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Lower Visual Avoidance in Dementia Patients Associated with Greater Psychological Distress in Caregivers

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Abstract

Caring for a spouse with dementia can lead to increased health problems in caregivers. The present study examined whether patient deficits in visual avoidance, a common form of emotion regulation, are related to greater psychological distress in caregivers. Participants were 43 Alzheimer's disease patients, 43 behavioral variant frontotemporal dementia (bvFTD) patients, and their spousal caregivers. Patient visual avoidance (e.g., gaze aversion) was measured using behavioral coding of head, body, and eye position while viewing a disgusting film. Caregiver psychological distress was measured using a standard self-report symptom inventory. Lower use of visual avoidance by patients was associated with greater psychological distress in their caregivers. This relationship was partially mediated by patient overall emotional functioning (as reported by caregivers), such that patients with less visual avoidance were seen as having worse emotional functioning, which in turn related to greater caregiver psychological distress. Dementia diagnosis moderated this effect, with diminished patient visual avoidance particularly detrimental to caregiver psychological distress of bvFTD caregivers. Findings suggest that use of visual avoidance may serve as a marker of overall emotional functioning in patients and that preservation of this emotion regulatory behavior may help reduce the negative effects of caregiving.

Keywords

emotion regulation; caregiver psychological health; Frontotemporal dementia; Alzheimer's disease

Introduction

Neurodegenerative diseases are expected to affect over 115 million people worldwide by 2050 [1]. Among these diseases, Alzheimer's disease (AD) accounts for 60–70% of all dementias. AD primarily affects medial temporal brain regions and its primary symptoms include progressive memory loss and declines in visual-spatial processing [2–4]. Frontotemporal dementia is less prevalent overall but is the second most common early

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Conflicts of Interest Statement

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onset dementia, with prevalence rates similar to early onset AD [5–7]. Frontotemporal dementia primarily affects frontal and temporal brain regions, limbic structures, and insular cortex [7]. Behavioral variant FTD (bvFTD) is characterized by progressive behavioral changes including changes in personality, emotional blunting, increased disinhibition, and inappropriate interpersonal behavior [8–9]. Given the progressive and debilitating nature of these diseases, individuals diagnosed with AD and bvFTD typically come to depend on caregivers to provide for their psychological and physical needs.

Caregiver Psychological Distress

Caring for a loved one with dementia is an important and meaningful part of family life. However, it is associated with increased burden that can lead to a host of negative outcomes including increases in physical illness, mental illness (especially depression and anxiety) and mortality [10–13]. Importantly, not all caregivers suffer these negative consequences. Thus, it is important to identify factors in the patient, the caregiver, and in the patient-caregiver relationship that create greater vulnerability or resilience to the negative effects of caregiving. Previous research has indicated that declines in patients' emotional functioning are strongly linked with increased psychological distress in caregivers [14–16]. In addition, declines in patients' emotional functioning can negatively impact the marital relationship. For example, we have found that caregivers of patients with bvFTD are less satisfied with their marriages than caregivers of patients with AD [17]. One factor that likely accounts for this difference is that poor emotion regulation, which is one of the symptoms of bvFTD [18], is particularly damaging to interpersonal relationships [19]. In studies of dementia caregiving, patients' premorbid emotion regulation patterns have been associated with individual differences in patient attachment styles, which in turn predict greater caregiver burden [20]. Thus, the extent to which patients' emotion regulation abilities are diminished may contribute importantly to increases in caregiver psychological distress.

Visual Avoidance: An Important Form of Emotion Regulation

Although a great deal of contemporary research on emotion regulation has focused on behavioral suppression and reappraisal strategies [21], emotion regulation can take a number of different forms [22]. Among "antecedent focused" strategies, one of the most common and powerful forms of emotion regulation is visual avoidance. Limiting visual processing of an unpleasant emotion-eliciting stimulus (e.g., by looking away, closing one's eyes) reduces visual sensory input and thus decreases the capacity of the stimulus to initiate a full-blown emotional response. Previous work from our laboratory has shown that dementia patients show deficits in their use of visual avoidance (Otero & Levenson, under review). Given that the ability to regulate emotion is a cornerstone of successful emotional functioning, diminished visual avoidance in patients may be linked to negative consequences for caregiver psychological distress by virtue of related deficits in both emotion regulation and in overall emotional functioning.

