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Participant and Caregiver Perceptions of the Benefits of a Dementia-Specific Adult Day Program

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by Catherine Blake

Participants at the Alzheimer Outreach Services Day Program of McCormick Home in London, Ontario may have memory problems, but they're passionate about how important the program is to them.

"It keeps me from going crazy," said one participant. "I find it very fulfilling. There are so many activities and no one really bossing you around. The programs are really good - better than staying at home. I'm grateful."

Added another, "If I didn't come here I'd be bored to death. I'd be triple bored."

Dementia-specific adult day programs, such as the one at Alzheimer Outreach Services of McCormick Home, are community-based settings that offer a range of services to those facing the challenges of this type of cognitive impairment. They are designed to enhance client well-being and quality of life and to reduce the burden on family caregivers.

McCormick's Alzheimer Outreach Services Day Program opened in 1985 and is the largest of its kind in Ontario. It serves an average of 75 clients per day and 365 clients per year.

Through the use of modern technology and a highly skilled team, the program provides persons with dementia with socialization, physical exercise and cognitive stimulation geared to their abilities through games, art therapy, horticulture and music.

Day program staff members include therapeutic recreation specialists, nurses, personal support workers and social workers who maintain close contact with family caregivers and monitor the psychosocial and physical well-being of each client. Private bus transportation to and from the program is available to clients who request it.

These findings arose out of larger research collaboration with Baycrest Health Sciences that focused on understanding the psychosocial outcomes of attending the adult day program. We were interested in learning what benefits and challenges participants experienced from attending, what benefits and challenges their family caregivers perceived for the participants, and what benefits and challenges the family caregivers experienced themselves.

We conducted individual interviews at baseline, two months, six months and one year with day program participants (n=175) and family caregivers (n=175) using four short-answer, open-ended questions:

-What does coming to the day program mean to you? -What are the reasons you began coming to the day program? -What keeps you coming to the program? -How would your life be different if you weren't coming to the program?

Participants told us how vital the program is, not just in terms of relieving boredom but also in helping them make social connections.

"I love to be around people. With having a little bit of dementia, it helps to talk to people," said one participant.

Another commented, "I like it here. I thought it would be nice to do things and talk to people my age. We can still have fun. I'm a people person. I like company."

Some participants mentioned they attended the program because of concerns they had about their own safety. One participant told us, "First of all, I get myself out of danger at home. I burned three tea kettles. I have to recognize that I am now an old person. My memory is poor."

Participants commented on the value of sharing experiences about their condition. "I learn every time I talk to someone new," said one participant. "I just hope to learn something in each encounter." Another said, "The other participants, the conversation about the process is number one for me. I learn so much."

But others acknowledged that the program is also beneficial for their caregivers. "It's a complete break from home and a change," one participant said. "It gives my wife a break and it gives me a break. She can do her thing and I can do mine."

Family caregivers also found the day program helpful. According to their responses, they believe the benefits to their family members included increased alertness, delayed admission to long-term care and improved overall safety.

"The hour after he's dropped off at home is the best time of the week," said one caregiver about the effect of the day program on her husband. "He's alert, has conversation and is cheerful."

Another caregiver pointed out that it is their family member's interaction with the day program staff that makes such a difference because they understand dementia so well. "She's around other people who get it. It means the world to both of us. I try to model the home environment on what the staff do at the day program."

The caregivers also acknowledged that the day program benefits them. They receive education about how to care for someone with dementia. As one participant said, "I had some caregiver education about how to communicate and came to a new understanding. I have more patience. Without the education, I would have been a jerk."

Caregivers also appreciated the peace of mind and relief from the daily challenges they face.

One participant explained that "it gives me three days where I don't have to worry. It gives me freedom. I'd be a basket case otherwise. The day program is a godsend." Another caregiver mentioned that "I get peace of mind knowing he's at a caring facility specifically for dementia. It's guilt-free time [for me] when he's at the program."

Although nearly all the feedback on the program was positive, some participants said they would prefer to stay home and felt they were made to attend by family members. "I wasn't interested because I thought they'd put me away, and I'm not ready for that," said one person we interviewed. Another told us "I come because my daughters make me."

Some caregivers also felt the program didn't give them enough of a break. "It's not that much of a help to be honest," said one. "I run around like crazy when he's gone doing errands."

But overall, our research indicates that there are many more pros than cons when people with dementia get the opportunity to spend a day or more a week at a day program, to be active and to share experiences. One participant mentioned the comradery that comes with being in a program with others who also face the challenges associated with dementia.

"Because we are all the same, we share little tips and tricks. I really love it. I can hardly wait for Thursday to come."

This research has contributed to our understanding of the important role day programs play in the continuum of care for persons with dementia. Day programs promote socialization and well-being for participants; caregivers get much needed respite and are able to keep their family members at home longer, reducing the burden and cost to the health care system.

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Catherine Blake is the Research Assistant for Alzheimer Outreach Services, at McCormick Home and can be contacted at cmblake@uwo.ca for further information.

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