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Cover Page Footnote

I would like to thank all participants who completed the survey for their valuable perspectives as well as guest speakers at the support group. I would also like to thank Lisa Di Prospero, Dr. Carole Cohen and Bailey Hollister for their feedback, support and encouragement. This article is associated with the Patient, Family & Community Engagement lens of The Beryl Institute Experience Framework (<https://www.theberylinstitute.org/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_PtFamComm

The value of community psychiatric services for the elderly's dementia caregiver group: Exploring the perspectives of participants

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Abstract

Community Psychiatric Services for the Elderly (CPSE) at a large teaching hospital in Toronto has offered a monthly support group for caregivers of persons with dementia for over 30 years. Participants were surveyed in January 2018 about group attendance, benefits of attending the group, and areas for improvement. Results are shared in this case study. A total of 8 participants responded to the survey with a response rate of 47%. The feedback was predominantly positive. The most prevailing theme that emerged from the survey responses was group members' appreciation for the opportunity to meet with one another to discuss relevant issues and gain support from the facilitator and each other. Feedback from the survey also revealed opportunities for improvement on how the group could be better facilitated to elicit more equal participation from all group members. Formally assessing the value of the group from the perspectives of participants confirmed that the group is a safe place for dementia caregivers to get support and a valuable way to access knowledge from dementia care experts. COVID-19 has fostered evolution of the group from in-person to virtual meeting, opening opportunities for more feedback from members to help create the future of the dementia caregiver support group.

Keywords

Dementia, caregiving, person-centred, patient satisfaction, support group

Background

Dementia

Neurocognitive disorders including dementia can be caused by a variety of diseases or injury to the brain that produce deterioration in cognition and functioning.⁴ Dementia is associated with poorer health, greater disability and is a life-limiting illness for those who acquire it.⁵ In addition to the effect on individuals, the social impact of dementia is great and ever-growing. In the Province of Ontario, it was estimated that 255,000 people were living with dementia in 2020, and over 430,000 Ontarians will be living with dementia by 2038.^{6,7} On a national scale, there are over 400,000 Canadians over the age of 65 living with dementia, and this number is expected to grow significantly over the next 20 years.⁸ By 2031, it is estimated that dementia will cost Canada's health care system over \$16,000,000,000 CAD.⁵

The loss in ability to function independently due to dementia generates an increasing need for support from others. The toll of caring for a person with dementia on family caregivers is well established. The caregiver role has been linked to increased incidence and prevalence of depressive disorders⁹ and increased risk for cardiovascular disease.¹⁰ Spousal caregivers are at an even greater risk of developing depression¹¹ and for spousal caregivers who are elderly, there is an increased risk for mortality.¹² These

factors highlight the need for caregiver support services, including groups.

Dementia Caregiver Support Groups

There is clear evidence to support the effectiveness of support groups in fostering hope in their participants and improving their well-being.¹³ The benefits of participating in support groups for dementia caregivers are apparent when looking at multiple outcome measures, including psychosocial well-being, burden, anxiety and depression.^{14,15} However, there are barriers to caregiver involvement in groups, such as lack of transportation and difficulty finding help to care for the person with dementia while their family caregiver attends the group.¹⁶ Caregiver groups also exist online and help many caregivers virtually participate in groups when they may not have been able to attend them in person. However, online groups are not without their drawbacks. For instance, in their pilot study of a virtual reality caregiver group using avatars, O'Connor, Arizmendi and Kaszniak (2014)¹⁷ noted issues such as technical difficulties and perceived time constraints when trying to respond to posts from other group members.

The CPSE dementia caregiver group meets in person once a month for two hours at the hospital. Caregivers go through a screening and registration process prior to attending. Caregivers can join the group at any time and can be present or absent from session to session with no

maximum number of sessions or time frame, making it an open group.^{3,18} The openness of the group respects the practical issue that members may not have the ability to attend every session related to the demands of their caregiver roles. The group is attended by caregivers of persons with dementia at different stages of the illness. Group members share their experiences, challenges, information about resources and discuss care of their person with dementia with each other and the facilitator. Occasionally, guest speakers come to the group to discuss a relevant topic and stimulate discussion.