Present Study

The present study sought to explore the relationship between patient's use of visual avoidance and caregiver psychological distress. Our primary hypothesis was that less use of visual avoidance by patients assessed when watching a disgusting film in our laboratory

would predict greater caregiver psychological distress as measured by a self-report inventory of mental illness symptomatology. Assuming this association was found, we planned to determine whether it was mediated by caregivers' ratings of patients' emotion functioning (reflecting our view that loss of visual avoidance in dementia patients is a marker of declining overall emotional functioning). Because cognitive and neuropsychiatric deficits are so prominent in AD and other dementias, we also planned to test an alternative model that linked patients' cognitive functioning and neuropsychiatric symptomatology with caregiver psychological distress. Given prior findings of widespread losses in other areas of emotional functioning in bvFTD (e.g., emotion generation and recognition) [23, 24,18], we hypothesized that found effects would be moderated by patient diagnosis, with deficits in visual avoidance being particularly detrimental to bvFTD caregivers' mental health. Finally, although our primary focus is on overall psychological distress, we planned to conduct exploratory analyses examining particular mental health symptoms (depression and anxiety) reflecting the high prevalence of mood and anxiety disorders among dementia caregivers [25–28, 10].

Method

Participants

Eighty-six patients with dementia (43 with AD, 43 with bvFTD) and their caregivers participated in this study. Participants were recruited through the Memory and Aging Center (MAC) at the University of California, San Francisco. AD and bvFTD diagnoses were based on a comprehensive assessment that included a clinical interview, neurological and neuropsychological testing, and structural MRIs. AD patients met the Neurological and Communicative Disorders and Stroke and Alzheimer's Disease and Related Disorders Association criteria, and bvFTD patients met the Neary criteria [29]. Caregivers were all either spouses or domestic partners who identified themselves as serving as the patient's primary caregiver and playing a central role in the patient's daily life.

Procedure

Patient laboratory assessment—Patients and their caregivers came to the Berkeley Psychophysiology Laboratory at the University of California, Berkeley for a daylong session designed to provide a comprehensive assessment of emotional functioning [30]. Upon arriving, participants signed consent forms that explained the day's tasks (approved by the Committee for the Protection of Human Subjects at the University of California, Berkeley). The current study focused on a task in which patients: (a) sit quietly for a 60-second baseline period; (b) watch a 101-second film clip taken from the television show, *Fear Factor,* which shows a man sucking digestive fluids from cow intestines and has been validated as a disgust and visual avoidance elicitor in neurologically healthy adults [31, Otero & Levenson, under review]; (c) sit quietly for a 60-second post-film period; and (d) answer a series of questions assessing their comprehension and memory of the film's content and their emotional experience while viewing the film. Throughout the task, participants were videotaped for later coding of visual avoidance behaviors and a number of psychophysiological measures were obtained (these physiological data were not used in the present study). At the end of

the day, patients gave written consent for the use of their video recordings and were paid $30 for their participation.

Audio visual apparatus—Patients' facial behavior and body movements were recorded using a remotely controlled high-resolution color video camera hidden behind tinted glass on a bookshelf. All experimental stimuli were presented on a 21-inch LCD monitor positioned 24 inches from the participant. An audio track with task instructions and post-task questions was played through the monitor's speaker.

Caregiver assessment—While patients participated in the laboratory assessment, caregivers completed self-report questionnaires that assessed their psychological distress and various areas of patient functioning.

Measures

Visual avoidance—Patient behavior was coded using a behavioral coding system developed for this study. The coding system consisted of 9 head, body, and eye movements identified in the literature as indicating attentional disengagement (i.e., visual avoidance) [32, 33, 34]. The 9 visual avoidance codes were as follows: (a) head turning, (b) head down, (c) head up, (d) headshakes, (e) gaze aversion, (f) blinks, (g) eyes closed, (h) eyes covered, (i) squint. Four of the 9 codes (i.e., head turn, head down, head up, head shakes) were rated using a 4-point intensity scale with 0= no code, 1= slight intensity, 2= moderate intensity, 3= extreme intensity. Two codes (i.e., eyes closed, eyes covered) were rated using a 3-point intensity scale with 0=no code, 1=partial eye coverage, and 2= complete eye coverage. Three codes (gaze aversion, blinks, squints) were measured by tallying the total number of times the code occurred. Participants' second-by-second behavior was coded throughout the trial.

