional day program and they would walk in and right away would know that it's just... They don't fit in."

Carolyn (caregiver): "This seemed right for him. It's a better fit than going to some building with a bunch of 80 year olds that are, that had dementia. He can't relate to that."

Benefits for Caregivers

Judy (caregiver): "This program has been great for me. It gives me a lot of peace of mind knowing that he's with people his own age."

Emily (caregiver): "I live a very busy life. I have my own stressors in my life. With this program, I know that Louise goes somewhere where she is safe, she is comfortable, she is having really fun experiences, she is learning new skills, she is developing positive relationships with various people."

Impact on Program Participants

Louise (participant): "There's a routine there, like when I was working. It reminds me that I have some strengths to offer, qualities I can share, experiences that others find interesting. It reminds me that I am still me. It's a welcomed break from my struggles with my brain."

Julia (staff): "It is cool to see two like, as their relationships build they would talk very openly about like losing their license or you know not allowed to cook anymore or can't go for a walk."

Program Challenges

Diana (staff): "And even just getting, I mean these people who've often - generally lost their license but then the families are working so trying to get them to the program has been - has been a challenge."

Susan (participant): "We were on the way to Niagara... the first time we went our bus broke down and that was really crappy... so twice the buses broke with us and that's crappy."

Suggestions for Improvement

Henry (participant): "Because of our loved ones, okay, and how we affect them when they bring us here was to - maybe a bus service can come and pick everybody up... if they could provide that service in the future I think would maybe increase the people we may have."

Elizabeth (caregiver): "The other thing that I would like to see is communication to the caregivers, to let them know that other caregivers are there and willing to talk to them if they need somebody to talk to."

Discussion and Conclusion

- ❖ Individuals diagnosed with YOD face unique challenges^{1, 2, 4}
- ❖ Caregivers of those with YOD are generally younger and have different life situations compared to caregivers of older adults with dementia⁵
- ❖ There is a need for the development of specialized services for this population
- ❖ We undertook a participatory and consultative approach to this project to understand the role and potential benefits of these programs, and how they might be improved to better serve the needs of this population
- ❖ These programs accommodate the active lifestyle of younger persons with dementia and have a positive impact on the program participants in a variety of ways. Examples include: peer support, development of relationships, exercise, purpose, feeling of belonging
- ❖ Examples of benefits for caregivers include: time, peace of mind, connections to services, relationships and support with other caregivers
- ❖ Example areas of improvement include: transportation, more days of service, enhance caregiver support and opportunities to connect caregivers
- ❖ This evaluation will be helpful to support the planning of future programs for individuals with YOD

Next Steps

- ❖ Initial themes, consultations with program staff, and feedback from program participants and their caregivers will inform refinement of the program model by addressing barriers and building on facilitators
- ❖ A continuation of consultations with program staff, as well as individual and focus group interviews
- ❖ Goal Attainment Scaling will be used at the two sites to measure individual goals and outcomes
- ❖ Knowledge Translation: This project is guided by the integrated knowledge translation protocols as outlined by the Canadian Institutes of Health Research⁶. Within this process, a continuous feedback-loop occurs between the researcher and the program staff regarding the emerging information. Collaboration between all those involved will both inform the refinement of the program model, as well as aid in future decisions and steps in the project.

References:

1. Alzheimer Society Canada. (2015). Young onset dementia. Retrieved from <http://www.alzheimer.ca/en/About-dementia/Dementias/young-onset-dementia>; 2. Jefferies, K., Agrawal, N. (2009). Early-onset dementia. *Advances in psychiatric treatment*, 15, 380-388; 3. Braun, V., Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101; 4. Van Vliet, D., de Vugt, M., Bakker, C., Pijnenburg, Y., Vernooij-Dassen, M., Koopmans, R., Verhey, F. (2012). *Psychological Medicine*, 43, 423-432; 5. Dupuis, S., Epp, T., Smale, B. (2004). Ontario dementia caregiver needs project: A literature review. 1-111; 6. Canadian Institutes of Health Research (CIHR). (2015). Integrated knowledge translation (IKT). Retrieved from <http://www.cihr-irsc.gc.ca/e/45321.html#a3>

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