RESEARCH REPORT

Assessing the Quality of End-of-Life Care for Older Persons with Advanced Dementia Living in the Community

Netta Bentur ♦ Shelley Sternberg ♦ Jennifer Shuldiner

The study was funded with the assistance of the Helen Daniels Bader Fund of Bader Philanthropies of Milwaukee, Wisconsin
Assessing the Quality of End-of-Life Care for Older Persons with Advanced Dementia Living in the Community

Netta Bentur\textsuperscript{1}  Shelley Sternberg\textsuperscript{2}  Jennifer Shuldiner\textsuperscript{1}

The study was funded with the assistance of the Helen Daniels Bader Fund of Bader Philanthropies of Milwaukee, Wisconsin

\textsuperscript{1} Myers-JDC-Brookdale Institute  \\
\textsuperscript{2} Maccabi Health Services

Jerusalem  May 2015
Related Myers-JDC-Brookdale Institute Publications


To order publications, please contact the Myers-JDC-Brookdale Institute, P.O.B. 3886, Jerusalem, 91037; Tel: (02) 655-7400; Fax: (02) 561-2391; E-mail: brook@jdc.org.il

Reports and English summaries are also available on the Institute website: [www.jdc.org.il/brookdale](http://www.jdc.org.il/brookdale)
Executive Summary

1. Introduction
Dementia is one of the most prevalent and devastating illnesses affecting older persons. It is the sixth most common cause of death in Western countries. According to a 2002 Israeli national survey, approximately 16% of community-dwelling older persons were at the time living with dementia. Five percent of older persons have advanced dementia and are unable to perform any self-care functions such as eating without assistance (98%) and often suffer from communication and behavioral problems.

Caring for older persons with advanced dementia (OPsWAD) is very challenging for members of their families and for the formal health and social service systems.

Numerous studies around the world have found that OPsWAD and their primary caregivers have substantial unmet needs. They advocate a palliative care approach that focuses on the quality of end-of-life care and involves families in the provision of care. However, to date, hospice and palliative-care programs in Israel have hardly addressed the needs of OPsWAD.

Until now, no comprehensive study has been conducted in Israel that can provide information about the quality of end-of-life care of OPsWAD living in the community and serve as the basis for addressing the multiple challenges of caring for this population.

2. Study Goals
1. To examine the quality of care that the health services provide to OPsWAD at the end of life, including symptom management and comfort in dying.
2. To examine the unmet needs of family members caring for OPsWAD in the community, the burden of care on these families, their satisfaction with the care provided by the health services to OPsWAD at the end of life.
3. To examine the extent of advance care planning (ACP) for end-of-life situations and situations in which the OPsWAD are unable to express what they want.

3. Study Design
The patients were identified from a list of members of one of the health plans who had died in 2012 and from the patient roster of the homecare program in the same health plan. Advanced dementia was defined as stage 6-7 on the Global Deterioration Scale. Interviews were held with 117 family caregivers, 65 of whom were caring for an OPsWAD living at home and 52 of whom had cared for an OPsWAD who had died in the community in the previous 3-6 months. No differences were found between the demographic and health characteristics of those still living and those who had died.
Since the OPsWAD themselves were unable to communicate, and in an attempt to learn about the needs of their families, information was collected in face-to-face interviews with members of their families using a closed structured questionnaire. The questionnaire included three instruments developed by Volicer et al.\(^1\) specifically used to measure and assess the quality of care of OPsWAD. The three instruments are the Symptom Management at the end of life (SM-EOLD) scale, measuring the frequency of symptoms occurring in the last 90 days; the Comfort Assessment in Dying (CAD-EOLD) scale, measuring physical distress, emotional symptoms and well-being during the last 7 days of life; and the caregiver’s satisfaction with care at the end of life (SWC-EOLD). These measures have been used extensively in western countries as standard instruments to examine the quality of care at the end of life for OPsWAD. Secondary outcome measures included caregiver burden (using Zarit Burden Interview – ZBI), and bereavement (using the Revised Grief Experience Inventory).

