

# Development and validation of a scale to assess caregiver management behaviors in response to the decreased engagement of people with dementia in daily activities.

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**Running title:** Development and validation of the CSDC scale

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**Abstract:**

**Objective:** To explore types of caregivers' management approaches, to develop a scale to assess caregivers' management behaviors and their relationship implications and to examine the scale's psychometric qualities.

**Method:** First, based on a qualitative study, developing the corpus of items to align as closely as possible to caregivers' experience using their own words; second, exploring the structure of the scale and reducing the number of items; and third, studying the validity of the scale.

**Results:** After assessing the validity requirements of the original corpus of items, an exploratory factor analysis of the first version of the scale with 62 items permitted the identification of three dimensions of caregiver management: "Negative control", "Positive stimulation" and "Overwhelming feeling". Because of its redundancy with respect to existing scales, the last dimension was removed. In the last step, a confirmatory factor analysis showed that a 13-item two-order factor model was in an acceptable model.

**Conclusion:** The 13-item scale can be used to identify caregivers facing difficulty adapting their support as a baseline for following caregivers over time or evaluating the effectiveness of an intervention.

**Clinical implications:** This scale can rapidly evaluate caregivers' management behaviors and their relational consequences and monitor outcomes of support interventions.

**Keywords:** caregivers, dementia, scale, management, engagement

## **Introduction**

Studies have shown that persons with dementia gradually disengage from complicated tasks that they used to have the competence to perform before symptom onset (e.g., electrical installations or car maintenance) (Vikström, Josephsson, Stigsdotter-Neely, & Nygård, 2008), from instrumental activities of daily living (IADL) (e.g., meal preparation, management of finances, housework, or medication management) and activities of daily living (ADL) (e.g., bathing, eating, or dressing) (Gendron & Levesque, 1993; Lawton, & Brody, 1969; Sikkes, De Lange-de Klerk, Pijnenburg, & Scheltens, 2009). This disengagement can be explained by symptoms that cause limitations in the initiative and/or ability to perform or fulfill everyday activities (deterioration of cognitive, social and motor skills) or by the avoidance of failure (Nygård & Öhman, 2002; Vikström et al., 2008). Persons with dementia thus receive increasing daily support that is provided, in most cases, by family members, usually spouses and children (Brodaty & Donkin, 2009). This support concerns emotional, psychological, physical and financial forms of assistance, such as repeating and recalling information in case of forgetfulness; offering physical assistance in daily tasks; handling administrative tasks (mail, paperwork, financial management); supervising treatment; managing changes in the behavior of the person with dementia and symptoms such as depression, apathy or agitation; and assisting with the management of home and personal care (hygiene and meals) (van der Lee, Bakker, Duivenvoorden, & Dröes, 2014).

To provide this support, caregivers tend to plan, monitor and use supporting, accompanying, guiding or compensatory strategies (Jansson, Nordberg, & Grafström, 2001; Phinney, 2006; Vikström, Borell, Stigsdotter-Neely, & Josephsson, 2005). However, caregivers often feel insufficiently prepared to manage the challenging behaviors of persons with dementia (Scott, Lewis, & Loughlin, 2005) and caregiving situations (Ducharme et al., 2009).

Caregivers' challenges involve knowing what level of support to provide to persons with dementia and to what extent to involve persons with dementia in tasks (Wawrziczny, Antoine, Ducharme, Kergoat, & Pasquier, 2016). Vikström et al. (2008) highlighted that caregivers regularly face a dilemma between management approaches: encouraging the initiative and efforts of the person with dementia or taking over daily chores. Caregivers are aware of changes in the independence of persons with dementia, which is why they try to promote their autonomy, value their contributions, enhance their self-esteem, reduce their feelings of uselessness (Merrick, Camic, & O'Shaughnessy, 2016; Wadham, Simpson, Rust, & Murray, 2016) and adapt to the unpredictability and fluctuation of the symptoms (Vikström et al., 2008). However, this adjustment is sometimes complicated by emotional or organizational constraints. While caregivers might observe better performance when persons with dementia do something on their own initiative rather than under the supervision of someone else (Vikström et al., 2005, 2008), caregivers might want to save time or fear that persons with dementia may not be able to assess danger or react properly in dangerous situations (Wawrziczny et al., 2016). Caregivers then adjust their level of assistance to ensure the safety of persons with dementia, to prevent them from being confronted with their disease or with failure and to manage their own anxiety (Lockeridge & Simpson, 2013).