Methodology

Caregiver Support Group Evaluation Questionnaire

Informal feedback about the group is requested on an ongoing basis by the facilitator. However, formal written feedback had not been sought for at least 2 years prior to this review of the group. An online questionnaire was created (Appendix A) and distributed via SurveyMonkey® to elicit feedback from participants. The online format was chosen for convenience. It was free to use and easy to distribute to the group by email. Responses would be available quickly and easy to analyze. The questionnaire was designed to draw from the perspectives of group members and test the effectiveness of the group in terms of how valuable it is to participants and the organization.¹ The questionnaire was designed to be a satisfaction survey and self-report on progress by participants to improve the quality of the service. Ethics approval was not required for completion of this project as determined by the hospital's Ethics Review Self-Assessment Tool (ER-SAT) and validated by the hospital's Ethics Office.^{19,20}

The questionnaire collected information about the relationship between the person with dementia and their caregiver as Pinquart and Sörensen (2011)¹¹ and Schultz and Beach (1999)¹² identified that caregiving may affect individuals differently based on whether the caregiver was a spouse or a child of the person with dementia. Frequency of attendance at the group was requested from respondents to better understand the breadth of their experience with attending group. A five-point Likert scale from "Strongly Agree" to "Strongly Disagree" was used to gauge subjective experiences of group members. Open-ended questions allowing for free text responses prompted respondents to comment on their level of satisfaction and how to make the group more useful in their own words. Consent was indicated by completion of the online survey. All answers were confidential and anonymous.

Analysis

Simple descriptive statistics such as means and frequency counts were used to analyze the rankings and demographic data. Open-ended questions from the questionnaire and from observational study were transcribed. A qualitative descriptive approach was used to review this data. The

data was analyzed for the purposes of quality improvement to identify emerging themes and categorize what was going well about the group and what could be improved. Emerging themes were identified by the authors from reviewing free text responses by caregivers. The presence of echoed answers, similarity of topics and expressed sentiments, and related vocabulary helped to identify themes. Data was anonymized for statistical analysis and reporting, and no personal identifying data was collected.

Results

In 2017, monthly group meetings consisted of five participants on average. From January 2, 2018 to February 22, 2018 eight total survey responses were received from caregivers who attended the group in 2017 and previous years (response rate of $8/17 = 47\%$). The number of group session respondents who said they attended was evenly divided with a quarter of respondents who said they attended 1-2 sessions, a quarter who attended 3-5 sessions, a quarter who attended 6-8 sessions and the last quarter who said they attended 10-12 sessions (Figure 1). Spouses/partners of a person with dementia made up the majority of caregivers that responded at 62.5%. The remaining 37.5% respondents were children of a person with dementia (Figure 2).

The next set of questions used five-point Likert scales to survey respondents' experience of attending the group. The points on the scales were labelled "Strongly Agree," "Agree," "Neutral," "Disagree," and "Strongly Disagree." The questions asked caregivers how much they felt supported and safe while attending the group. The group facilitator is currently, and has historically always been, a social worker on the hospital's psychogeriatric outreach team. As such, it was important to the facilitator that social work values such as accepting and valuing the client and building relationships by adopting a non-judgmental stance were upheld from the perspectives of group members.²¹ Questions were formulated to elicit whether this was the case. Caregivers were asked how much they felt engaged in group discussion and how much they benefitted from attending the group. They were also asked how likely they would recommend the group to others. Responses were positive overall. All respondents (100%) either "strongly agreed" (87.5%) or "agreed" (12.5%) that they felt supported by the group facilitators. Seven respondents (87.5%) "strongly agreed" (62.5%) or "agreed" (25%) that they felt engaged in group discussion. One respondent (12.5%) felt "neutral" about feeling engaged in the discussion. This could be a reflection of some comments made by respondents that some members seemed to dominate discussion and more equal participation would be helpful. The same respondent (12.5%) selected "neutral" about not feeling judged at group. It's not clear to authors whether being "neutral"