Coders were two male and one female upper level undergraduate research assistants who were naïve to the study's goal and patient diagnoses. Each coder underwent six-weeks of training consisting of formal instruction based on a coding manual, weekly practice coding assignments, bi-weekly one-hour meetings to discuss coding disagreement, and a final coding examination. Inter-rater reliability at the end of training was high (intra-class correlation coefficient = .90). To assess reliability, all three coders coded 20% of the study sample. Inter-rater reliability for the study was good (intra-class correlation coefficient = . 86). Inter-rater reliability for individual codes is shown in Table 1.

Caregiver psychological distress—Caregiver psychological distress was assessed using the Symptom Checklist 90-Revised (SCL-90-R) [35]. The SCL-90-R is a 90-item questionnaire that assesses nine domains of psychopathology (somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism). For each item, caregivers rated themselves on a five-point scale of distress from 0 (none) to 4 (extreme). For the present study, we used the Global Severity Index (GSI), which is the average score of all 90 items, and is thought to be a good indicator of psychological distress [36]. Because of the high levels of depression and anxiety disorders in caregivers [26], exploratory analyses were conducted using the depression and anxiety

subscales of the SCL-90. The SCL depression subscale (DEP) consists of 13 items assessing dysphoric mood and affect, including feelings of hopelessness and self-blame, and decreases in energy. The SCL anxiety subscale (ANX) consists of 10 items assessing somatic and psychic anxiety, including nervousness, tension, and physical trembling.

Patient dementia severity—Dementia severity was assessed using the Clinical Dementia Rating Scale (CDR) [37]. Caregivers rated patients' level of impairment in several domains found to be impaired in dementia (memory, problem-solving, orientation, judgment, community affairs, home and hobbies, and personal care). A CDR Box Score was created for each participant by summing the total scores for each domain, with higher scores indicating greater dementia severity.

Patient emotional functioning—Patient emotional functioning was assessed using the Caregiver Assessment of Socio-emotional Functioning (CASEF), a 44-item questionnaire we developed to assess 6 aspects of emotional functioning (emotional reactivity, cognitive empathy, emotional empathy, emotion regulation, emotional memory, affection, and compassion) and 6 aspects of social functioning (tendency to follow social norms, adherence to standards of morality, self-centeredness, social interest, social appropriateness, and insight into one's own emotion and behavior) [38]. For each item, caregivers rated the patient's tendency to engage in certain behaviors during the past month on a 5-point scale from 0 (not at all) to 4 (a lot).

Because of our interest in examining whether the relationship between patient visual avoidance and caregiver psychological distress was mediated by patient overall emotional functioning, we only utilized the 33-item emotional functioning subscale (e.g., "Patient expresses anger", "Patient is warm/affectionate toward spouse/partner/family") in the present study. A score for overall emotional functioning was computed by averaging all 33 items. Inter-item reliability was good (Cronbach's α = .94).

Patient cognitive functioning—Patient cognitive functioning was assessed using the cognitive subscales of the CDR (i.e., memory, orientation, and problem-solving). Caregivers rated patients' cognitive functioning on a 0–3 scale, with higher scores representing greater levels of cognitive impairment. A composite cognitive functioning score was computed by averaging the total score of each cognitive domain.

Patient neuropsychiatric symptomatology—Patient neuropsychiatric symptoms were assessed using a clinician rated Neuropsychiatric Inventory (NPI) total score [39]. The NPI total score consists of the sum of 12 subscale scores including delusions, hallucinations, dysphoria, irritability, agitation, anxiety, apathy, disinhibition, euphoria, aberrant motor behavior, night-time behavior disturbances, and appetite and eating abnormalities.

Caregiver wellbeing—Caregiver wellbeing was assessed using the Medical Outcomes Study 36-Item Short Form Health Survey (SF-36) [40]. The SF-36 consists of 8 subscales including, 1) physical functioning; 2) role limitation due to physical health problems; 3) role limitations due to emotional problems; 4) bodily pain; 5) social functioning; 6) general mental health (psychological well being and distress); 7) vitality (energy and fatigue); 8)

general health perceptions. A SF-36 composite score was compute by averaging the scores of all 8 subscales.