Even if the motivations of caregivers are benevolent and protective, the management behaviors they adopt in response to the decreased engagement of persons with dementia can have individual and relational implications. Vikström et al. (2008) showed that the more persons with dementia disengage from activities, the more they and their caregivers perceive the need for the nearness in daily life. This nearness can sometimes be perceived as an asset for the relationship, but most of the time, it is perceived as hindering their involvement in mutual everyday engagements, leisure activities, and social networks, causing loneliness and a burden (Vikström et al., 2008). In addition, Wawrziczny et al. (2016) showed that caregivers and

persons with dementia do not always have the same perception of symptoms, spared abilities, and the level of help required. Too much divergence between the two partners' perceptions can lead to conflicts between them. Indeed, caregivers may feel ongoing uncertainty about the appropriate management behavior, feel guilty and question the help provided. Persons with dementia may feel observed, monitored, devalued, or useless. Furthermore, the receipt of help can be embarrassing and difficult to accept for persons with dementia. They may express indifference, hesitation or rejection with respect to caregivers' help, which is often a source of tension and distance between the two partners (Wawrziczny et al., 2016). This tension is even more salient when persons with dementia minimize their problems in order to maintain their self-esteem and their lifestyle or are unaware of their symptoms (Robinson, Clare, & Evans, 2005). Conversely, Oliver, Murphy, & Cox (2010), Sebern & Whitlatch (2007), and Wawrziczny et al. (2016) showed that the relationship is more mutually satisfying and less stressful when caregivers are able to adapt to the symptoms and their fluctuation, when recipients of care are able to express gratitude and appreciation in return for help from caregivers, and when both partners are able to discuss and make joint decisions about how to manage day-to-day living.

While most previous studies have focused on outcomes such as the burden or mental health of caregivers, few studies have focused on the interaction processes between persons with dementia and their caregivers. Nevertheless, these few studies have shown major implications of caregivers' management behaviors for the caregiving situation at both the individual and relational levels (Oliver, Murphy, & Cox, 2010 ; Vikström, Borell, Stigsdotter-Neely, & Josephsson, 2005; Vikström et al., 2008). There is thus major interest in improving our understanding of the caregiving situation to address caregiver management behaviors in response to the decreased engagement of persons with dementia and how these behaviors impact caregiver and care recipient well-being as well as the caregiving relationship. A better

understanding of the caregiver experience overall could help practitioners develop interventions to manage behaviors and improve caregiver well-being. The main objective of the study was to determine the different facets of caregivers' management behaviors and their implications for the caregiving relationship. The second aim was to develop a scale of caregivers' management behaviors and their daily positive and negative implications for caregiving relationships and to examine the scale's psychometric qualities. To assess the experiences of dementia caregivers in caregiving situations, studies have used either nonspecific tools such as the Hospital Anxiety and Depression Scale (HADS) to assess levels of distress (Zigmond & Snaith, 1983) or more specific tools such as the Zarit Burden Interview to evaluate caregivers' senses of "burden" (Zarit, Reever, & Bach-Peterson, 1980) or the Caregiver Reaction Assessment (CRA) to assess positive and negative consequences of the caregiving situation (Given et al., 1992). To assess the impact of family care on the quality of dyadic relationships, studies have used the Dyadic Relationship Scale (DRS) (Sebern & Whitlatch, 2007).

While these tools are valid and have good psychometric qualities, they do not evaluate caregiver management behaviors or their relational consequences independently or on the same scale. The current study was conducted in 3 phases based on the recommendations of Hofmann et al. (2016). *First*, items were generated based on a qualitative study to avoid imposing preconceived theoretical restrictions and to represent caregivers' experiences as accurately as possible. The items were revised by experts. *Second*, an initial exploratory component analysis was performed to analyze the structure and develop a shorter version of the scale. *Third*, the properties of the final scale were examined with exploratory analysis and confirmatory factor analyses to assess its convergent and discriminant validity.

