Process evaluation of pilot day programs for individuals with young onset dementia

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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 65.
- Some unique characteristics of YOD can include:
  - Working at time of diagnosis
  - Physically fit
  - Difficulty accepting loss of skill
  - Lack of appropriate services

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

Sample Description

- Roles:
  - Community Program Supervisor
  - Recreation Therapist
  - Recreation Assistant
  - Family Support Coordinator
  - Manager of Community Programs

- People with Dementia:
  - Aged 53-69
  - 4 males, 4 females
  - Diagnoses: Alzheimer’s Disease, Fronto-temporal
  - Behavioural variant: Vascular
  - Not confirmed

- Caregivers (CG):
  - Aged 42-70
  - Wives: 5
  - Husbands: 1
  - Sisters: 2
  - Sons: 1
  - Friends: 1

Methods

- Consultations with Program Staff
  - Purpose sampling
  - Information session with program participants
  - Semi-structured interview guides

- Data Collection
  - Thematic Analysis
    - NNvivo 10
    - Line-by-line
    - Initial nodes

- Participatory and Consultative Methods
  - Categories
  - Subcategories
  - Revision

A Selection of Themes

Diagnosis

Andy (participant): “It took 2 years to get it diagnosed...Yeah 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...they take things away from you. You’ve memory, you’re ability to do certain things...it never gives you an add, it’s always a take.”

Impact on Program Participants

Louise (participant): “There is 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.”

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.”

Program Challenges

Diana (staff): “And even just getting, I mean these people who’ve ever...generally lost their license but then the families are working 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.”

Benefits for Caregivers

Jody (caregiver): “This program has been great for us. 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.”

Suggestions for Improvement

Henry (participant): “Because of our loved ones, okay, and how we affect them when they bring us home to me in the end, maybe a bus service can come and pick everybody up...if they could provide that service in the future I think I 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.
- Caregivers of those with YOD are generally younger and have different life situations compared to caregivers of older adults with dementia.
- 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.
- Examples of 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.

References