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ORIGINAL ARTICLE

Considering management behaviours to identify vulnerable caregivers of persons with dementia

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INTRODUCTION

Throughout the evolution of their disease, persons with dementia (PwDs) gradually disengage from daily life activities (e.g. meal preparation, housework, medication management, bathing or dressing) and from complicated tasks that they used to be able to perform (e.g. electrical installations or car maintenance).^{1,2} This disengagement may be explained by limitations in completing daily activities owing to their symptoms (deterioration of cognitive, social and motor skills) and by the anticipation and avoidance of

Abstract

Background: Persons with dementia gradually disengage from daily activities, and therefore require increasing daily support. Caregivers face a dilemma as to whether they should encourage the persons with dementia in terms of initiative and autonomy, or supervise and take charge of tasks, which may cause distress for both parties. This study seeks to better understand how caregivers manage the disengagement of the persons with dementia and the repercussions on their caregiving experience.

Methods: A total of 217 caregivers participated. Their management behaviours and the characteristics of their caregiving experiences were assessed with questionnaires. A cluster analysis was first performed to identify possible profiles of management behaviours and comparison, which were then compared to identify the caregiving experience associated with each profile.

Results: The first cluster (25.8% of the sample) corresponds to caregivers with high negative control behaviour scores and high positive stimulation behaviour scores; the second cluster (43.8% of the sample) corresponds to caregivers with low positive stimulation behaviour scores and high negative control behaviour scores; and the third cluster (30.4% of the sample) corresponds to caregivers with low negative control behaviour scores and high positive stimulation behaviour scores. Caregivers in Clusters 2 and 3 differ in terms of anxiety, depression, burden, gratification, health and financial problems. Cluster 1 is an intermediate profile with similar characteristics to Cluster 3.

Conclusions: Our results support the idea of considering management behaviours to identify vulnerable caregivers and highlight the deleterious role of negative control behaviours, especially when they are not offset by positive protective stimulation behaviours.

failure.^{2,3} Moreover, symptoms such as apathy and lack of communication may lead those around PwDs to treat them as a child.^{4,5} They thus experience a sense of loss of autonomy, a decrease in self-esteem and a loss of social role.^{6,7} These changes can trigger negative effects on their quality of life and a high level of distress.⁸

PwDs need increasing emotional, psychological, physical and financial daily support, usually provided by spouses and children.⁹ This support consists in repeating and recalling information to compensate

for forgetfulness, handling home and administrative tasks, supervising treatment and managing changes in behaviours, symptoms and emotions of PwDs.⁹ However, caregivers often feel unprepared to deal with these situations, manage these behaviours and provide the adequate level of help to support PwDs in their daily tasks.^{6,10,11} They may be unsure of the appropriate management behaviour and face a dilemma as to whether they should promote the PwDs in terms of sense of initiative and autonomy, thus encouraging their contribution and enhancing their self-esteem, or resort to directive behaviours, supervise things, use compensatory strategies and take charge of daily tasks.^{6,12–14}

Caregivers' management behaviours have implications for both caregivers and PwDs, and their relationships. Directive and control behaviours are associated with greater levels of anxiety, burden and guilt in caregivers, as well as a sense of monitoring, devaluation, infantilisation and uselessness in daily decisions in PwDs.^{6,12} Furthermore, these behaviours lead caregivers to be constantly present for supervision or assistance. Although this forced closeness may sometimes be experienced as an asset to strengthen the relationship, it is most often considered as a hindrance to their mutual activities and social networks, resulting in loneliness and burden.^{2,6} Stimulation behaviours are associated with a sense of joy and gratification in caregivers.¹⁵ These behaviours allow PwDs to continue their activities as long as possible and maintain their preserved capacities, and they also promote self-esteem and well-being.^{16,17}

Interestingly, there may be divergences between the two partners' perceptions of symptoms and preserved capacities, and the level of support required, particularly when PwDs minimise their symptoms or are unaware of them.^{2,6,18} The latter can thus have difficulties accepting help, which is often a source of conflict and distance between the two partners.⁶

Given the impact on caregivers' and PwDs' well-being and on their relationship, it is crucial to better understand how caregivers deal with PwDs' disengagement. As suggested by Wawrziczny *et al.*¹⁵ characterising the profile of caregivers according to their management behaviours would help identify the most vulnerable of them. The first objective of this study was to identify various possible profiles of management behaviours through cluster analysis,

with distinct patterns of control and stimulation behaviours. We then sought to examine the caregiving experience associated with each profile.