Data Reduction

Visual avoidance—Preliminary analyses revealed that two of the nine codes (squints and eyes covered) rarely occurred (squint in 4.2% of participants and eyes covered in 0.8% of participants). Thus, they were excluded from further analyses. This left seven visual avoidance codes: head turning, head up, head down, gaze aversion, blink, eye closed, and headshake.

An overall visual avoidance score for each patient was computed as follows. First, for each of the seven coded behaviors, the intensity scores for each second of the film were summed and divided by 101 (the duration of the film in seconds) producing an average intensity per second. These average intensity scores were then converted to z-scores (using the mean and standard deviation from the entire sample) and summed to create a single composite score of visual avoidance for each participant. The reliability of this overall score was moderate (Cohen's α = .53) [41]. To control for Type I error, we conducted our primary analyses using this overall score, but also conducted follow-up analyses using the individual codes.

Results

Demographic and Clinical Variables

A chi-squared test was used to examine the distribution of males and females within the diagnostic groups. No sex differences were found, χ^2 (2, N=86) = .44, *ns.* An analysis of variance (ANOVA) was used to examine age differences between the groups. No age differences were found between AD and bvFTD patients, F (1, 84) = 11.91, *ns*. ANOVAs were also used to examine diagnostic group differences in patient disease severity and neuropsychiatric symptomatology, as well as overall caregiver health. BvFTD patients showed significantly greater disease severity, F (1, 84) = 77.71, p = .001, and NPI total scores, F (1, 82) = 53.52, p < .001, compared to AD patients. No differences were found between bvFTD and AD caregiver health, F (1, 80) = 1.45, *ns* (see Table 2 for means and standard deviations)

Patient Visual Avoidance and Caregiver Psychological Distress

Caregiver psychological distress—We conducted a multiple linear regression analysis to examine whether visual avoidance in patients predicted caregiver psychological distress. To control for dementia severity, we entered the CDR Box Score in the first step. In the second step, we entered patient visual avoidance, which accounted for significant additional variance (F *change* (1, 83) = 5.80, p = 0.018). In this second step, dementia severity did not predict caregiver psychological distress (t (83) = 0.23, p = 0.816), but less patient visual avoidance significantly predicted greater caregiver psychological distress (β = −0.26, t (83) = −2.41, p = 0.018) (see Table 3 for patient visual avoidance means and standard deviations).

Indirect Effect of Patient Emotional Functioning

Having established an association between lower patient visual avoidance and greater caregiver psychological distress, we next conducted a mediation analysis to test whether this association was mediated via caregiver reports of lower patient emotional functioning. This analysis utilized a least squares path analysis in which patient visual avoidance was the independent variable, caregiver psychological distress was the outcome variable, and caregiver ratings of patient emotional functioning was the mediator. In order to control for the impact of overall caregiver wellbeing on caregiver perception of patient emotional functioning, caregiver SF-36 total score was included as a covariate.

Results revealed a significant indirect effect of patient emotional functioning on patient visual avoidance and caregiver psychological distress, [*IE*] = −0.01, *SE* = 0.01, 95% *CI* −0.03 – 0.00, indicating that patients who showed less visual avoidance in the laboratory assessment were seen by their caregivers as having lower levels of overall emotional functioning which in turn was associated with greater caregiver psychological distress, even when controlling for overall caregiver wellbeing (see Figure 1). There was also evidence for a direct effect of less patient visual avoidance on greater caregiver psychological distress, [*DE*] = −0.01, *SE* = 0.01, 95% *CI* −0.03 – 0.00, *p* = .021, indicating that some of the association between lower visual avoidance by patients and greater caregiver psychological distress may be transmitted in other ways besides lower patient emotional functioning.

Other possible candidates accounting for the association between lower patient visual avoidance and greater caregiver psychological distress are lower patient cognitive functioning and greater patient neuropsychiatric symptomatology. To test this possibility, we conducted a multiple mediation analysis in which patient visual avoidance was the independent variable, caregiver psychological distress was the dependent variable and all three patient factors (emotional functioning, cognitive functioning, and neuropsychiatric symptomatology) were mediators. This analysis revealed that the indirect effect of lower patient emotional functioning remained significant even when patient cognitive functioning and neuropsychiatric symptomatology were entered into the model, [*IE*] = −0.01, *SE* = 0.01, 95% *CI* −0.03 – 0.00. A comparison of indirect effects showed that the indirect effect of lower patient emotional functioning was significantly stronger than both the indirect effect of lower patient cognitive functioning, [contrast *IE*] = −0.01, *SE* = 0.01, 95% *CI* −0.03 – 0.00, and greater neuropsychiatric symptoms, [contrast IE]= −0.01, SE= .01, 95% C1 −0.03 – 0.00. Thus, we conclude that in this sample of patients lower patient emotional functioning is more important than lower patient cognitive functioning and greater neuropsychiatric symptomatology for understanding the relationship between lower patient visual avoidance and greater caregiver psychological distress.

