

Structured Pre-Consultation Interview at the First Call of Caregiver Regarding Memory Consultation: Effects on Caregiver Burden, Expectations, and Quality of Life

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Keywords

Caregiver burden · Pathways of care · Health-related quality of life

Abstract

Introduction: Case managers can guide caregivers during their search for care for relatives with neurocognitive disorders. The present study aimed to evaluate the effects of this procedure on caregiver burden and quality of life. **Methods:** Family caregivers searching for care at a memory clinic before the first consultation were provided written information and they provided verbal consent to participate in this pre-post intervention study. Intervention was a structured pre-consultation phone call interview given by the case manager to inform and organize individualize pathway of care. The mini-Zarit Burden Interview and the EuroQol five-dimensional questionnaire quality of life scores were recorded by an independent assessor before the intervention and 1 month thereafter. An expectation questionnaire was also completed during the assessments. The pre and post scores were compared using the Wilcoxon signed-rank test. **Results:** In total, 45 participants were enrolled and 35 were assessed twice. There was no significant change in the total

mini-Zarit Burden Interview score; however, the levels of stress due to caring and meeting familial responsibilities ($p = 0.025$), and the fear of what the future holds for the participants' relative ($p = 0.01$) was lower at 1 month. The need for information about the pathways of care decreased, but no change in support satisfaction was observed. Quality of life was good and did not change. **Conclusions:** During the pre-consultation intervention, the case manager may fulfill several needs of caregivers, particularly to obtain personalized information, which should be implemented in memory clinics.

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Introduction

The major neurocognitive disorders involve multiple cognitive deficits that lead to dependence and stigma [1]. The caregiver burden increases with the severity of cognitive impairment [2]. In Europe, caregivers reported delayed access to specialized care [3] and diagnosis [4]. Family caregivers provide indispensable, difficult, and unique support to the elderly. The majority of caregivers are woman, spouse, or non-cohabiting offspring [5].

Compared with the general population, family caregivers have more frequent health problems, higher mortality rate, greater social isolation [5], and higher expenditures related to dementia care [6, 7]. Therefore, the assessment of caregiver burden is an important outcome of interventions for severe cognitive disorders and other chronic diseases, particularly those causing disability or requiring palliative care. The Zarit Burden Interview was developed and validated for the evaluation of caregiver burden [8]. The full-length version of this scale includes 22 items and shorter versions contain a selection of them varying from 1 to 12 [9]. These scales explore caregivers' subjective feelings and experience related to the person being cared for, as well as the need of support, health, and social life issues.

The responses of professionals often do not meet the caregivers' expectations [5, 10]. There is a need for more informative tools to assess caregivers expectations [11]. However, efforts are being to improve the accessibility of healthcare providers for caregivers [12, 13]. We offer telephone contact with a nurse case manager for caregivers who want information regarding the diagnosis and follow-up of their relative's cognitive problems. We developed a structured interview to address the caller's main concerns and provide information on care pathways for patients with cognitive problems. We evaluated the responses to improve this service. We hypothesized that this strategy may reduce the burden and improve the quality of life (QoL) of caregivers. The main objective of the present study was to determine the mini-Zarit Burden Interview score [9] and to evaluate QoL before and 1 month after the phone call, as well as before the memory consultation.

Materials and Methods

Study Design

This is a pre-post intervention study. The outcomes were scored by a medical secretary at baseline and a clinical research assistant at the 1-month visit. The pre and post tests were conducted at an interval of 30 + 7 days and before the memory consultation. Before the first assessment, participants received by mail information, and verbal consents were obtained. The Ethical Review Board of the University Hospital approved the study protocol (agreement CER-BDX-2022-17) and stated that no written consent was required. The phone interviews were not recorded, and the data collected were anonymized.