### **Phase 1: Developing the corpus of items**

### ***Generation of the items***

This step was based on interviews from a qualitative study conducted with couples in which one member had Alzheimer's disease (AD) (Wawrziczny et al., 2016). The topics addressed during these interviews related to symptoms, difficulties encountered, needs and coping strategies, the implications for each partner and for the couple and the evolution of the couple relationship (i.e., What has changed in your couple relationship since the onset of the disease? What difficulties have you encountered since the onset of the disease? How do you manage these difficulties in daily life?). A pool of items was developed in two steps. *First*, to capture the way participants expressed their experiences in their own words, we listed extracts related to the caregivers' experiences managing the decreased engagement in daily activities of the person with dementia; these included protection, motivation, reinforcement, compensation, assistance, monitoring, negotiation, and supervision *and* their daily negative and positive implications for both partners as perceived by the caregiver. *Second*, these extracts were partially simplified and reformulated to correspond to the item format of a questionnaire. A corpus of 100 items was thus created.

### ***Judges' method***

Five clinical psychologists working with caregivers and 10 caregivers assessed the items for validity requirements (generalizability to all caregivers; expression of a single, unambiguous idea; ease of understanding; and relevance and usefulness in clinical practice). This evaluation enabled us to classify the items. These two steps of corpus evaluation allowed us to eliminate 38 'candidate' items, and 10 items were rewritten for clarity to arrive at a temporary 62-item version of the scale. At this phase, we decided to use the Likert format (from 1 "strongly disagree" to 5 "strongly agree") because of its relative ease for respondents and for scoring. The following instruction was written: "You are the caregiver of a person with AD or a related

disease. For each of the following statements, indicate whether it corresponds to what you have felt or experienced recently while caring for your relative."

## **Phase 2: Exploring the structure of the scale**

### ***Method***

#### *Participants and procedure*

Participants were recruited from the internet (forums and social networks dedicated to caregivers of persons with dementia), from the Regional University Hospital Center of Lille in northern France and from the network of respite platforms for caregivers in the region of Hauts-de-France. The inclusion criteria were as follows: the caregiver had to be caring for a person with AD or a related disease (e.g., mixed dementia, frontotemporal dementia, or Lewy body dementia), and the person with dementia had to live at home (with or without the caregiver), not in residential care. In total, 266 caregivers participated in the study. The participants were mostly women (N = 184; 69.4 %). The caregivers had an average age of 60 years (SD = 15.25). Persons with dementia had an average age of 74.12 years (SD = 11.74) and had exhibited cognitive impairment for an average of 7.97 years (SD = 8.53). The persons with dementia had been diagnosed for an average of 5.69 years (SD = 5.23).

#### *Assessment*

First, the caregivers responded to a set of self-administered questions that included items addressing their sociodemographic status and that of the person with dementia (i.e., sex, age), the diagnosis of the person with dementia, the date of the diagnosis and the date of the first signs. Second, they completed the 62-item scale.

#### *Analysis*

We acknowledged that a 62-item scale was impractical for most purposes, so the analyses were



guided by the goal of analyzing the factor structure and reducing the number of items to develop a shorter version. Descriptive analyses of the responses to the items made it possible to identify and eliminate items whose distributions were excessively flattened, asymmetrical and/or poorly dispersed, contributing little to the tool's ability to discriminate (the skewness and kurtosis indexes were 1.5 or more in absolute value). Inter-item correlational analyses were performed to identify highly correlated items ( $r > 0.60$ ) in order to avoid redundancy and artificial clusters.

Following the recommendations of Antoine, Antoine, & Nandrino (2008), we used principal component analysis and employed three methods to estimate the optimal number of components to retain. The Kaiser criterion and the scree test generally lead to overestimation of the number of components (Tzeng, 1992; Zwick & Velicer, 1986). The third criterion was component representativeness. The representativeness of each component after rotation gives the number of nonnegligible loadings. In line with Kline's recommendations (Kline, 2014), varimax rotations were applied to yield the number of nonnegligible loadings and the factorial structure with relatively independent constructs. Cases of double loading were minimized by accepting those where the highest loading was greater than 0.30 and the difference between the highest loading and the other loadings was greater than 0.20 (Antoine et al., 2008; Connors, Sitarenios, Parker, & Epstein, 1998).