Figure 1. Group Sessions Attended in 2017 by Percentage (%) (y) of Responses and Number of Sessions (x) **Figure 2. Caregiver Relationship by Percentage (%) of Responses (y) and Relationship Type (x)**

about feeling engaged in discussion is connected with being “neutral” about not feeling judged. The other seven respondents (87.5%) “strongly agreed” that they did not feel judged by the group. All respondents “strongly agreed” (87.5%) or “agreed” (12.5%) that they felt safe to share their thoughts. All respondents “strongly agreed” (75%) or “agreed” (25%) that they felt benefited from attending group. All respondents “strongly agreed”

(87.5%) or “agreed” (12.5%) with the statement that they would recommend the group to others (Figure 3).

Group members were invited to give suggestions about how the group could be improved. Respondents requested more direction from the facilitator and more opportunity for all members to participate equally: “Although difficult to control, to promote more equal participation from all attendees. I have not attended many sessions but have

Figure 3: Participants' Experience of Attending Group by Percentage of Responses (y) and Response Scale (x)

found some few people tend to dominate the discussion.” Equal opportunity to speak and share in group is needed for all participants to benefit from coming to group.¹ Three respondents (37.5%) observed that certain group members tended to dominate discussion, which may have impacted their participation and experience of the group. More direction and intervention from the facilitator were suggested. One respondent provided a suggestion on how to help all group members participate more equally: “It will be more helpful if everyone in the group gives a brief update about their loved one’s condition without going into deep personal issues to give a chance for everyone to have a turn.”

Feedback from the group on occasional guest speakers was predominantly positive: “I think it’s of great benefit to have a guest/speaker, as this gives us more insight and understanding of dementia which helps us to deal with our loved ones.” One respondent said they felt “neutral” about the guest speakers. Another respondent commented that guest speakers were “[e]xcellent. All professionals with first-hand daily experience with people with dementia. All caring, understanding, very experienced and knowledgeable.”

Discussion

Respondents appeared to be enthusiastic about the group’s relevance and helpfulness overall. The most prevailing theme that emerged from the survey responses was group members’ appreciation for the opportunity to meet with one another to discuss relevant issues and gain support

from the facilitator and each other. The ability to learn and get support from the group was identified as the most helpful aspect of attending the group from almost all respondents. This was mentioned on a practical level as illustrated by the previously discussed positive feedback about the guest speakers. Group members also learned from each other. More than one respondent commented that they learned from hearing about others’ experiences: “The support from group members, learning from others; behavior management, available resources in the community and how to navigate/an understanding of the health system.”

Support from the group on an emotional level was also highlighted by respondents. Feedback indicated the group provided a safe, supportive, non-judgmental forum to share their experiences and learn from others. :

Listening to other people's experiences and how they dealt (sic) with them as well as I got lots of encouragement and was never judged for my reactions when I was overwhelmed. Thank you for making this wonderful group possible. I was not sure about attending a support group until I discovered this one.

Some members of the group made connections that extended beyond the monthly meetings based on shared emotions and understanding of what it’s like to care for someone with dementia. One respondent commented; “Sympathy and understanding, shared experience, well developed sense of humour produced by the horror of living with dementia. Fellow attendees are now good friends.” Positive feedback focused on the mutual support and educational aspects of attending the group as being

most beneficial as reported in the literature.^{14,15} Results from this project are also supported by publicly available summaries on the value of caregiver groups from the perspectives of caregivers.²²

For the most part, the group appreciated the occasional guest speakers and wanted the opportunity to continue to hear more from “experts.. Participants used the term “experts” to refer to healthcare professionals who work in the field of dementia, such as speech-language pathologists, social workers, and physicians, as well as dementia researchers. Continued visits from guest speakers were requested. One respondent requested a future guest speaker who could speak about medical-legal issues such as powers of attorney.