Participants

The study enrolled family caregivers with a "natural or informal" attitude who were ready to accompany the patient during their care. The persons being helped were older than 75 years. Caregivers were not enrolled if they already had a contact with the care setting prior to the phone call. Based on an expected difference

between the pre- and postintervention of at least 1 point on the mini-Zarit Burden Interview, a correlation between the pre- and postintervention scores of 0.3, similar standard deviation of 1.94, bilateral alpha risk of 5%, and power of 0.8, we planned to include 44 participants.

Intervention: Case Manager Pre-Consultation Interview by Phone Call

In our memory clinic, clinical case management is routinely performed prior to the medical consultation, which often requires several telephone calls. The coordinating nurse is the case manager.

The case manager lets the caller express their request regarding the person being assisted. Information related to the memory consultation was collected through a semi-structured interview. The interview was conducted over one or more calls and was used to collect information to determine the need for rapid care for the patient, based on the information provided by the caregiver and the general practitioner (GP). This information included the sociodemographic data of the caregiver and patient; the ethical dimension of the request is checked to know the level of consent of the patient to come for consultation. The degree of isolation, care pathways, level of physical dependence, comorbidities and list of medications, as well as any nondrug management of the patient are sought. Finally, the memory complaints were evaluated using the McNair and Kahn scale [14]. Caregiver fatigue was formally evaluated using the collected information and tone of the conversation (e.g., sighing, sobbing, or laughing) during the interview about the health status of the person being cared for. Based on this information, the case manager evaluated the relationships among the level of dependence, patient frailty, and caregiver burden, which enabled identification of fatigue denial and thus aided in determining the appropriate management. The interview also included advice, reassurance, and various personalized information.

The form of involvement of the attending physician, coordinator of care at home, and the opinion of any health professionals involved were documented. The GP was involved in the final decision to take care of the patient in the memory clinic. The interview also aimed to guide the caregiver in the early stages of care, to gather all the necessary elements for the consultation, and to "emotionally unburdening" for the caregiver.

The case manager was a permanent point of contact between the pre-consultation call and medical consultation. The data collection form and five algorithms for the most frequently encountered situations allowed fair and factual responses to the consultation requests (see online suppl. File; for all online suppl. material, see www.karger.com/doi/10.1159/000526669).

Main Outcomes

The French version of the mini-Zarit Burden Interview was used to measure caregiver burden. Several short scales that include different items have good performance compared with the full 22-item scale, according to receiver operating characteristic curve analysis. The French version of the scale consists of seven items [15, 16] (Table 1), and a score of 7 indicates maximal burden.

The EQ-5D-3L is a measure of health-related QoL (HrQoL) and a trademark of the EuroQol group (France [French] © 2010, EQ-5D™) [17]. This generic questionnaire evaluates five dimensions of HrQoL: mobility, autonomy, daily activities, pain/discomfort, and anxiety/depression. The scores range from 0 to 2 for each item,

Table 1. Change in the mini-Zarit Burden Interview score between baseline and the 1-month follow-up ($n = 35$)

		Baseline ($N = 35$)	One month ($N = 35$)	p value baseline/ 1 month ^a
Total score, median (IQR)		3.0 (4.0)	3.0 (2.5)	0.218
Stressed between caring and meeting familial responsibilities (N)	0	14	20	0.025
	0.5	14	12	
	1	7	3	
Your relative affects your relationships with others in a negative way (N)	0	19	16	0.197
	0.5	13	14	
	1	3	5	
Your health has suffered because of your involvement with your relative (N)	0	12	15	0.536
	0.5	15	12	
	1	8	8	
Embarrassed over behaviors? (N)	0	12	8	0.134
	0.5	15	18	
	1	8	9	
Afraid of what the future holds for relative (N)	0	2	9	0.01
	0.5	14	18	
	1	19	8	
You could just leave the care of your relative to someone else (N)	0	21	20	0.981
	0.5	8	10	
	1	6	5	
Overall, how burdened do you feel in caring your relative? (N)	0	17	16	0.448
	0.5	8	14	
	1	10	5	

^a Comparisons were done using the Wilcoxon signed-rank test.

with a score of 2 indicating the worst HrQoL. The EQ-VAS involves a single question: “how is your health today on a scale of 0 (worst) to 100 (best)?”

