



Myers JDC
Brookdale

Helpline and Home Visit Program for People with Dementia and Their Families: A Formative Evaluation Study

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Abstract

Background

Family members caring for people with dementia have a key role to play, given the latter's high dependence on their carers and the comorbidities attendant on that condition. The Israeli Medical Center for Alzheimer's in Ramat Gan was selected by the National Insurance Institute to operate a helpline for senior citizens with dementia who live in the community and for their family members. The helpline is designed to provide response in routine and emergency situations when the family needs help in coping with illness symptoms. The helpline is unique in four respects: it is operated by professionals; it provides home visits; it is available 24/7; and it responds also to the patients themselves, rather than only to their caregivers.

Objective

The Myers-JDC-Brookdale Institute has conducted a formative evaluation study to assess the helpline's ability to reach out and contribute to the relevant target population. Namely, to assess the degree to which it meets the needs of the patients and their families in routine and emergency situations and help them cope with the illness symptoms.

Methods

The research design includes a mixture of quantitative and qualitative methods. It includes semi-structured in-depth interviews with the helpline staff, phone interviews with callers, and analysis of administrative data on the helpline's operations.

Results

- During its first two years, the helpline responded to 6,752 calls (of which about one third were identified) and held some 400 home visits. Three percent of the callers called on their own behalf. Most of the identified callers were family caregivers: children calling for their parents (58%), partners (22%) or other relatives. Most family members reported that the burden they faced in coping with the patients was heavy. Most calls had to do with the progression of the illness and the difficulty of coping with the constant deterioration in the patient's condition (including the behavior disorders attendant on the illness).

- Only a few calls were made at night or on weekends. In other words, most were not emergency calls.
- The examination of the helpline's benefits to the callers indicated that two-thirds (65%) received replies to their questions; more than half (56%) reported feeling supported by talking to the helpline representative; 41% felt the talk helped them cope with the patient's illness and its treatment; and 29% felt it helped them locate services to help them with the treatment.
- Analysis of the benefits to the callers by type of relation indicated that those calling on behalf of their parents felt that they benefitted more than those calling on behalf of their spouses. A periodic analysis indicated that the benefit to callers during the COVID-19 pandemic was higher on most indicators mentioned above compared to previous periods. Sixty percent said they would call the helpline should they have additional questions in the future.
- Those calling on their own behalf did so due to the cognitive deterioration that concerned them and the resulting sense of helplessness. They were less satisfied and felt that the conversation contributed less to them.

Discussion and Recommendations

- **Meeting the target population's needs:** The helpline reached the relevant target population of family members coping with heavy burden of caring for a person with dementia. Those calling the helpline on behalf of their parents were more satisfied and felt they benefitted more from the talk compared to those calling on behalf of their partners. **It is therefore recommended to examine how to improve the response to partners.** Perhaps a more accessible response or a longer conversation would ensure greater satisfaction and more perceived benefits. It is also evident that the home visits were particularly helpful for partners. The current structure of the service is not adjusted well enough to the patient population, and we therefore recommend that **the responses given to them be further refined.** Moreover, as in other programs designed for family carers, greater effort should be made to reach out to **unique populations**, including Arabs, ultra-Orthodox Jews and migrants from the former Soviet Union, as well as disadvantaged populations more generally.
- Given that dementia is characterized by gradual deterioration and as the family members have expressed this need, **it is important to structure the continuity of contact between the helpline and the callers.**
- **The helpline's uniqueness:** Upon its establishment, the helpline had four unique features: being staffed by professionals, 24/7 service, home visits, and response to the patients themselves. The findings suggest the need to **provide more home visits and to reduce nighttime availability**, thereby taking more effective advantage of the helpline's strengths and the potential help provided by home visits. The continued response to the patients themselves need to be reexamined.

