

Support Groups for Family Caregivers of Elders with Dementia Evaluation Study

Ayelet-Berg Warman

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Related Myers–JDC–Brookdale Institute Publications

Berg-Warman, A., Brodsky, J., Laron, M., Spalter, T., and Resnizky, S. (2016). *Support Groups for Family Caregivers of Elders with Disabilities: Evaluation Study*. Published by the National Insurance Institute, Fund for the Development of Long-Term Care Services (Hebrew only).

Bentur, N., Laron, M., Palach, A., Sternberg, S., Radomyslsky, Z., Vardi, D. and Ben Zion, I. (2016). *Quality of Care for Dementia Patients, their Unmet Needs and those of their Families*. RR-733-16 (Hebrew).

Bentur, N., Sternberg, S. and Shuldiner, J. (2015). *Assessing the Quality of End-of-Life Care for Older Persons with Advanced Dementia Living in the Community*. RR-652-15 (Hebrew).

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Abstract

Background

The project of support groups for family caregivers reflects growing recognition of the important role played by caregivers of elderly family members, the implications of caregiving for them (e.g., the burden of care and adverse effects on their quality of life), and the perception that, as a target population, they should have special programs developed for them. The project began in April 2015. Over 30 months of implementation, 74 support groups were founded, numbering 1,050 participants. The project was implemented and funded by the National Insurance Institute and Emda, the association for patients with Alzheimer's, dementia and similar diseases in Israel, in partnership with local authorities and the Ministry of Labor and Social Affairs and Social Services. The groups aimed to assist family caregivers of elders with dementia by providing knowledge and support. The project followed on from a previous initiative, in 2011-13.

This report presents the findings of the evaluation study conducted by the Myers-JDC-Brookdale Institute (MJB). MJB studied both the earlier initiative and the current project from its establishment.

Goal

The main goal of the study was to examine the outcomes of three implementation models over time: 1. Caregivers who participated in a closed support group only; 2. Caregivers who participated in a closed support group and afterwards continued to an open-ended group (monthly meetings, with no time limitation, participants may attend as many meetings as they like); 3. Caregivers who participated in open-ended groups only.

Method

The interviews with group participants were conducted in two waves. The first took place some six weeks after the end of the group meetings and included telephone interviews with 309 caregivers who had participated in closed groups, and an additional 52 participants of open-ended groups. The second wave took place about six months after the first – 222 participants of the closed groups were re-interviewed, 61 of whom had continued with an open-ended group, and 137 who had not. In addition, repeat interviews were conducted with another 36 caregivers who had participated in open-ended groups only.

Findings

Most of the participants were women and adult offspring who cared for elders of limited functioning and mental capacity. A considerable proportion of the participants, particularly spouses and daughters, reported a sense of burden. Satisfaction with the way that the groups were conducted was very high (96% of the participants were satisfied or very satisfied). Regarding the outcomes, the groups' main contribution was reported as emotional support (average score 4.15 out of 5, SD 1.059). As was true of the findings of the earlier initiative, the meetings enabled the participants to receive practical advice and to share their difficulties with other caregivers and with professionals. The project helped improve the caregivers' ability to cope, to make care-related decisions, and to set priorities including in their personal lives. Moreover, improved caregiving was also reflected in better interpersonal relations with the elders, and in the procurement of more assistance for all aspects of care. Another aspect found expression in personal empowerment – the participants' ability to better look after their own physical and mental health, broaden their social contacts, and leave more time for recreation.

Eight months after the end of the meetings, the participants still felt the benefits to their eldercare and their own personal lives. In the nature of things, the sense of contribution decreased over time; this applied to the easement of the burden (a decline from 3.08 to 2.67, $p=0.001$), retention of acquaintances among group members (a decline from 4.40 to 4.04, $p=0.001$), and maintenance of the ability to cope with the inherent difficulties of care (a decline from 3.95 to 3.70, $p=0.001$). We found that the group contribution was retained in the provision of knowledge on the illness, the ability to cope with one's negative emotions, and the activities undertaken by the caregivers for themselves. The contribution was longer lasting among the elders' spouses than their adult offspring.

A comparison of the contribution of participation to caregivers continuing in an open-ended group (model 2) with that of participants not continuing after the closed group (model 1) showed that the former rated the contribution higher for the following aspects: The easement of the burden, respites, and the acquisition of skills and tools of care to cope with the difficulties involved (versus participants who did not continue). On the other hand, as far as self-care was concerned, the higher contribution was perceived among participants who did not continue to an open-ended group.

Furthermore, the contribution perceived by participants of the closed groups (models 1 and 2) was similar to that of the participants of the open-ended groups only (model 3).

Group participation engendered change in the caregivers' lives. We examined the extent to which the changes reported six weeks after the end of the meetings were sustained also six months later. The most prominent changes sustained in the six months between the two interviews were: A decrease in the improved relations with elders that had been cited in the first wave – from 42% to 37%; increased consideration for the elder's opinion (from 28% to 33%, $p=0.012$); and a higher rate of participants reported greater assistance from a foreign worker or other family members. The rates of improvement were similar for nearly all the aspects examined, both in the closed group (model 1) and in the continuing group (model 2).

The first wave of interviews in the project, conducted some six weeks after the end of the support groups, provided an opportunity for a quasi-“repeat experiment” regarding the outcomes of the previous support-group project (2011-13). Both studies, conducted independently, yielded a similar contribution, which corroborates the findings as it were.

Recommendations

Support groups for family caregivers of elders with dementia are an important service that help the former cope with the burden of care over time, as regards three main dimensions: Emotional support, assistance in the provision of tools and skills of care, and self-care.

If we were to recommend the preferred model of the three – the dimensions of respites and easement of the burden of care appear more advantageously in the continuing model (open-ended, model 2) than the closed model only (model 1).

In a comparison of the participants of the closed groups (models 1 and 2) with the open-ended group (model 3) – we found that the latter's perception of the contribution in its various aspects, and the changes ensuing from participation over time, were similar in most aspects to those reported in the closed groups. In light of the fact that open-ended groups require fewer resources and a smaller commitment from participants, this group, ostensibly, would be the preferred model. However, in developing the service, different target populations should be considered. Offspring and spouses tend more to participate in open-ended groups, which can stretch over time, whereas adult offspring tend more to participate in closed groups with a finite number of meetings, more suited to them. This conclusion should be regarded with caution, given the small number of participants interviewed from the open-ended group.

To conclude, the establishment of a modular modus operandi, as was the form used in this project, would facilitate choice and flexibility in the provision of the service and its adaptability to target populations; offspring may choose the model of the closed group to suit their preferences. Spouses, on the other hand, may enjoy the continuing activity of an open-ended group over time, benefiting from ongoing support apace with the progressive stages of the illness.

The study's unique contribution is its examination of the impact over time of support groups on family caregivers of elders with dementia. The findings can help policymakers and service developers devise services for this target population.