In the present study, a questionnaire was constructed by the nurse case manager to explore the caregivers’ need for information regarding the memory consultation pathway (delay, course of consultation, announcement of the diagnosis, and follow-up). In addition, we evaluated the satisfaction with home care and domestic social support for daily living. This questionnaire was named the “Caregivers’ Expectation Questionnaire.”

Analysis

Categorical variables are expressed as numbers (%) and were compared using the χ^2 test. Ordinal and non-normally distributed variables, such as the mini-Zarit Burden Interview and EQ-5D-3L scores, are presented as medians with the interquartile range (IQR). The scale and subscale scores of the Caregivers’ Expectation Questionnaire, mini-Zarit Burden Interview, EQ-5D-3L, and EQ-VAS were compared using the Wilcoxon signed-rank test.

Results

In response to the information letter, 45 caregivers provided verbal consent to participate (Fig. 1). Six patients lived outside the geographical coverage area of the

memory clinic. Of the 45 caregivers, 21 were younger than 60 years, 28 were females, 15 were the spouse of the patient, and 30 called the case manager according to their GP’s advice. A quick memory consultation was requested by 19 caregivers, and no professional help was available at home for 27 caregivers.

The case manager decision situations are shown in Figure 1. Thirty-five caregivers participated in the 1-month phone assessment. The nonrespondents and respondents did not differ in age, gender, relationship to the patient (spouse, offspring, or other), or mini-Zarit Burden Interview score. None of the patients were hospitalized during the 1-month period.

The median total mini-Zarit Burden Interview score was 3.0 (IQR = 4.0) at baseline (Table 1) and did not significantly change at 1 month. However, the scores of the following two items improved between the calls: the stress related to caring for the patient and fulfilling familial responsibilities ($p = 0.025$) and concern for the patient’s future ($p = 0.01$).

The QoL of the participants was generally good (mean EQ-VAS score = 80, IQR = 20) (Table 2), and only two caregivers had an EQ-VAS score of 50 at baseline. The

