Effects of a Psychoeducational Program on Caregivers of Patients with Dementia

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Keywords

Dementia · Caregiver · Institutionalization ·
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Abstract

Background: The number of demented patients has increased significantly in recent years. The many challenges that dementia causes increase the stress of their caregivers and lead to shortening the time to institutionalization compared to the general population. A psychoeducational program for these accompanying persons was set up in Brussels. This type of program resulted in a 557-day delay in institutionalization in New York City. The objective of our study was to check whether our program also has such an impact, but also to see its potential effect on the psychobehavioral disorders of patients and the burden of caregivers. **Methods:** We recruited two groups without randomization: psychoeducated caregivers and caregivers interested in the program and contacted regularly (every 6 months) without having participated. They were all contacted by telephone and responded to the NCPI and Zarit Burden Scale (ZBS) questionnaires. **Results:** We could not demonstrate any significant impact, either on the institutionalization delay ($p = 0.960$), on

the frequency of psychobehavioral disorders in demented patients ($p > 0.05$), or on the burden of caregivers ($p = 0.403$). However, the survival rate among the demented patients with psychoeducated caregivers was significantly higher than that among the demented patients with nonpsychoeducated caregivers ($p < 0.001$). **Conclusions:** Our small-sample, nonrandomized study did not reveal any differences in institutionalization delay, caregiver burden, or perception of psychobehavioral disorders related to our psychoeducational program. A new study should be carried out on the impact of psychoeducation on the survival of demented patients, in view of our preliminary analyses.

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Introduction

Dementia is one of the major causes of disability and dependency and concerns around 46.8 million patients worldwide. This number is predicted to increase to over 130 million by 2050 [1]. Epidemiological studies carried out in Western Europe have shown the prevalence of dementia to increase with age and to be higher among women [2]. In 2011, the definition of dementia due to Alz-

Fig. 1. Study flowchart.

heimer disease (AD) required impairments in at least 2 neuropsychiatric or cognitive domains that are not better explained by nondegenerative or primary psychiatric disorders or systemic conditions [3]. In 2013, dementia syndrome has been revised into major neurocognitive disorder (MND) [4]. MND can be categorized into 5 main clinical etiologies: prion-related disorder, AD, frontotemporal dementia (FTD), Lewy body dementia (LBD), and vascular dementia [5].

Given the irreversibility of these diseases, the caregiver, defined as the person who provides most of the care of the patient affected by MND, is expected to assume increased responsibilities as the patient progressively deteriorates. The term “caregiver burden” is often used and was defined by Zarit et al. [6] as “the degree to which a carer’s emotional or physical health, social life or financial status has suffered as a result of caring for their relative.”

Many patients with MND are eventually institutionalized, at a rate of about 20% in the first year after diagnosis,

reaching 50% after 5 years, with the median delay ranging between 30 and 40 months [7]. Caregiver burden has been identified as a risk factor for nursing home placement [8–10].

Caregiver support, in the form of counseling programs and respite services, has proved effective in reducing or delaying the institutionalization of patients with MND, as well as improving the quality of life of the caregivers themselves [11–14]. In New York, Mittelman et al. [14] thus demonstrated the impact of their psychoeducational program (PP) on the spouses of patients with AD in delaying the need for institutionalization.

In this context, the memory clinic at our institution in Brussels has set up a PP for caregivers of patients with MND called “Pour mieux vivre avec la maladie d’Alzheimer” [15]. The aim of this study was to analyze the potential beneficial effects of our PP. The primary outcome was delay until institutionalization, whilst the secondary outcomes were the quality of life and degree of burden experienced by caregivers.

Subjects and Methods

This is a single-center study conducted at Hopital Erasme, Brussels, Belgium, using a case-control design with retrospective inclusion of caregivers of patients with MND.

Selection and Collected Data

The “case” group included participants who had attended our PP. The inclusion criteria for the case group were participation in the complete PP between February 2008 and September 2014, with agreement to undergo the telephone interview. The complete details about our PP are available in the online supplementary Appendices (see www.karger.com/doi/10.1159/000509169 for all online suppl. material.).