Summary

Background

Family members caring for people with dementia have a key role to play, given the latter's high dependence on their caregivers and the comorbidities attendant on that condition. The gradual aging of the population and the emerging policy of aging in place have increased the burden of care on informal caregivers and imposed multiple demands on family members, who struggle to cope with the dynamic needs involved in home care for a person with a progressive illness such as dementia. These tasks contribute to growing levels of physical, psychosocial and economic burden on them (Schulz & Martire, 2004).

Phone support is one way of providing informal caregivers with information, training, psychosocial counselling, problem-solving coaching and coping strategies, and is considered cost-effective. In April 2015, the Nursing Fund of the National Insurance Institute (NII) published a call for the establishment and operation of a helpline for senior citizens with dementia living in the community and their family members. A helpline program can help family caregivers but can also provide support for people with dementia or suspected dementia.

The Israeli Medical Center for Alzheimer's in Ramat Gan was selected by the NII to operate the helpline. The helpline is designed to provide response in routine and emergency situations when the family needs help in coping with illness symptoms. The program includes the option for home visits by a social worker, a registered nurse and in special cases a doctor as well. These visits include an evaluation of the person's functioning and home environment and its suitability for coping with the illness, as well as of the family members' needs. The helpline and home visit services are provided free of charge. With the support of the NII's Nursing Fund, the helpline began operating in May 2018.

The Myers-JDC-Brookdale Institute was selected in a tender by the NII to conduct a formative evaluation study of the helpline. The study is designed to improve the responses and solutions it offers to the target audience and refining them to provide optimal support for people with dementia in Israel.

Objective

The study is designed to accompany the program for establishing and operating a helpline for people with Alzheimer's and dementia and their family members, and to assess its ability to reach out to the relevant target audience and the degree to which it meets the needs of the patients and their families in routine and emergency situations.

Methods

The research design includes a mixture of quantitative and qualitative methods. It relies, among others, on the following sources of information:

1. Semi-structured in-depth interviews with the helpline staff during the first months of preparations and operations (September-December 2018)
2. Phone interviews with callers (October 2018-February 2019; January-May 2020)
3. Administrative data on the helpline's operations

Main Findings

- During its first two years (May 2018-May 2020), the helpline responded to 6,752 calls (2,992 identifiable clients) and held some 400 home visits.
- Out of the identified callers, 3% called on their own behalf and the rest on behalf of another. Out of the latter category, 58% called for their parents, 22% for their partners, 15% for other relatives, and 5% were formal caregivers calling on behalf of their patients.
- Most callers were Israeli natives with higher education, and most were able to meet the monthly expenses of their household. Most of them reached the helpline after viewing ads on the internet and Facebook.
- Most (77%) of the callers on behalf of family members reported that the burden of caring for them was "heavy" or "very heavy" – a high rate compared to what is known from previous studies on the population of family members caring for a person with dementia.
- Most calls had to do with the progression of the illness and the difficulty of coping with the constant deterioration in the patient's condition (including the conduct disorders attendant on the illness).
- The center offered various kinds of help: 27% of callers received information (for example, suggestion to submit a request to the NII given a deterioration in the patient's condition); 27% were offered a home visit; and 23% were coached on how to cope with the patient's condition (such as suggesting getting out of the house more often). However, 15% claimed calling the helpline did not help them.
- Most of the calls took place during daytime hours and on weekdays. Only a few calls were made at night or on weekends. In other words, most were not emergency calls. Almost all conversations were held in Hebrew.
- A large majority (92%) were satisfied with the courteousness of the responders, but there was less satisfaction (75%) with their professionalism. Analysis by type of relation indicated that those calling on behalf of their parents were satisfied on all indicators more than were those calling on behalf of their partners.