4. Findings
4.1 Health Status
- 65% of the OPsWAD were women. Their average age was 87; their average education was 11 years. They had suffered dementia for 6.5 years on average and the advanced stage had lasted on average 3 years.
- About 28% of OPsWAD used feeding tubes (16% nasogastric and 12% PEG), 58% received medication for behavioral control, 36% suffered pain daily, 36% suffered from pressure sores, 30% had frequent diarrhea and 24% had fallen at least once. These patients suffered on average from 4.4 additional illness that were not connected to dementia and took on average 5.5 medications.

4.2 Quality of Care Measures
- The mean symptom-management score was 29 (range 0-45, with higher scores indicating better symptom management).
  - 35% suffered from pain every day, 17% suffered several times a week, and 11% suffered once or twice a month.
  - 36% had cracks in their skin, that without treatment could turn into pressure sores, all of the time; 26% had cracks some of the time.
  - 32% suffered from depression all of the time and 25% had depression between several times a week and once a month.
  - 16% were agitated all of the time, 23% several times a week, and 17% sometimes.
- In order to improve the quality of symptom management, we identified, using a multivariate analysis, characteristics that, if addressed, will reduce the symptoms suffered by the OPsWAD. Improved symptom management was found to be associated with 4 variables:

fewer co-morbidities and longer duration of the illness among the OPsWAD and post-secondary education and not suffering from depression among the family caregivers. Evidently, higher education allows the family to develop knowledge and skills associated with caring as well as enlisting support from the system. Education is also associated with a higher income, which gives access to additional resources.

- The 52 bereaved primary family caregivers reported a mean comfort in dying assessment score of 31.3 points (range 14-42, with higher scores representing greater comfort close to death). In several areas, there was a higher rate of discomfort close to death: 73% suffered discomfort, 69% pain, 67% difficulty swallowing, and 55% shortness of breath. These high percentages also indicate deficiencies in the quality of care close to death.

- The primary family caregivers of the OPsWAD reported a mean satisfaction with care score of 31.8 (range 10-40, with higher scores indicating greater satisfaction). Particularly low satisfaction was found in two areas:
  - Information and knowledge: 31% said that they did not understand the patient’s condition. Furthermore, 64% indicated that they might have made different decisions had they been better informed
  - Care management: 86% did not always know which physician or nurse was responsible for caring for their relative and 58% felt that the relative needed better medical care at the end of life.

- In order to help the health care system to increase the satisfaction of the family caregivers, we identified, using a multivariate analysis, factors that could affect satisfaction. Three factors were found to contribute to a higher level of satisfaction: Better symptom management, the sense that the physicians are conversant with the patient’s problems and know how to care for a person with dementia and better team work, as perceived by the families. These findings underlines the importance of a good relationship with the care system and a sense within the family that the system is familiar with the patient’s problems and knows how to deal with them.

- The homecare team of the health plan cared for 86% of the OPsWAD in our study. Still, 28% used emergency room services during the day and 35% used emergency room services during the night, during their last year of life. This could indicate the some of the medical problems are not dealt with adequately in the community. It may also be related to the fact that the health care team is only available during the daytime.

- The mean score for the caregiver burden was 31.5 (range of 3-70, with higher scores indicating greater burden). On this scale 36% of caregivers were found to be very burdened and at risk for depression. The family members were also asked direct questions to assess the extent of burden due to caring for the patient. Seventy-four percent report that it was "heavy" or "very heavy." More family members who lived with the patient responded this way than those not living with the patient. Further, 43% of the caregivers reported that taking care of the OPsWAD had been a very heavy or heavy financial burden.
Only 20% had written advance care directives in the event that they would be unable to express their wishes for medical care and only 22% had signed a power of attorney with a lawyer. In addition, only 15% of the caregivers reported discussing advance care planning with a professional from the medical team. Nevertheless, despite the fact that insertion of a feeding tube requires that the patient, a guardian, or someone with power of attorney sign a consent form, only 46% of the family caregivers reported being consulted before the insertion of a feeding tube. It may be that the family members were given a short explanation and asked to sign the form, but that they did not fully understand the meaning of the permission they were giving and the medical staff did not check whether the family member had understood it. Similarly, 36% of the family caregivers stated that they probably would have made different decisions, had they been better informed before the procedure.