The “control” group included participants who were interested in our PP but had not participated in it. The inclusion criteria for the control group were recruitment and interest in the PP between July 2009 and September 2014, without participating before January 2015, with agreement to undergo the telephone interview (see the flowchart shown in Fig. 1).

The exclusion criteria for both groups were:

- Death of the patient with dementia (by the time of the phone interview)
- Institutionalization prior to the PP
- Institutionalization and/or death during the PP
- Refusal to undergo the telephone interview
- Failure to reach the caregiver by telephone
- Data had been collected anonymously

For the caregivers of patients deceased prior to or during the PP, only the patient’s date of death (month and year) was collected. For the caregivers of patients institutionalized prior to or during the PP, only the patient’s date of institutionalization (month and year) was collected.

The caregivers of patients still living at home answered two questionnaires during a telephone interview. The first questionnaire was the Zarit Burden Scale (ZBS) [16], and the second was the NCPI questionnaire derived from the Neuropsychiatric Inventory (NPI) questionnaire [17].

The NCPI questionnaire consists of questions about memory disorder, orientation disorder, communication/speaking disorder, apraxia, agnosia, thinking difficulties, and attentional disorder. The complete details about the NCPI questionnaire are available in the online supplementary Appendices.

The subtypes of MND were noted and classified according to the DSM-5 criteria into AD, vascular MND, FTD, LBD, mixed MND (combined vascular and Alzheimer etiology), other dementia, and dementia of uncertain etiology [4].

The caregivers were classified as “spouse” or “other,” with the latter category encompassing relations such as son/daughter, grandson/grand-daughter, mother/father, brother/sister, or friend. Other epidemiological data were collected from the medical files available from our institution, including the psychological support received by the caregiver, the number of medications taken by the caregiver, the formal care being given at home (nurse, healthcare assistant, etc.), and attendance at daycare centers by the patient.

Statistics

Statistical analyses were performed with SPSS software. Comparisons were done using χ^2 and Fisher tests, the Mann-Whitney U test, and the Kruskal-Wallis test. Correlations were quantified

Table 1. Demographic and clinical characteristics of the patients and caregivers

	Cases (n = 46)	Controls (n = 45)
<i>Patients</i>		
Median age (IQR), years	77.5 (68–81.75)	79 (70–82)
Female, n (%)	24 (52.2)	28 (62.2)
Median MMSE score (IQR)	21.5 (16–24)	21.5 (14.75–25)
Subtype of dementia, n (%)		
AD	16 (34.8)	29 (64.4)
VD	4 (8.7)	5 (11.1)
FTD	6 (13)	5 (11.1)
LBD	2 (4.4)	2 (4.4)
Mixed	8 (17.4)	3 (6.7)
Other	1 (2.2)	0 (0)
Uncertain	9 (19.6)	1 (2.2)
<i>Caregivers</i>		
Median age (IQR), years	58 (49–74)	64.5 (49.5–77)
Female, n (%)	34 (73.9)	28 (62.2)
Patient-caregiver relation, n (%)		
Spouse	24 (52.2)	22 (48.9)
Other	22 (47.8)	23 (51.1)
Son/daughter	21 (45.7)	18 (40)
Grandson/grand-daughter	0 (0)	1 (2.2)
Friend	0 (0)	2 (4.4)
Mother/father	1 (2.2)	0 (0)
Brother/sister	0 (0)	2 (4.4)

AD, Alzheimer disease; VD, vascular dementia; FTD, frontotemporal dementia; LBD, Lewy body dementia.

using the nonlinear Spearman correlation test. Kaplan-Meier estimation, with a log-rank test for comparison, was used to study the institutionalization delay. A p value <0.05 was accepted as the threshold for statistical significance.

Results

The demographic and clinical characteristics at baseline of the patients with dementia and their main caregiver are summarized in Table 1. No significant differences were identified between the two groups ($p > 0.05$). The delay in institutionalization was not different between the patients with caregivers who had completed the PP and those with caregivers who had not (Fig. 2).