## ***Results***

### *Descriptive results*

Five items for which the skewness and kurtosis indexes were more than 1.5 in absolute value were eliminated at this stage. None of the items were highly correlated.

### *Multidimensional results*

Fifteen components had an eigenvalue above 1 (Kaiser criterion). The shape of the eigenvalue curve suggested retaining five components (scree test criterion). After analysis of the factor

weights and iterative elimination of items that did not meet the selection criteria, 38 items were left. These items were organized into three components that explained 45.58% of the total variance. The first component, called “Negative control”, was associated with seven items that explained 20.54% of the variance. This schema corresponded to the negative implications of the caregiver's directive and supervisory behaviors for the caregiver (doubt, guilt) and for the relationship with the person with dementia (tension). The internal consistency value for this component was 0.80. The second component, called "Positive stimulation", explained 14.68% of the variance. The seven items associated with this component corresponded to the positive repercussions of the caregiver's stimulating and supporting behaviors toward the person with dementia in daily actions for the relationship with the person with dementia and for the caregiver (valuation, grateful, appreciation). The internal consistency value for this component was 0.71. The third component, called “Overwhelming feeling”, was associated with five items that corresponded to the negative feelings perceived by the caregiver regarding having to manage everything alone and being overwhelmed; this component explained 10.35% of the variance. The internal consistency value for this component was 0.76. The last component was composed of items that were closely aligned with those of existing scales such as the CRA or the Zarit Burden Interview. Since the objective of this study was to create an original tool that does not evaluate what has already been evaluated, we chose not to keep the items of this dimension.

### **Phase 3: Studying the validity of the scale**

#### ***Method***

##### *Participants and procedure*

The same recruitment procedure as in Phase 2 was used. In total, 282 caregivers participated in the study. The participants were mostly women (N = 196; 71.8 %). The caregivers had an average age of 59.43 years (SD = 12.54). The persons with dementia had an average age of

76.75 years (SD = 10.19) and had exhibited cognitive impairment for an average of 6.75 years (SD = 5.41). The persons with dementia had been diagnosed for an average of 4.54 years (SD = 4.28). A subgroup of 152 participants also completed concurrent validity questionnaires. To verify the questionnaire's reliability, a second subgroup of 63 participants completed the 14-item scale 15 days after the first test.

### *Assessments*

All caregivers responded to a set of self-administered questions that included items addressing their sociodemographic status and that of the person with dementia (i.e., sex, age), the diagnosis of the person with dementia, the date of the diagnosis and the date of the first signs; then, the caregivers completed the 14-item scale.

A subgroup completed the concurrent validity questionnaires mentioned above.

The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) is a self-assessment for depression and anxiety. This scale is composed of 14 items rated using a 4-point scale from 0 to 3. Seven questions are related to anxiety (total A), and seven are related to depression (total D); thus, two scores are yielded (maximum score for each dimension=21). The higher the score, the more anxious or depressed the participant is.

The Zarit Burden Interview (Zarit et al., 1980) is a scale that assesses the subjective level of burden perceived by caregivers with 22 questions. The responses are distributed on a 5-point scale ranging from 0 (never) to 4 (almost all the time). The total score is between 0 and 88, thus making it possible to identify 4 degrees of perceived burden: an absent to light burden (score < 21), a light to moderate burden (score between 21 and 40), a moderate to severe burden (score between 41 and 60) and a severe burden (score > 60).

The CRA (Given et al., 1992) specifically assesses caregivers' experiences. Five negative and positive dimensions of caregiver reactions are evaluated: negative disruption of schedules, financial problems, lack of family support, health problems, and positive effects on self-esteem.

The questionnaire contains 24 items that employ a 5-point response scale ranging from 1 (strongly disagree) to 5 (extremely agree). A higher score indicates a more negative impact on the caregiving situation, except for the “self-esteem” dimension.