Moderation by Diagnosis

To determine whether patient diagnosis moderated the effect of patient visual avoidance on caregiver psychological distress, we included the interaction of diagnosis and patient visual avoidance behavior in a regression analysis (patient visual avoidance was mean-centered and patient diagnosis was coded as AD = 0, bvFTD = 1). Results revealed a significant interaction between patient diagnosis and visual avoidance behaviors ($\beta = -0.05$, $t(82) =$

−2.39, 95% *CI* −0.09 – −0.01, $p = 0.020$), such that lower patient visual avoidance was associated with greater caregiver psychological distress in bvFTD couples ($t(82) = -2.84$, 95% *CI* −0.09– −.02, $p = 0.006$), but not in AD couples, ($t(82) = -0.59$, 95% *CI* −0.02 – 0.1, $p = 0.559$. These results indicate that the associations among lower visual avoidance in patients and greater psychological distress in caregivers are particularly pronounced for bvFTD patients and their caregivers.

Exploratory Analyses

Patient Visual Avoidance and Caregiver Depression and Anxiety—Exploratory analyses were conducted to determine whether less patient visual avoidance was associated with greater caregiver depression and anxiety, as assessed by the DEP and ANX subscales of the SCL-90. Two separate multiple regression analyses were used with CDR Box Score as a covariate, patient visual avoidance as the predictor variable, and caregiver DEP and ANX scores as outcome variables (see Table 4 for caregiver means and standard deviations).

Caregiver depression: To control for dementia severity, we entered the CDR Box Score in the first step. In the second step, patient visual avoidance accounted for additional variance (F *change* $(1, 79) = 4.02$, $p = 0.048$). In this second step, dementia severity did not predict caregiver depression ($t(79) = 0.24$, $p = 0.815$), but less patient visual avoidance predicted greater caregiver depression ($\beta = -0.22$, $t(79) = -2.01$, $p = 0.048$).

Caregiver anxiety: To control for dementia severity, we entered the CDR Box Score in the first step. In the second step, patient visual avoidance again accounted for additional variance (F *change* $(1, 79) = 4.37$, $p = 0.040$). In this second step, dementia severity did not predict caregiver anxiety ($\beta = 0.05$, $t(79) = -0.04$, $p = 0.966$), but less patient visual avoidance significantly predicted greater caregiver anxiety ($\beta = -0.23$, $t(79) = -2.09$, $p = 0.040$).

Individual Visual Avoidance Codes as Predictors of Caregiver Mental Illness

An exploratory multiple regression was also conducted to examine the relationship between individual visual avoidance codes and caregiver psychological distress. To control for dementia severity, we entered the CDR Box Score in the first step. Patient individual visual avoidance codes (i.e., head turn, head down, head up, head shake, gaze aversion, blinks, eyes closed) were entered in the second step and accounted for additional variance (F *change* $(7, 76) = 2.27$, $p = 0.037$). In this second step, dementia severity did not predict caregiver psychological distress ($\beta = -0.00$, $t(76) = -0.03$, $p = 0.979$), but fewer patient headshakes (i.e., turning the head from side to side in a successive manner) predicted greater caregiver psychological distress ($t(76) = -2.09$, $p = 0.040$). In addition, less eye closures marginally predicted greater caregiver psychological distress ($\beta = -0.23$, $t(76) = -1.99$, $p = .050$).

Discussion

Using a laboratory-based assessment of visual avoidance in response to a disgust-eliciting film, we found that low levels of visual avoidance in dementia patients were associated with high levels of psychological distress in their familial caregivers. Meditational analyses

revealed that this relationship was accounted for more by lower levels of emotional functioning (measured by caregiver report on the CASEF) than by lower levels of cognitive functioning (measured by caregiver report on the CDR cognitive subscales) or higher levels of neuropsychiatric symptoms (measured by clinician report on the NPI total score). Finally, the relationship was stronger in patients with bvFTD, a form of dementia associated primarily with declines in social and emotional functioning, than in patients with AD, which is associated primarily with declines in cognitive functioning [42].