For a second analysis, we reanalyzed our data by adding 6 months to the duration of follow-up of the patient caregivers having completed the PP. We consider that 6 months corresponds to the delay between agreement to participate in the PP and actual enrollment in our program, because our program takes place twice a year. This second analysis did not reveal significant differences between the two groups either (Fig. 3).

Fig. 2. Delay in institutionalization (log-rank test: $\chi^2 = 0.003$; DDL = 1; $p = 0.960$).

The delay in institutionalization was not influenced by the age of the patient ($p = 0.169$), the age of the caregiver ($p = 0.352$), the sex of the patient ($p = 0.651$), the sex of the caregiver ($p = 0.0692$), or the Mini-Mental State Examination (MMSE) score ($p = 0.085$). However, the delay was affected by the subtype of MND. Indeed, patients with LBD and FTD were institutionalized earlier, followed by patients with AD and mixed dementia. In our cohort, patients with vascular dementia and other types of MND (e.g., Korsakoff syndrome) were not institutionalized, but these represented a very small proportion of our groups.

The relationship between the patient and their caregiver also had a significant impact on this delay ($p =$

0.036), since patients with a spouse as a caregiver tended to be institutionalized at a later stage. No significant difference was observed between the group with and that without the PP with regard to psychobehavioral disorders of the patients (NPI total score, $p = 0.42$; NPI distress total score, $p = 0.956$; Δ NCPI – NPI total score, $p = 0.813$; Δ NCPI – NPI distress total score, $p = 0.782$).

The caregivers who participated in the PP did not show a lighter burden than those who had not participated, as expressed by the ZBS score ($p = 0.403$). Some demographic and clinical variables showed a significant impact on the behaviors of patients with dementia (Table 2) and the burden of caregivers (Table 3).

Fig. 3. Adjusted delay in institutionalization (log-rank test: $\chi^2 = 0.355$; DDL = 1; $p = 0.551$).

Table 2. Impact of the demographic and clinical characteristics on psychobehavioral disorders

Variables	Δ NCPI total		Δ NCPI distress total		NPI total		NPI distress total	
	rho	p value	rho	p value	rho	p value	rho	p value
Patient age	-0.076	0.576	-0.095	0.486	0.029	0.831	-0.032	0.816
Patient sex		0.334		0.969		0.623		0.679
Caregiver age	-0.054	0.7	0.021	0.879	-0.245	0.074	-0.304	0.026
Caregiver sex		0.685		0.014		0.134		0.011
Relation patient-caregiver (spouse vs. other)		0.356		0.348		0.224		0.034
MMSE score	-0.495	<0.001	-0.423	0.002	-0.177	0.21	-0.029	0.84
Type of dementia (AD + MD vs. FTD + LBD vs. VD + OD)		0.624		0.372		0.47		0.159
Psychological support of caregiver		0.332		0.941		0.646		0.965
Number of medications of caregiver	0.018	0.891	0.134	0.317	0.062	0.645	0.03	0.821
Helps at home		0.072		0.629		0.409		0.755

Bold type denotes significance. AD, Alzheimer disease; MD, mixed dementia; FTD, frontotemporal dementia; LBD, Lewy body dementia; VD, vascular dementia; OD, other dementia.

Fig. 4. Survival rates of the patients with MND, comparing those with PP and those with non-PP caregivers. MND, major neurocognitive disorder; PP, psychoeducational program.

Table 3. Impact of the demographic and clinical characteristics on caregiver burden

Variables	Rho	<i>p</i> value
Patient age	-0.21	0.878
Caregiver age	-0.74	0.597
Patient sex		0.548
Caregiver sex		0.366
Relation patient-caregiver (spouse vs. other)		0.562
Type of dementia (AD + MD vs. FTD + LBD vs. VD + OD)		0.701
Number of medications of caregiver	0.5	0.969
Psychological support of caregiver		0.45
Daycare center for patients		0.842
Helps at home		0.597

AD, Alzheimer disease; MD, mixed dementia; FTD, frontotemporal dementia; LBD, Lewy body dementia; VD, vascular dementia; OD, other dementia.