### *Analysis*

A principal component analysis permitted verification of the factor structure of the 14-item scale. According to the criteria of Antoine et al. (2008) and Conners, Sitarenios, Parker, & Epstein (1998), one item showed a double loading, with a highest loading (0.43) on the first component greater than 0.30 and a difference with the loading on the second component (0.29) no greater than 0.20. This item was removed, and the final 13-item scale was obtained. A principal component analysis was also used to verify the overall quality of the structure of the 13-item scale. Pearson's correlations were used to assess the convergent and discriminant validity of the 13-item scale. The internal consistency of the two components was calculated using Cronbach's alpha. Confirmatory factor analysis (CFA) was conducted with JASP using the diagonally weighted least squares (DWLS) method. This method performs well across many conditions (Flora & Curran, 2004). Moreover, in this study, the data were collected using Likert scales. Thus, the data were ordered categorical. The DWLS estimator based on the polychoric correlation matrix avoids biased parameter estimates that could appear with the maximum likelihood estimations. The DWLS estimator is considered a more reliable option with ordered categorical variables (Savalei & Rhemtulla, 2013; Xia & Yang, 2018). Model fit was assessed using criteria based on the comparative fit index (CFI) and Tucker-Lewis index (TLI) (good fit:  $\geq 0.95$ , acceptable fit:  $\geq 0.90$ , respectively), the root mean square error of approximation (RMSEA) and standardized root mean residual (SRMR) (good fit:  $< 0.06$ , acceptable fit:  $< 0.08$ , respectively) and the goodness of fit index (GFI  $> 0.85$ ) (Anderson & Gerbing, 1984; Cole, 1987; Hu & Bentler, 1999; Marsh, Balla, & McDonald, 1988).

## Results

### *Multidimensional results*

The principal component analyses showed that one item, “I ask my relative for help with tasks at home”, obtained a difference smaller than 0.20 between the highest loading and the other loadings. We decided to remove this item to minimize the effect of double loading. We therefore obtained a 13-item scale organized into the same two components as those in step 1 that explained 46.19% of the total variance (Table 1). The first component, “Negative control”, was associated with seven items and explained 27.68% of the variance. The second component, “Positive stimulation”, was associated with six items and explained 18.52% of the variance.

INSERT TABLE 1

### *Correlations between the components, internal consistency and reliability*

The correlation matrix of the two components scores showed that the “Negative control” score was not correlated with the “Positive stimulation” score ( $r = -0.05$ ;  $p = 0.39$ ). The internal consistency of these two components was 0.82 for the “Negative control” component and 0.70 for the “Positive stimulation” component. Reliability over time (15 days) was 0.62 ( $p = 0.00$ ) for the “Negative control” component and 0.71 ( $p = 0.00$ ) for the “Positive stimulation” component.

### *Confirmatory factor analysis*

Fit indexes for the 13-item scale exhibited a satisfactory goodness of fit, with  $\chi^2 = 164.75$  (ddl: 64),  $p < 0,001$ ; RMSEA = 0.08, IC 90 [0.06 - 0.09]; SRMR = 0.09; CFI = 0.91; TLI = 0.90 and GFI = 0.96. The 13-item two-order factor model was an acceptable model.

### *Concurrent validity*

Table 2 shows that the “Negative control” component score was significantly and positively correlated with anxiety, burden and impact on finances. Most of these correlations were relatively low (less than 0.30); only the “Positive stimulation” component score was significantly and positively correlated with self-esteem ( $r = 0.44, p < 0.001$ ).

INSERT TABLE 2

## **Discussion**

The aim of this study was, first, to explore different facets of management approaches of caregivers faced with the decreased engagement in daily activities of persons with dementia and, second, to provide initial evidence for the reliability and validity of a newly developed tool, i.e., the Control and Stimulation in Dementia Caregiving (CSDC) scale. The CSDC-13 was developed and validated in a manner consistent with the experiences of caregivers and couples described in a previous study (Wawrziczny et al., 2016). The scale is intended to improve the identification of caregivers facing difficulties in order to better support them and improve the caregiving relationship.