METHODS

Participants and procedure

Participants were recruited from: (1) internet social networks dedicated to caregivers of PwDs (via e-mails sent to social networks and forums inviting people to participate in a survey, explaining the study briefly, listing the inclusion criteria and containing the URL where participants could access the information letter, consent form and questionnaires); and (2) the Regional University Hospital Centre of Lille in northern France and the network of respite platforms for caregivers in the Hauts-de-France region (caregivers who met the inclusion criteria were selected by the staff, who explained the objectives of the study, requested their participation, provided an information letter and a consent form before the completion of the questionnaires).

The inclusion criteria were as follows: the caregiver had to be caring for a PwD, who had to be living at home (either with the caregiver or not). In total, 217 caregivers participated in the study: 177 women and 40 men.

Ethical issues

The survey was approved by the National Ethics Committee (CCP15/48) and complied with the tenets of the Helsinki Declaration of 1975.

Measures

Participants responded to questions addressing their sociodemographic status and that of the PwD, the nature of their relationship, the average caregiving time per day, the caregiver's education level, the diagnosis of the PwD, the year of diagnosis and that of the first signs. The caregivers then completed the four scales described below.

The Control and Stimulation in Dementia Caregiving (CSDC) scale¹⁵ assesses two facets of the management approaches of caregivers facing the disengagement from daily activities of the PwDs, with 13 items: seven for negative control and six for positive stimulation, rated on a five-point scale (from 1 to 5). A higher score indicates that the participant either adopts more negative, directive and supervisory

management behaviours or positive, stimulating and supportive management behaviours. The reliability coefficients obtained in our study were 0.65 for positive stimulation and 0.82 for negative control.

The Hospital Anxiety and Depression Scale (HADS)¹⁹ is a self-assessment questionnaire for depression and anxiety comprising 14 items (seven for anxiety and seven for depression) rated on a four-point scale. The higher the score, the more anxious or depressed is the participant. The reliability coefficients obtained in our study were 0.84 for depression and 0.81 for anxiety.

The Zarit Burden Interview²⁰ is composed of 22 items rated on a five-point scale assessing the subjective level of burden perceived by caregivers. The higher the score, the more burdened the participant feels. The internal reliability (Cronbach's alpha) in this study was 0.91.

The Caregiver Reaction Assessment (CRA)²¹ assesses caregivers' experiences considering four negative (disruption of schedule, financial problems, lack of family support, health problems) and one positive (self-esteem/gratification) dimension of the caregiving situation. The scale is composed of 24 items on a five-point response scale. A higher score indicates a more negative impact on the caregiving situation, except for the 'impact on self-esteem' dimension. The reliability coefficients obtained in our study were 0.88 for self-esteem, 0.77 for disrupted schedule, 0.75 for financial problems, 0.84 for lack of family support and 0.84 for health problems.

Analysis

Statistical analyses were performed using SPSS software (version 25). In the first descriptive step, means, SDs and percentages were calculated depending on whether the variables were continuous or categorical.

Participants' scores were then classified according to the two dimensions of the CSDC scale:¹⁵ the positive stimulation dimension and the negative control dimension. On the vertical axis, the higher the scores, the more negative directive and or controlling behaviours were adopted. On the horizontal axis, the higher the scores, the more positive stimulating or supporting management behaviours were adopted. We used a two-step method developed by Chiu *et al.*²² for large datasets that correspond to a mixed (or combined) approach. This method consists of rapidly creating a pre-cluster of observations in a

high number of classes (in the order of a few 10s or even 100s) using a rapid partitioning method (K-means with few iterations), and then performing a hierarchical aggregation from these pre-clusters to benefit from the readability of the results associated with the dendrogram. We chose to use a likelihood measure, the calculation of a Bayesian information criterion (BIC)-type and the ratio between the two largest values of the distance ratio to identify the number of classes. We identified the values of the BIC for partitions into K classes ranging from 1 to $K_{max} = 15$. Concerning the classification quality indicator, a classification is considered correct when it is between 0.2 and 0.5 and good when it is between 0.5 and 1. Finally, once the clusters were identified, new comparisons were made between the new groups using an analysis of variance, followed by post-hoc analyses with a Bonferroni correction for pairwise comparisons of the different caregiving experience variables.