5. Implications of the Findings
OPsWAD living in the community and their caregivers were found to have substantial unmet needs. The findings indicate the need to formulate a comprehensive policy for the development of services for this population and to improve the quality of care provided. Among the important steps to consider:

- Training of healthcare teams in the community (physicians and nurses in community clinics and homecare units) on the special symptom-management needs of this population, particularly on the setting of goals of care, identification of pain and depression, skincare, and management of swallowing and eating problems
- Providing guidance to all staff members about the importance of giving explanations and involving family caregivers in the difficult decisions
- Improving knowledge about dementia among family caregivers by providing training and reducing the care burden through support programs for the families.
- Advising family members with the special difficult issues arising close to death such as eating and swallowing problems
- Defining criteria for provision of palliative care for OPsWAD, introducing incentives for home-hospice referral and expanding the availability of palliative care in the community. At the same time, providing incentives for round-the-clock care in medical homecare frameworks.
- Educating the general public through the dissemination of information about the importance of advance care planning and the need for guardianship.
- Expanding the implementation of palliative care principles.

The findings contribute to two current initiatives: The National Program for Treatment of Patients with Dementia, which is currently implemented by the Ministry of Health, and a new national program of palliative care for people with incurable illnesses, which is in its preliminary stages as a joint initiative of the Ministry of Health, JDC-ESHEL, and the Myers-JDC-Brookdale Institute.
Acknowledgments

Many people assisted in this study and we are grateful to all of them. Firstly, we would like to thank the management of Maccabi Healthcare Services for introducing us to this complex, sensitive and important area and allowing us to conduct the study. We are also grateful to the managers of the Maccabi homecare unit for their cooperation and assistance with the study.

We thank all those who read the earlier drafts of the report for their useful comments and insights and all the staff at the Myers-JDC-Brookdale Institute who assisted us during the study. Special thanks to Jack Habib, director of the Institute, for his insightful comments, which enhanced the report. Thanks also to the Fieldwork Unit for their energetic response to the demanding task of conducting the interviews. We thank Bilha Allon and Jenny Rosenfeld for editing the report and Leslie Klineman, who prepared it for publication.
Table of Contents

1. Introduction 1
2. Study Goals 2
3. Study Design 2
   3.1 Study Population 2
   3.2 Data Collection Methods and Instruments and Study Variables 3
4. Findings 6
   4.1 Characteristics of the OPsWAD 6
   4.2 Characteristics of the Family Members 9
   4.3 Quality of Care Measures 10
   4.4 Health Service Utilization 15
   4.5 Feelings of Depression and Burden among the Caregivers 16
   4.6 Feelings of Bereavement among the Family Caregivers 17
   4.7 Advance Care Plan 18
5. Policy Implications 19
Bibliography 21

List of Tables

Table 1: OPsWAD Characteristics 7
Table 2: Characteristics of the Caregivers 9
Table 3: Distribution of Symptom Management Index during Final Three Months 11
Table 4: Multivariate Linear Regression Analysis of Symptom Management 11
Table 5: Distribution of Comfort Assessment in Dying Index 12
Table 6: Distribution of Satisfaction with Dementia Care at the End of Life Index 14
Table 7: Multivariate Linear Regression Analysis of Patient Satisfaction 15
Table 8: Utilization of Health Services in Final Year 15
Table 9: Multivariate Linear Regression Analysis of Care Burden 17

List of Figures

Figure 1: Medical Characteristics of OPsWAD 8
Figure 2: Tools for Advance Care Planning 19