The first important results are the identification of two categories of management approaches that emerged from the analyses: control behaviors and stimulation behaviors. The category of control behaviors included principally the caregiver's directive and supervisory behaviors. We might have expected the bipolarity of items concerning these types of behaviors with items that assessed both the negative and positive implications of control behaviors for caregiving relationships. However, the analyses revealed that caregivers' control behaviors were mentioned only in a negative way. This result is consistent with previous studies showing that when caregivers manage by adopting rigid control behaviors, persons with dementia may feel infantilized and deprived of their freedom to make decisions and their involvement in daily

decisions, thus creating long-term conflicts between the two partners (Lockeridge & Simpson, 2013; Wawrziczny et al., 2016). This scale will make it possible to identify caregivers who adopt negative control as management behavior. This might help practitioners adapt their support for caregivers by increasing caregivers' psychological flexibility and focusing caregivers' attention on functional rather than dysfunctional aspects of persons with dementia and on evaluating their residual abilities in real time to adapt the level of support accordingly (Larochette, Wawrziczny, Papo, Pasquier & Antoine, 2019; Wawrziczny, et al., 2019).

Concerning stimulation behaviors, this category of management approaches principally concerned the caregiver's behaviors that stimulated and supported the person with dementia in daily actions. We also did not observe bipolarity of items, so the items evaluating stimulating behaviors did not assess both the negative and positive implications of stimulating behaviors for caregiving relationships. Instead, the analyses revealed that caregivers' stimulating and support behaviors were mentioned only in a positive way. These results are consistent with those of previous studies showing that if management by stimulation is carried out to enhance and encourage all kinds of initiatives and efforts of persons with dementia, then the management allows persons with dementia to actively pursue their activities as long as possible and maintain their current abilities and sense of well-being (Bond & Corner, 2001; Mezey et al., 2000). This type of support is highly recommended (Bond & Corner, 2001; Mezey et al., 2000). Thus, it is important for practitioners to identify caregivers who do not use these management behaviors in order to help caregivers develop them and to help caregivers who do use them to strengthen and maintain them so that caregivers can benefit from their positive personal and relational implications.

Another important result of the study is the independence of these two components. A previous study showed caregivers' gradual transitions from protective behaviors to behaviors demonstrating more rigid control over persons with dementia (Wawrziczny et al., 2016).

Therefore, we expected a negative correlation between stimulation and control behaviors. Nevertheless, the results showed that these two components were completely independent, which implies that caregivers can use both control behaviors with negative implications for the caregiving relationship and stimulation behaviors with positive implications. Many researchers have demonstrated that the positive aspects of the caregiving situation (gains and satisfaction) and the sense of burden (strain) are not the extremities of a continuum. Rather, these aspects reflect independent dimensions of the caregiving experience (Boerner, Schulz, & Horowitz, 2004) and have different impacts on well-being (Rapp & Chao, 2000). Future research could focus on clusters based on these two independent components to identify the most vulnerable caregivers.

Finally, despite the good internal consistency of the two components, the reliability over time was slightly lower for the “Negative control” component than for the “Positive stimulation” component. This result suggests that “Negative control” behaviors could fluctuate more and be more sensitive to personal or environmental conditions and therefore more sensitive to intervention strategies, while the “Positive stimulation” behaviors could be more stable and therefore, once strengthened, maintained over the long term.

The relationships of the CSDC subscales with existing measures also provided some insight into the nature of caregiver management as measured by the CSDC. The “Negative control” score demonstrated a positive moderate association with the anxiety dimension of the HADS and the Zarit score. This finding may suggest that caregivers who have more rigid caregiving attitudes are more anxious and burdened. Many studies have identified negative consequences of these control behaviors on both psychological and physical levels, resulting in an increased risk of somatic and psychiatric decompensation (Vitaliano, Young, & Zhang, 2004) as well as an increase in mortality (Schulz & Beach, 1999).