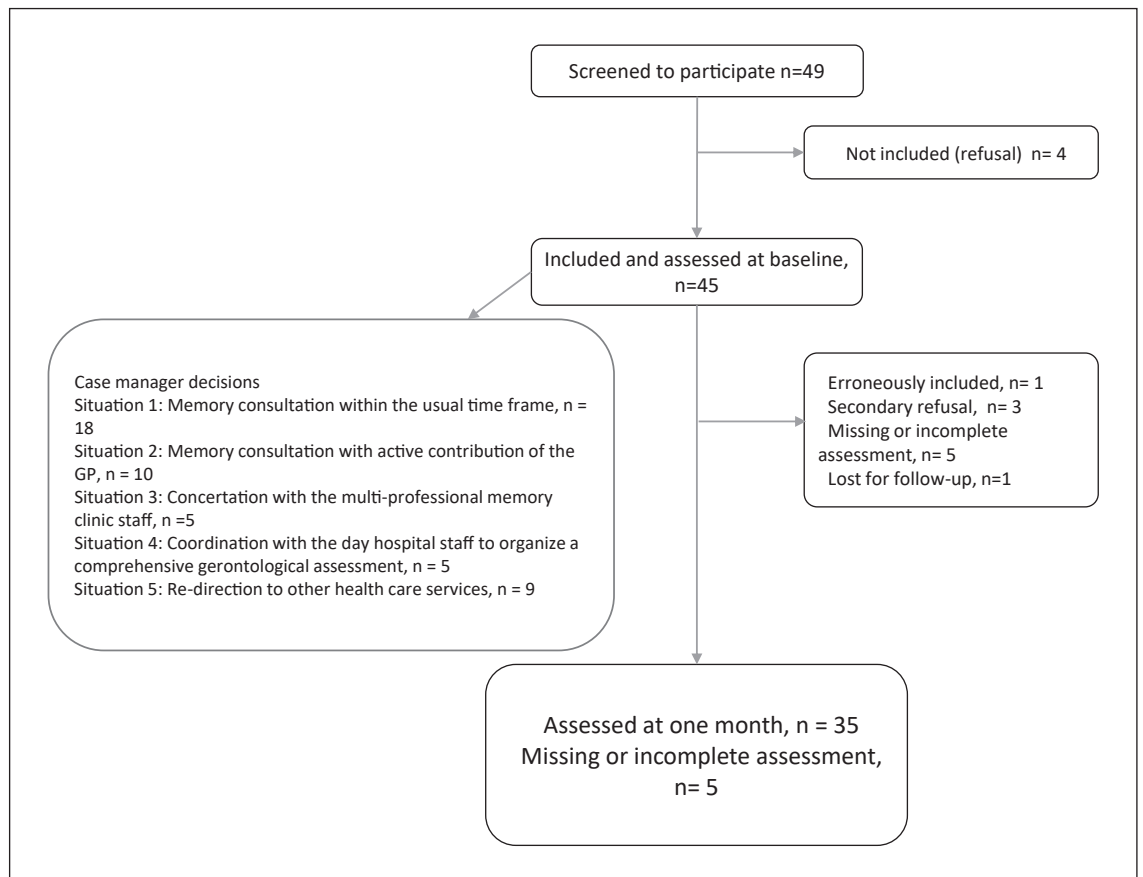


Fig. 1. Flowchart of the study population.

participants reported problems mainly in the anxiety/depression and pain/discomfort domains. No changes were observed at the 1-month visit.

The Caregivers' Expectation Questionnaire showed a high need for information regarding the practical aspects of the care pathways for memory complaints. Most participants had no questions at 1 month (Table 3). However, satisfaction with the support did not change, or even slightly worsened, for family or professional support.

Discussion

The study participants required information from the memory clinic regarding the course of care. Although digital information was available on the hospital website, it was probably insufficient or too general rather than individualized. It was shown elsewhere that face to face interactions using video calls improved interactions [18]. In

most cases, the pre-consultation interview addressed the caregiver's expectations. The needs expressed by the caregivers did not differ according to the consultation date. The pre-consultation interview is intended to reassure caregivers that their care needs will be adequately addressed. On the other hand, the interview may fail to identify the difficulties and increase the stress of caregivers. Therefore, the case manager must be empathetic and respond to requests without creating additional stress. This implies that the case manager must be a healthcare worker trained in the concerned disease.

Although the global caregiver burden did not change, the responses of caregivers showed that their feeling of conflict between the need to care for the patient and the time spent with the family was lessened. We also suppose that individualized information on pathways of care mediated the decreased concern regarding the patient's future. On the other hand, the pre-consultation interview did not affect the satisfaction with the organization or

Table 2. Impairment in caregivers' HrQoL according to the EQ-5D-3L questionnaire at baseline (pre) and the 1-month follow-up (post) (n = 35)

	Mobility (N)		Self-care (N)		Usual activities (N)		Pain/discomfort (N)		Anxiety/depression (N)		EQ-VAS Median (IQR)	
	pre	post	pre	post	pre	post	pre	post	pre	post	pre	post
Level 1	33 (91.7)	33 (91.7)	35 (100)	35 (100)	32 (88.9)	32 (88.9)	20 (55.6)	21	15 (42.9)	17 (47.2)	80 (20)	80 (20)
Level 2	2 (5.6)	2 (5.6)	0	0	2 (5.6)	2 (5.6)	15 (41.7)	13 (36.1)	17 (47.2)	14 (38.9)	0.343	0.343
Level 3	0	0	0	0	1 (2.8)	1 (2.8)	0	1 (2.8)	3 (8.3)	1 (2.8)		
p value (pre/post) ^a	1	1	-	-	1	1	1	1	0.830	0.830		

^a Comparisons were done using the Wilcoxon signed-rank test.

support at home. In addition, because of the generally good HrQoL of the participants, no change was expected at 1 month.