Finally, patients without PP caregivers presented a significantly higher rate of mortality than those with PP caregivers ($p < 0.0001$; Fig. 4).

Discussion

In our study, the PP did not result in a delay in institutionalization. As a limitation, when comparing the two groups, the initial PP starting times were not defined in the same way. In the group who completed the PP, the initial time was set as the beginning of the program, whereas in the group without the PP, the initial time was defined as the date of agreement to participate in the program. However, there is often a time lag of several months between the agreement date and the start of the PP. A means of overcoming this incongruity was to add 6 months to the follow-up time for the group who had completed the PP. However, this amendment did not lead to any significant difference between the two groups, perhaps because the added delay could have been longer than 6 months, since the PP only takes place twice a year. Another limitation is that the size of our population could be insufficient to identify an effect of the PP. Furthermore, several subtypes of MND were included in our population. A more restricted selection of patients – for example, only patients with AD – could maybe reveal an effect of the PP on the delay in institutionalization. A final limitation of the present study lies in the nonrandomized distribution of our samples. This could lead to potential biases, such as self-selection or selection bias. The group who completed the PP actually needed help (such as a program of support or psychological education) and would experience worsening without the PP. This group represents those who would benefit the most from the program.

Unlike the present study and a Dutch randomized multicenter trial looking at the impact of a family meeting intervention on the delay in institutionalization [18], Mitelman et al. [14] succeeded in identifying a benefit of their program in delaying institutionalization. However, one should take into consideration that this study took place in a different socioeconomic and cultural context, looking at Hispanic spouses living in New York City. This ethnic group is known to look after their relatives at home longer than caregivers of many other cultures [19]. These populations could thereby benefit more from support programs, particularly in delaying nursing home placement.

In Brussels, the patients with FTD or LBD had a shorter delay until nursing home placement than the patients with other subtypes of MND. LBD is known to be charac-

terized by psychiatric symptoms such as depression [20], personality and behavioral (sexual or eating) changes, and disinhibition [21], leading to interpersonal and social difficulties, and thereby contributing to a high caregiver burden [22] and stress level [23]. In our study, caregiver stress was identified as a risk factor for earlier institutionalization for this subgroup. The distress experienced by caregivers related to behavioral disorders proved to be greater with FTD patients than with AD patients [24].

For patients with spouses as caregivers, nursing home placement occurred later than for patients with other types of caregiver. A similar impact has already been described for daycare center attendance [25]. Our data highlighted a tendency towards a shorter delay until institutionalization the older the patient was. However, this trend was not statistically significant. Yaffe et al. [8] obtained comparable statistically significant results in 2002. In the study by Yaffe et al., a MMSE score < 20 points was a risk factor for earlier nursing home placement.

No significant variation was observed in NPI, NPCI, and ZBS scores in association with the PP, although these scores are based on the subjectivity of questionnaires filled in by caregivers [26, 27]. No evidence of the efficacy of psychological intervention or support on caregiver burden has been published in the past. However, a lower caregiver burden (< 10 points on the ZBS) was clearly associated with later institutionalization [25].

Finally, survival was significantly longer in the group with caregivers having completed the PP. However, these results need to be interpreted with caution. The present study was not designed for this purpose. Patient comorbidities, cause of death, and treatments were not recorded, which would be crucial for interpreting this result.

Conclusions

In conclusion, in the present study, our PP did not have a significant impact by delaying institutionalization. However, the subtype of MND and the relationship of the caregiver with the patient *did* have a significant impact on the delay. In the future, a randomized controlled study looking at selected subtypes of MND, with an analysis of relevant demographic and clinical characteristics, could be beneficial for further investigation of the impact of the PP on caregivers.

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Statement of Ethics

Written, informed consent was obtained from the patients or their authorized surrogates. The protocol of the study was approved beforehand by the Ethics Committee of Hopital Erasme in Brussels.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

C.D.: conception of the work; acquisition, analysis and interpretation of data; and redaction and revision of the manuscript. S.E.: acquisition and interpretation of data. D.V.D.B.: conception of the work and acquisition of data. J.-C.B.: conception of the work, acquisition of data, and revision of the manuscript.

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