Limitations

The number of respondents (8 total) was small, presenting limits to the generalizability of evaluation results. The questionnaire that was used was not a validated tool which could be considered a limitation of the evaluation. The use of validated tools such as the Burden Scale for Family Caregivers²³ to appraise the impact of the caregiver group may be incorporated into future evaluations. However, the questionnaire used did allow for respondents to provide rich description of their experience of attending the group which supported the project's aim of quality improvement. A small minority of the group did not have email/internet access, presenting another limitation.

Conclusions and Implications for Future Practice

Time is precious to dementia caregivers, and feeling supported is vital to being able to continue to carry out the caregiver role. The Community Psychiatric Services for the Elderly dementia caregiver support group is meeting its purpose according to valuable feedback from group participants gained over the course of this project. However, there is room for improvement. Key learnings and recommendations for future practice include:

1. The importance of democratic participation during group sessions is crucial. Effective intervention from group facilitators is needed to foster equal opportunity for members to participate.
2. Providing a safe place for caregivers to talk about their experiences and learn from others, free of feeling judged is essential to meaningful support group functioning.
3. Access to “experts” in the form of guest speakers at the group was highly valued by survey responders. Dementia caregiver groups benefit from including guest speakers who present relevant topics and stimulate helpful discussions.
4. Evaluating the quality of caregiver groups is a very valuable and necessary exercise. Evaluations should be a regular practice for group facilitators.

COVID-19 and Beyond

Since this evaluation was completed the global COVID-19 pandemic has had a significant impact on care for individuals with dementia who live either at home or in institutions and has amplified the burden of caregiving for their families and friends. Visits for individuals living in long term care have been restricted or altered and sometimes terminated depending on infection rates in the community or outbreaks in facilities. In Canada, long term care residents, especially those with dementia, have suffered the highest rate of COVID deaths which has been disproportionate compared with other Western countries.²⁴ These factors have resulted in heightened distress for family caregivers who often feel helpless given the unique circumstances they are facing and whose experiences have been shared through popular media.²⁵ For family caregivers who are caring for their person with dementia at home, the pandemic has altered or halted many of the services that have helped them cope. For instance, there have been closures of adult day programmes which provided socialization, activities and meals for individuals with dementia and needed respite for their caregivers. Caregivers have reported more stress and isolation.²⁶ There is more need than ever for meaningful help for dementia caregivers, such as support groups.

COVID-19 is transforming healthcare. Several caregiver support options that were in-person pre-pandemic are now offered virtually, either over the phone or using video conferencing software. The format of the CPSE's dementia caregiver support group changed as this manuscript was being submitted for consideration of publication from meeting in-person to virtual meetings due to the COVID-19 pandemic. There are benefits and potential draw backs of online caregiver groups.¹⁷ Whether the transition to virtual caregiver support was smooth or has been meaningful remains to be seen. It will be interesting to see how this change will be reflected in the quality of the service provided by the group from the perspectives of caregivers. Additionally, the full impact of the digital divide on older caregivers who have difficulty participating on this new forum or caregivers who cannot afford the technology is not yet known.

Preliminarily, informal feedback from group members sought by the facilitator has resulted in tangible changes to the group. In addition to the change in forum from in-person to virtual, the frequency and duration of the group has changed. It is now occurring twice a month for 75 minutes, as a result of reports of increased loneliness and isolation from group members and requests to meet more often because of the fast-changing world the pandemic has catalyzed. Since these changes have been made, group attendance has increased. However, there have been barriers to participation identified, such as technical difficulties and lack of privacy to participate from home. These barriers echo what we have seen in the literature.^{16,17}

The role of group facilitator has evolved and more time is required to plan the group, to try to mitigate barriers to participation, and to meet the need for caregivers to have more opportunities to participate. Members continue to provide helpful suggestions. Authors remain enthusiastic about receiving ongoing feedback from caregivers who attend the group whether in-person or virtually and look forward to sharing their perspectives in the future. Their feedback will contribute to our understanding of the extent of the impact of COVID-19 on caregiver support services, including caregiver support groups.