One month of follow-up in the period preceding the memory consultation may be too short to detect any significant changes. However, a longer follow-up duration may be associated with an unfavorable clinical course, which may affect caregiver burden, unrelated to the case manager's intervention. Because of the small sample size and lack of a control group, it was not possible to determine the preventive effect of pre-consultation interviews on the hospitalization rate, as shown by a previous large study [19].

This study had several limitations, including the pre-post study design. An expectation bias due to recruitment of the volunteers may have affected the results. Furthermore, participation in a study may improve patient outcomes independently of the intervention. However, we did not observe a decrease in the score of the EQ-5D-3L anxiety/depression domain. This was a single-center study with a unique case manager. We did not compare our results with those of other organizations, which would have made the results more robust. However, a pilot study was necessary to identify the main domains of interest. The objective was perhaps too ambitious, and the choice of mini-Zarit Burden Interview items that could be modified in this period would have been preferable. This study also had some strengths. The outcomes were recorded by assessors independent of the case manager intervention; furthermore, different assessors evaluated the caregivers at both follow-ups. The study was conducted before the memory consultation, which limited the factors that may influence the responses to the various questionnaires.

Conclusions

The pre-consultation interview may address the caregivers' need for information in an individualized manner, which is not limited to the memory consultation. This strategy may reduce certain domains of burden. However, the comparison of our results with those of other care organizations may help improve case manager intervention. The implementation in memory clinics of case managers with the relevant training may meet certain caregiver needs, particularly regarding personalized information.

Table 3. Changes in the need for information and daily life satisfaction according to the “Caregivers’ Expectation Questionnaire” completed during the two interviews ($n = 35$)

	Baseline, N (%)	One month, N (%)	p value baseline/ 1 month ^a
Need for information about: yes			
Timeframe of the consultation	25 (69.4)	3 (8.3)	<0.000
Course of the consultation	17 (47.2)	6 (16.7)	0.005
Announcement of the diagnosis	27 (75.0)	1 (2.8)	<0.001
Organization of the follow-up	26 (72.2)	4 (11.1)	<0.001
Daily living satisfaction for: yes			
Care organization	25 (69.4)	19 (52.8)	0.157
Organization of the domestic life of the assisted person	24 (66.7)	21 (58.3)	0.439
Existing familial or professional support	28 (77.8)	21 (58.3)	0.052

^a Comparisons were done using the Wilcoxon signed-rank test.

Statement of Ethics

We confirm that the research was conducted ethically in accordance with the World Medical Association Declaration of Helsinki. This study protocol was reviewed and approved by the “Comité d’Éthique de la Recherche, Centre Hospitalier Universitaire de Bordeaux,” and the reference of the approval is CER-BDX-2022-17. Written consent was not required according to the Ethical Committee, but an oral consent after full information was obtained from participants according to the approved protocol. Declaration of the study to the CNIL (French agency for digital personal data protection).

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

Study concept and design: Isabelle Guillard, Fabien Salesses, Isabelle Bourdel-Marchasson, Valérie Berger, and Aurélie Lafargue; data analysis and interpretation: Isabelle Guillard, Isabelle Bourdel-Marchasson, and Aurélie Lafargue; manuscript drafting: Isabelle Guillard, Fabien Salesses, and Isabelle Bourdel-Marchasson; critical revision of the manuscript for important intellectual contribution: Claire Roubaud Baudron.

Data Availability Statement

In accordance with the French data protection law, the data are not public but can be obtained from the author.

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