RESULTS

Characteristics of participants

Table 1 shows the sociodemographic data and mean scores of scales for all participants. The latter were mostly women ($n = 177$; 81.6%), adult children ($n = 106$; 48.8%) or spouses ($n = 93$; 42.9%). They were aged 58.24 years on average ($SD = 11.92$), and 50.2% of them had a high education level. They took care of a PwD for an average of 9.97 h per day ($SD = 7.64$). 41.9% of PwDs were diagnosed with AD, 10.6% with Lewy body dementia, 5.5% with frontotemporal dementia, 3.2% with mixed dementia and 37.7% with other forms of dementia. They were aged 75.76 years on average ($SD = 14.22$), exhibited the first signs of the disease 7.50 years ($SD = 6.16$) prior to the study on average and were diagnosed 5.55 years ($SD = 5.43$) prior to the study on average.

Cluster analysis

The results of the cluster analysis regarding caregivers' management behaviours indicate an optimal three-factor solution, illustrated in Fig. 1. The quality indicator of the classification into three groups corresponds to a correct classification with a score of 0.5. The three clusters account for 25.8%, 43.8% and 30.4% of the sample, respectively.

Table 1 Sociodemographic data and mean scores of scales

Variables	All participants			
	(N = 217)			
	Mean	SD	n	%
Characteristics of caregivers				
Age, years	58.24	11.92		
Gender				
Male			40	18.4
Female			177	81.6
Type of relationship				
Adult children			106	48.8
Spouse			93	42.9
Sibling			1	0.5
Aunt or uncle			0	0
Others			17	7.9
Education				
< High education level			108	49.8
> High education level			109	50.2
Caregiving time, average h per day	9.97	7.64		
Characteristics of persons with dementia				
Age, years	75.76	14.22		
Average time since diagnosis, years	5.55	5.43		
Average time since earliest signs of disease, years	7.50	6.16		
Diagnosis				
Alzheimer's disease			91	41.9
Frontotemporal dementia			12	5.5
Lewy bodies			23	10.6
Mixed dementia			7	3.2
Others			84	37.7
Caregiving experience				
CSDC negative control behaviours	20.92	5.59		
CSDC positive stimulation behaviours	21.49	3.79		
HADS Anxiety	11.80	4.46		
HADS Depression	9.47	4.58		
Zarit	48.74	15.86		
CRA Disruption of schedules	19.14	3.89		
CRA Financial problems	9.58	3.20		
CRA Lack of family support	17.41	5		
CRA Health problems	13.29	3.83		
CRA Self-esteem	24.43	5.72		

Abbreviations: CRA, Caregiver Reaction Assessment; CSDC, Control and Stimulation in Dementia Caregiving; HADS, Hospital Anxiety and Depression Scale.

Cluster 1 ($n = 56$) presents specific characteristics such as high levels of negative control behaviours (mean = 23.20; SD = 3.55) and high levels of positive stimulation behaviours (mean = 25.38; SD = 1.83). Cluster 2 ($n = 95$) corresponds to the participants with high levels of negative control behaviours (mean = 24.17; SD = 3.65) but low levels of positive stimulation behaviours (mean = 18.91; SD = 2.49). Cluster 3 ($n = 66$) is characterised by low levels of negative control behaviours (mean = 14.32; SD = 3.14) but high levels of positive stimulation behaviours (mean = 21.91; SD = 3.59).

Comparisons between the three clusters

Table 2 shows that caregivers in Clusters 1 and 2 did not differ from each other and both had more anxiety than those in Cluster 3. Caregivers in Cluster 2 had more depression and burden and less gratification related to the caregiving situation than those in Clusters 1 and 3, which did not differ from each other. Caregivers in Cluster 2 had more health and financial problems than those in Cluster 3, but Cluster 1 did not differ from either of the other two clusters.