The “Positive stimulation” score was consistently associated with the self-esteem dimension of the CRA. It may be that caregivers who experience more gratifying stimulation experience caregiving situations as enjoyable and gratifying. The occurrence of enrichment and positive events is greatly conditioned by the caregiver’s feeling of self-efficacy that influences the quality of the caregiver- person with dementia relationship as well as the caregiver’s feeling of accomplishment (Carbonneau, Caron, & Desrosiers, 2010). Positive aspects of the caregiving experience were correlated with less burden, better health and less negative reactions to the problems of persons with dementia (Brodaty & Donkin, 2009; Cohen, Colantonio, & Vernich, 2002; Roff et al., 2004).

This research must be considered in light of the following limitations. The first limitation concerns our composite sample. The sample included caregivers of persons with several types of dementia (AD, mixed dementia, frontotemporal dementia, and Lewy body dementia), with a preponderance of persons with AD. Moreover, all types of caregivers were represented (spouse, child, friend, etc.), with a preponderance of spouse caregivers. It would be interesting to balance the groups and to compare the experiences of caregivers according to the type of dementia and the type of relationship with the person with dementia. The second limitation concerns the size of the sample for phase 2. In phase 3, the principal component analyses were conducted with a sample of 282 caregivers, which gave a ratio of approximately 20 participants for one item. On the other hand, in phase 2, the 62-item scale was completed by 266 participants, which gave a ratio of approximately 4 participants for one item. We were well aware that this ratio was low; nevertheless, at this step, we were focused not on performing the factor analysis but on identifying the optimal number of components. For this reason, we felt it was important to conduct confirmatory analyses in phase 3 to validate this structure. Finally, the CSDC scale is appropriate at a stage of dementia when it is possible for the person with dementia to remain engaged in activities and when there is some choice involved in how much

initiative the person with dementia takes and how much assistance the caregiver gives. Therefore, in the same line as the DRS (Sebern & Whitlatch, 2007), it would be interesting to develop parallel versions of the scale and administer it to both members of the dyad to measure the person with dementia's and the caregiver's perceptions.

## **Conclusion**

The 13-item CSDC scale is a valid and reliable brief self-report measure of caregivers' management behaviors. This new assessment tool has 4 advantages. First, a strength of this study is that the items were empirically derived from participants' responses to semi-structured interviews about the dyads' adjustment to the symptoms (Wawrziczny et al., 2016). Thus, items were not limited by a priori theories on how such management occurs (Hofmann et al., 2016). Second, this scale consists of 13 items; therefore, the CSDC can be self-completed within 5 minutes, so it is quick to implement. Third, this tool presents satisfactory psychometric properties with acceptable reliability and validity. Fourth, the objectives of the scale are to assess the multidimensional aspects of caregivers' management approaches to the decreased engagement in daily activities of persons with dementia, including both negatively perceived control and positively perceived stimulation.

## **Clinical implications**

- This study allows practitioners to better understand caregiver management behaviors and how they impact the caregiving relationship.
- This extension of this understanding of the caregiver experience can help practitioners improve interventions and improve caregiver well-being.

- This scale is an ecological tool that can rapidly assess caregiver management behaviors and their relational consequences.
- This tool will make it possible to evaluate caregivers who face difficulties and might need additional support.

### **Conflict of interest**

None declared

### **Acknowledgment**

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Instruction: "You are the caregiver of a person with Alzheimer's disease or a related disease.

For each of the following statements, indicate whether it corresponds to what you have felt or experienced recently while caring for your relative."

<b>Items</b>	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Strongly agree</b>
<i>My relative is grateful for the help I give him/her</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<i>My relative feels watched over in daily actions</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<i>I stimulate my relative's memory by using his/her memories</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<i>My relative blames me for protecting him/her too much</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<i>My relative appreciates the help I give him/her in his/her daily tasks</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<i>I don't know if I help my relative properly</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<i>My relative doesn't appreciate it when I do things for him/her</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<i>I blame myself for infantilizing my relative</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<i>I ask my relative to participate as much as possible even if he/she makes mistakes</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<i>My relative blames me for being too directive</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<i>I have my relative do memory exercises</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<i>My relative is stressed by my questions</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<i>I can adjust to my relative's mood</i>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>