References

1. Toseland RW, Rivas RF. *An introduction to group work practice*. 5th ed. Boston: Pearson Education Inc.; c2005.
2. Bergerum C, Thor J, Josefsson K, Wolmesjö M. How might patient involvement in healthcare quality improvement efforts work-A realist literature review. *Health Expect*. 2019;22(5):952–964. doi:10.1111/hex.12900
3. Turner, H. Concepts for effective facilitation of open groups. *Social Work with Groups*. 2011;34:246-256. doi: 10.1080/01609513.2011.558822.
4. Diagnostic and Statistical Manual of Mental Disorders: DSM-5. 5th ed., American Psychiatric Association, 2013. DSM-V, doi-org.db29.lincweb.org/10.1176/appi.
5. Dementia in Canada, including Alzheimer's disease: highlights from the Canadian chronic disease surveillance system. Public Health Agency of Canada. <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-highlights-canadian-chronic-disease-surveillance.html>. Published 2017. Accessed October 15, 2020.
6. Smetanin P, Kobak P, Briante C, Stiff D, Sherman G, Ahmad S. *Rising tide: The impact of dementia in Ontario 2008 to 2038*. Alzheimer Society of Ontario & RiskAnalytica: Toronto, ON; c2009.
7. Developing Ontario's dementia strategy: a discussion paper. Ontario Ministry of Health and Long Term Care. https://files.ontario.ca/developing_ontarios_dementia_strategy_a_discussion_paper_2016-09-21.pdf. Published 2016. Accessed May 14, 2018.
8. A dementia strategy for Canada: together we aspire. Public Health Agency of Canada. <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy.html>. Published 2019. Accessed May 5, 2020.
9. Cuijpers P. Depressive disorders in caregivers of dementia patients: A systematic review. *Aging & Mental Health*. 2005;9(4):325-330. doi:10.1080/13607860500090078.
10. Känel RV, Mausbach BT, Patterson TL, et al. Increased Framingham Coronary Heart Disease Risk Score in Dementia Caregivers Relative to Non-Caregiving Controls. *Gerontology*. 2008;54(3):131-137. doi:10.1159/000113649.
11. Pinquart M, Sörensen S. Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging*. 2011;26(1):1-14. doi:10.1037/a0021863.
12. Schulz R, Beach SR. Caregiving as a Risk Factor for Mortality. *Jama*. 1999;282(23):2215. doi:10.1001/jama.282.23.2215.
13. Worrall H, Schweizer R, Marks E, Yuan L, Lloyd C, Ramjan R. The effectiveness of support groups: a literature review. *Mental Health and Social Inclusion*. 2018;22 (2):85-93. doi: 10.1108/MHSI-12-2017-0055
14. Chien L-Y, Chu H, Guo J-L, et al. Caregiver support groups in patients with dementia: a meta-analysis. *International Journal of Geriatric Psychiatry*. 2011;26(10):1089-1098. doi:10.1002/gps.2660.
15. Brodaty H, Green A, Koschera A. Meta-Analysis of Psychosocial Interventions for Caregivers of People with Dementia. *Journal of the American Geriatrics Society*. 2003;51(5):657-664. doi:10.1034/j.1600-0579.2003.00210.x.
16. Brodaty H, Thomson C, Thompson C, Fine M. Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry*. 2005;20(6):537-546. doi:10.1002/gps.1322.
17. Oconnor M-F, Arizmendi BJ, Kaszniak AW. Virtually supportive: A feasibility pilot study of an online support group for dementia caregivers in a 3D virtual environment. *Journal of Aging Studies*. 2014;30:87-93. doi:10.1016/j.jaging.2014.03.001.
18. Tourigny M, Hebert, M. Comparison of open versus closed group interventions for sexually abused adolescent girls. *Violence and Victims*. 2007;22(3): 334–349.
19. Sunnybrook Health Sciences Centre. *Ethics review – self-assessment tool (ER-SAT)*. 2014.
20. Ogrinc G, Davies L, Goodman D, Batalden P, Davidoff F, Stevens D. SQUIRE 2.0 (Standards for Quality Improvement Reporting Excellence): Revised Publication Guidelines from a Detailed Consensus Process. *The Joint Commission Journal on Quality and Patient Safety*. 2015;41(10). doi:10.1016/s1553-7250(15)41062-1.
21. Boggs, M. *Social work practice: concepts, processes, & interviewing*. New York: Columbia University Press; c2006.
22. Caregiver support groups: making a meaningful impact. Alzheimer's Society of British Columbia. <https://alzheimer.ca/sites/default/files/files/bc/programs-and-services/2014-08-29-csg-program-evaluation-summary-report.pdf>. Published 2014). Accessed May 14, 2018.