No difference was observed among the three clusters regarding caregivers' age, PwDs' age, the average time

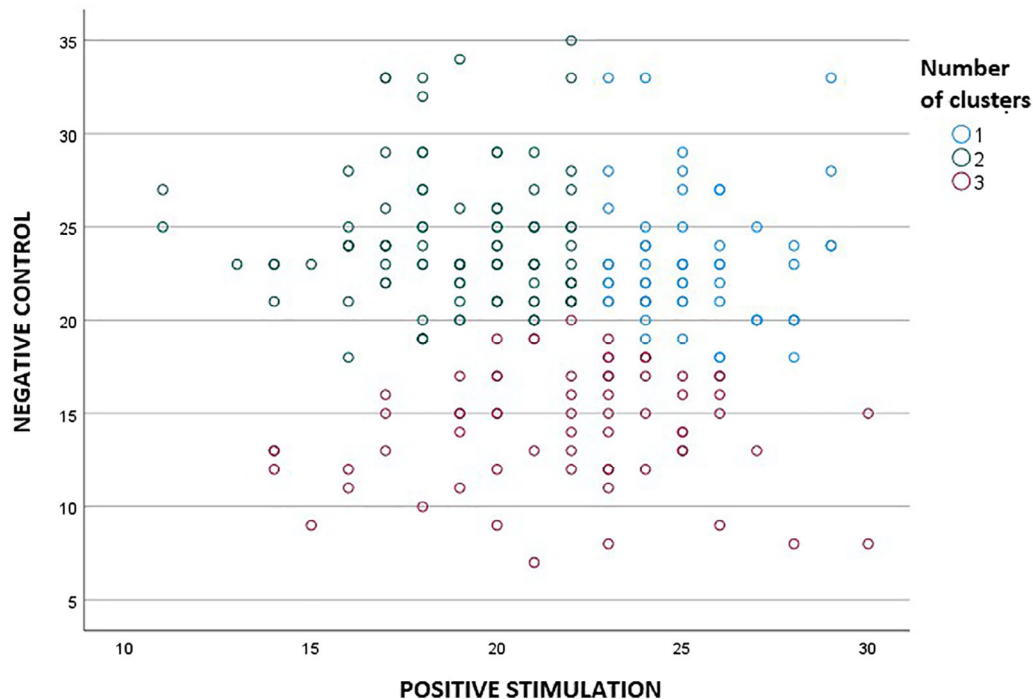


Figure 1 Scatterplot representing the three clusters according to negative control behaviours (vertical axis) and positive stimulation behaviours (horizontal axis).

Table 2 Comparisons of characteristics of three clusters

	Cluster 1, mean, (SD)	Cluster 2, mean, (SD)	Cluster 3, mean, (SD)	F (2, 216)	Diff C1 vs C2	Diff C1 vs C3	Diff C2 vs C3
Age of caregivers	59.59 (11.77)	57.96 (11.23)	57.48 (13.06)	0.52	1.63	2.10	0.47
Age of persons with dementia	75.43 (15.14)	74.89 (13.92)	77.32 (13.91)	0.58	0.53	-1.90	-2.43
Average time since earliest signs of disease	6.80 (4.99)	7.40 (6.41)	8.25 (6.74)	0.84	-0.60	-1.45	-0.85
Average time since diagnosis	4.60 (4.55)	5.84 (6.07)	5.90 (5.11)	1.07	-1.24	-1.31	-0.07
Average caregiving time per day	10.50 (7.81)	9.14 (7.46)	10.73 (7.73)	1.03	1.36	-0.23	-1.59
HADS Anxiety	12.55 (3.93)	12.83 (4.22)	9.67 (4.53)	12.02*	-0.28	2.89*	3.17*
HADS Depression	8.86 (4.17)	10.83 (4.36)	8.05 (4.73)	8.43*	-1.97*	0.81	2.79*
Zarit	46.23 (15.22)	54.48 (15.59)	42.61 (14.03)	13.20*	-8.25*	3.63	11.88*
CRA Disruption of schedules	18.95 (4.07)	19.28 (3.49)	19.09 (4.32)	0.14	-0.34	-0.14	0.19
CRA Financial problems	9.36 (3.32)	10.40 (2.88)	8.58 (3.27)	6.85*	-1.04	0.78	1.82*
CRA Lack of family support	16.95 (4.67)	18.34 (4.71)	16.48 (5.50)	3.06*	-1.39	0.46	1.85
CRA Health problems	13.05 (3.65)	14.18 (3.77)	12.21 (3.82)	5.50*	-1.13	0.84	1.97*
CRA Self-esteem	26.71 (4.83)	22.66 (5.62)	25.05 (5.82)	10.17*	4.05*	1.67	-2.38*

Abbreviations: C1, Cluster 1; C2, Cluster 2; C3, Cluster 3; CRA, Caregiver Reaction Assessment; Diff, difference in means; HADS, Hospital Anxiety and Depression Scale. * $P < 0.05$.

since the earliest signs of the disease, the average time since diagnosis, the average caregiving time per day, disruption of schedules or lack of family support.