Exploratory analyses revealed that lower levels of visual avoidance among patients predicted less caregiver depression and anxiety. Lastly, considering all individual visual avoidance codes together revealed that only less patient headshakes was significantly associated with greater caregiver psychological distress, above and beyond patient disease severity.

Implications for understanding and preventing caregiver psychological distress

Caring for a loved one with dementia can be a deeply rewarding experience; however, it is also extremely taxing for caregivers. The associated burden can lead to negative outcomes for caregivers including increases in mental and physical illness and mortality [12, 43, 44]. With the aging population and attendant rise in cases of dementia, an increasing number of people will be providing care for a loved one with dementia. Thus, it is critically important to improve understanding of the factors that contribute to vulnerability and resiliency to psychological distress in caregivers. This knowledge has implications both for understanding the etiology of mental illness in caregivers and for identifying potential targets for preventative and therapeutic interventions. Among these factors, patients' deficits in emotional regulation may be particularly important, given the importance emotion regulation has for adaptive interpersonal interactions [19] and the importance that social relationships have for mental health [45, 46]. The present study focused on visual avoidance, a common form of emotion regulation that limits visual sensory input when we are confronted with a powerful emotional stimulus. We found that low levels of visual avoidance in patients when viewing a disgusting film were associated with greater psychological distress in their caregivers.

Although declines in patients' visual avoidance behaviors by themselves may be quite stressful for caregivers (e.g., it is unsettling when someone fails to follow social conventions regarding attention and inattention), our mediation analyses suggest that deficits in visual avoidance are associated with caregiver-perceived deficits in broader areas of emotional functioning which, in turn, are associated with greater psychological distress in caregivers. These broader deficits could include declines in other emotional behaviors that are important for caregiver well-being such as reductions in patients' ability to empathize (e.g., inability to recognize emotions in others; Brown, et al., under review), react appropriately to other kinds of emotional stimuli (e.g., diminished self-conscious emotion) [47], and regulate emotion in other ways (e.g., by suppression) [48]. Research exploring the nature of declines in these and other areas of emotional functioning that accompany deficits in visual avoidance and their relative contributions to caregiver psychological (and physical) stress will be extremely valuable. Although the current study did not find that patient NPI total scores mediated the effect of patient visual avoidance on caregiver psychological distress, the negative impact of

patient neuropsychiatric symptoms on caregiver wellbeing is well documented [49–54]. Thus, future studies will also benefit from examining how patient emotional functioning relates to broader neuropsychiatric symptomatology known to negatively impact caregivers, such as behavioral disinhition (including sexual disinhibition), apathy, and aggression.

Deficits in patients' emotional functioning are likely to be particularly stressful and burdensome for caregivers, weakening interpersonal attachments [17], reducing the social and emotional support caregivers derive from these relationships, and contributing to psychological decline and development of mental illness in caregivers. In considering the burden experienced by caregivers of patients with bvFTD and AD, the behavioral changes in bvFTD can be particularly difficult for caregivers [17, 55–57]. We expect that this is why the relationships among deficits in patients' visual avoidance, low levels of patients' emotional functioning, and high levels of caregiver psychological distress were stronger when patients had bvFTD than AD. Patients with bvFTD are more likely to show declines in broad areas of emotional functioning than patients with AD (at least in the early stage of the disease) [58, 59]. Thus, declines in visual avoidance in patients with bvFTD are less likely to be offset by preservation of other areas of emotional functioning.

Strengths and limitations

This study found that deficits in patients' visual avoidance behaviors when viewing a disgusting film were associated with greater psychological distress in caregivers. Strengths of the study included: (a) using an objective measure of visual avoidance, an important and often understudied form of emotion regulation, (b) studying patients with multiple kinds of dementia (bvFTD and AD), (c) having a relatively large sample size for this kind of patient research, and (d) considering both emotional, cognitive, and neuropsychiatric mediators. Limitations included: (a) only measuring avoidance behaviors to a single film stimulus and a single emotion (additional film stimuli would allow us to examine the generalizability of our findings), and (b) measuring all variables close in time (a longitudinal design would have been preferable both for evaluating possible directions of influence and for providing a stronger test of mediators). In terms of bidirectional influence, declines in patients' visual avoidance and associated declines in their overall emotional functioning are plausible contributors to caregivers' psychological distress. Conversely, declining psychological health in caregivers could contribute to declining visual avoidance in patients (e.g., via distracted caregivers providing less corrective feedback to patients).