- The examination of the helpline's perceived benefits to the callers indicated that two-thirds (65%) received replies to their questions (to a high or very high degree); more than half (56%) reported feeling supported by talking to the helpline representative; 41% felt the talk helped them cope with the illness and its treatment; and 29% felt it helped them locate services to help them with the treatment (to a high or very high degree).
- Analysis of the benefits to the callers by type of relation indicated that those calling on behalf of their parents felt that they benefitted more than those calling on behalf of their partners. A periodic analysis indicated that the benefit to callers during the COVID-19 pandemic was higher compared to previous periods.
- Up to the COVID-19 outbreak, home visits were face-to-face. In March 2020, the help center offered virtual home visits. The satisfaction with home visits of both types was very high, but most clients who received a virtual home visits indicated that they would like a face-to-face visit.
- Seventy-one percent of family members said they would recommend the helpline to a friend coping with a similar situation; 60% said they would call the helpline once again should they have additional questions.
- Those calling on their own behalf were mostly Jewish men (mean age = 73; SD = 7.8), with high-school and lower education. Most called due to the cognitive deterioration that concerned them and the resulting sense of helplessness. Most reached the helpline following a newspaper ad.
- Compared to those calling on behalf of family members, those calling on their own behalf were less satisfied and felt that the conversation contributed less to them. Less than half (46%) said they would call again if need be, and only 37% said they would recommend the helpline to a friend.

Conclusion and Recommendations

- **The caller population experiences a very heavy burden of care:** 77% of the family caregivers reported heavy burden of care. In other words, the helpline reached the relevant target audience of family members distressed due to the burden of caring for a person with dementia. Two thirds (65%) of them felt they received answers to their questions to a high or very high degree.
- **Making information and solutions accessible to the callers:** Those calling the helpline on behalf of their parents were more satisfied and felt they benefitted more from the talk compared to those calling on behalf of their partners. This phenomenon frequently arises in other evaluation studies of programs for family caregivers. **It is therefore recommended to examine how to improve the response to partners.** Perhaps a more accessible response or a longer conversation would lead to greater satisfaction and more perceived benefits. Note that in the home visits there was no satisfaction gap between patients' partners and children. In addition, callers who failed to define the reason for their call reported receiving some kind of solution to a lesser degree than those able to define it. **Accordingly, the helpline should provided a better tailored**

response to those who find it difficult to pinpoint their needs out of distress and confusion. It is important to prepare for such cases in advance.

- **The patients** In most cases, patients call the helpline due to cognitive deterioration that concerns and frightens them. This population faces particularly complex challenges that make it difficult to provide a satisfactory solution. Indeed, many of them reported not receiving a response suitable to their problem. Currently, the response is not adjusted to the patient population, **and the solutions offered to them should be better tailored to their presenting problems.**
- **Repeat calls and long-term intervention:** 51% of the calls to the helpline were made as part of an intervention that involved more than one phone call. More than half (58%) of the interviewees showed interest in proactive and ongoing support by a help center professional. Given that dementia is characterized by long-term deterioration, it is doubtful whether all the tools offered by the help center may be exhausted in a single phone call. Therefore, it may be that the help center's follow-up procedure provides clients with the support, security and counselling necessary for coping with more complex problems. **It is therefore important that continuity of contact be established.** It also appears that the home visits have been particularly helpful for partners calling the helpline, and their importance for this target audience should be highlighted.
- **24/7 operations:** Since the huge majority of calls are received during regular working hours, the need for operating the help center 24/7 is questionable. **The cost-effectiveness of limiting helpline hours should be examined.**
- **Reaching out to alternative audiences:** As in other programs for family caregivers, unique populations, including Arabs, ultra-Orthodox Jews and migrants from the former Soviet Union, use the helpline services less than the general population, despite the fact that it offers services in several languages and is prepared to serve these very populations. **The reaching out strategy should therefore be better tailored to these populations. Efforts should also be made to reach other marginalized populations such as people with low functioning and low socioeconomic status, as well as people without access to a computer or the internet, and offer a dedicated response.**
- **The helpline's uniqueness:** Upon its establishment, the helpline was unique in four respects: being staffed by professionals, 24/7 service, home visits, and response to the patients themselves. After three years, the helpline still provides response by experienced team members. However, most calls are received from family members during regular working hours. We therefore **recommend increasing the number of home visits at the expense of reducing nighttime activity hours**, thereby taking more effective advantage of the help center's strengths and the potential helpfulness of home visits.