DISCUSSION

The main aim of this study was to identify caregiver profiles in light of control and stimulation behaviours

and the associated caregiving experience. This approach would permit us to consider the appropriate support for each profile.

The first interesting result showed that while all caregivers use both types of management behaviours, 69.6% of them (from Profiles 1 and 2) have a high level of negative control behaviours. Previous studies have shown that it is important for caregivers

to preserve the integrity of PwDs,²³ and that they may observe that PwDs perform tasks better when they do it on their own initiative rather than under the supervision of another person.^{2,14} However, caregivers tend to plan, watch over, give directions and instructions, tell what to do and compensate for the daily actions of the PwDs.^{13,14,24} They explain this by the fact that they feel responsible for the actions of the PwDs.² They also adjust the level of assistance according to emotional or organisational constraints, such as saving time, preserving a pleasant socio-environmental climate, avoiding failure or dangerous situations for the PwDs and reducing their own anxiety.^{2,6}

The second important finding of our study is that while caregivers use both types of management behaviours, how they use them seems to affect the caregiving experience. Indeed, caregivers who mostly use negative control behaviours show high levels of distress, burden, health problems and financial problems and a low level of gratification (Profile 2). While control behaviours may save time and avoid difficult situations, their predominant use is associated with negative consequences. This result is consistent with previous studies^{6,13,15} and can be explained by the fact that the more caregivers spend time controlling and supervising, the less they have time for themselves, and the more they increase their mental and physical load. Moreover, the PwDs may feel infantilised, devalued, frustrated and useless, they sometimes reject the offered support and they lack recognition, which can in turn increase caregivers' distress.^{6,13} Conversely, the predominant use of positive stimulation behaviours is associated with more gratification and fewer negative consequences (Profile 3). As shown in previous studies, positive stimulation behaviours are associated with gratification and recognition for the caregivers and with preserved abilities and well-being for PwDs by keeping them involved in their daily activities.^{2,6,13,15} Moreover, the relationship is more satisfying and less stressful for both partners when caregivers adapt their management behaviours to the PwDs' symptoms and when they can take joint decisions concerning daily life.^{6,25,26}

Finally, while Profile 1 caregivers used high negative control behaviours, they showed a caregiving experience close to those of Profile 3. This result could be explained by the fact that the simultaneous use of high positive stimulation behaviours could play a protective role. Although the disease makes

tasks increasingly difficult for PwDs and caregivers are concerned for their safety, high positive stimulation behaviours are strongly recommended to improve the caregiving experience^{13,16,17} and counteract the negative consequences of negative control behaviours.

This study has several limitations. First, although it is the case in most studies of caregivers of PwD, the participants in this study were mainly women. Second, most caregivers were spouses and children, and the caregiving implications are not the same depending on the type of relationship and on whether the caregiver is living with the PwD. It would thus be interesting to perform profile analyses based on the type of relationship. Finally, given that the support provided by the caregivers evolves throughout the progression of the disease, this evaluation could be performed at several timepoints to examine the evolution of the profiles.

Despite these limitations, our results suggest several clinical implications for caregivers. First, an assessment of management behaviours with the CSDC scale is recommended to identify the vulnerable profiles (i.e. Profiles 1 and 2, who use a high level of negative control behaviours). Second, clinicians may support caregivers of Profiles 1 and 2 in reducing their demands of the PwDs' involvement, increasing their psychological flexibility and letting go, and better identifying the preserved abilities of the PwDs. Caregivers would then be better able to adapt their level of support accordingly to the PwDs' capacities while the latter would be able to engage more serenely in their daily activities.^{13,27} Clinicians may also encourage caregivers to provide 'invisible' support so that the PwDs may better accept help without feeling threatened.¹³ They may also encourage couples to discuss their respective representations of the support needed and the best way to collaborate in their situation.² Third, clinicians may also help caregivers to develop positive stimulation behaviours (for Profile 2) or strengthen them (for Profiles 1 and 3) by stimulating and supporting the PwDs' initiatives, actions and decisions.

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DISCLOSURE

Authors declare no conflict of interests for this article.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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