23. Gräsel E, Chiu T, & Oliver R. *Development and validation of the Burden Scale for Family Caregivers (BSFC)*. Toronto, ON: Comprehensive Rehabilitation and Mental Health Services; c2003.
24. Hsu AT, Lane N, Sinha SK, et al. Impact of COVID-19 on Residents of Canada's Long-Term Care Homes – Ongoing Challenges and Policy Responses. International Long-Term Care Policy Network; 2020:17. https://ltccovid.org/wp-content/uploads/2020/06/LTCcovid-country-reports_Canada_June-4-2020.pdf. Accessed November 11, 2020.
25. McBride J. “Houses of horror.” *Toronto Life*, 11 November 2020, <https://torontolife.com/city/how-ontarios-long-term-care-homes-became-houses-of-horror/>. Accessed November 11, 2020.
26. Bocknek G. “My husband has dementia, and I feel as trapped as he does”. *The Globe & Mail*, 25 October 2020, <https://www.theglobeandmail.com/life/first-person/article-my-husband-has-dementia-and-i-feel-as-trapped-as-he-does/>. Accessed November 11, 2020

Appendix A. Evaluation

Caregiver Support Group Evaluation

This is an anonymous questionnaire. Thank you in advance for taking the time to answer the following questions.

1. I attended approximately the following number of group sessions this year (2017-2018)
 - a) 1-2 sessions
 - b) 3-5 sessions
 - c) 6-8 sessions
 - d) 10-12 sessions

2. I am a caregiver /care partner for a:
 - a) partner/spouse
 - b) sibling
 - c) parent
 - d) other

3. If you selected “other” to answer Question 2, please describe your relationship with the person with dementia.

4. Please select the response that best matches how you felt after attending group.

a) I felt supported by the group facilitators.			
Strongly agree	Agree	Neutral	Disagree Strongly Disagree
b) I felt engaged in the discussion.			
Strongly agree	Agree	Neutral	Disagree Strongly Disagree
c) I felt safe to share my thoughts in group.			
Strongly agree	Agree	Neutral	Disagree Strongly Disagree
d) I did not feel judged in group.			
Strongly agree	Agree	Neutral	Disagree Strongly Disagree
e) I felt like I benefited from attending this group.			
Strongly agree	Agree	Neutral	Disagree Strongly Disagree
f) I would recommend this group to other caregivers/ care partners.			
Strongly agree	Agree	Neutral	Disagree Strongly Disagree

5. What is your feedback on the occasional guest attendees/speakers we have at group?

6. What have you found helpful from attending the group?

7. What would improve your experience/increase the benefit of attending the group for you?

8. Do you have any other comments, questions, or concerns?