Conclusion

The present study found that lower levels of patients' visual avoidance in response to a disgusting film were related to higher levels of caregiver psychological distress and that this relationship was indirectly transmitted via lower overall patient emotional functioning (as rated by the caregiver) and not via patients lower cognitive functioning or greater neuropsychiatric symptomatology. In addition, results were moderated by patient diagnosis such that these associations were stronger in bvFTD caregivers than AD caregivers. With the rising rates of dementia and other neurodegenerative diseases, there will be increasing numbers of familial caregivers exposed to the challenges of caregiving. Thus, it is critically

important to identify factors in patients, caregivers, and patient-caregiver relationships that influence vulnerability and resiliency of caregivers to mental and physical illness. These factors can be used to identify individuals who are at heightened risk for negative outcomes associated with caregiving and as targets for preventative and therapeutic interventions.

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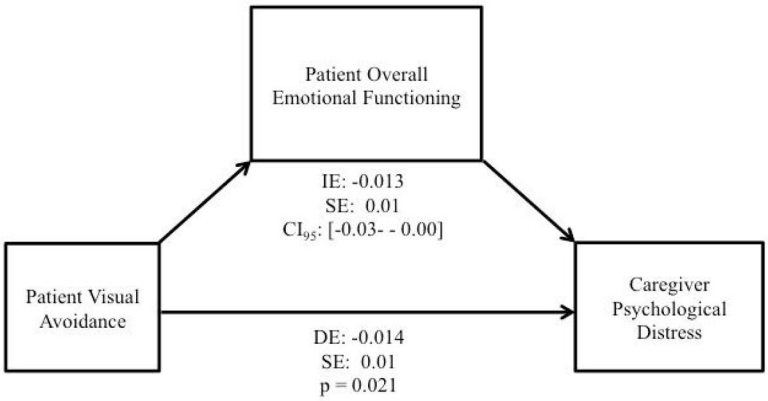

Figure 1.

The relationship between patient visual avoidance and caregiver psychological distress was indirectly transmitted by patient overall emotional functioning, even when controlling for caregiver wellbeing. There was also a direct effect of patient visual avoidance on caregiver psychological distress. independent of patient emotional functioning. Data represent indirect and direct effects and standard errors using 10.000 bootstrap samples to obtain bias-corrected and accelerated 95% confidence intervals and p values.

Table 1

Inter-rater Reliabilities for Individual Visual Avoidance Codes

Behavior	Inter-rater ICC
Blinks	1.00
Head Turn	0.76
Head Down	0.85
Head Up	0.58
Squints	0.99
Eyes Closed	0.91
Eyes Covered	1.00
Gaze Aversion	0.73
Head Shake	0.94

Table 2

Demographic and Clinical Variables

	AD	bvFTD
N	43	43
Sex (male)	18 (25)	15 (28)
	M (SD)	M (SD)
Age	61.81 (8.22)	61.07 (8.24)
CDR-BS	4.68 (2.17)	6.58 (3.04)
SF-36	76.72 (13.87)	72.94 (14.58)
NPI Total Score	18.33 (15.44)	46.19 (19.25)

Note. CDR-BS = Clinical Dementia Rating Scale- Box Score; SF-36 = Medical Outcomes Study 36-Item Short Form Health Survey; NPI = Neuropsychiatric Inventory

Table 3

Patient Visual Avoidance Composite (Entire Task), Patient Overall Emotional Functioning, Cognitive Functioning, & Neuropsychiatric Symptomatology

	AD	BvFTD
	M (SD)	*M (SD)*
Visual Avoidance	1.16 (4.42)	−1.16 (1.85)
CASEF Emotional Functioning Subscale	2.06 (.61)	1.25 (.60)
CDR Cognitive Subscales Average	.82 (.34)	1.07 (.42)

Note. CASEF = Caregiver Assessment of Socioemotional Functioning

Table 4

Caregiver Psychological Distress, Anxiety, & Depression

	AD	bvFTD
	M (SD)	M (SD)
SCL-90-R-GSI	.56 (.23)	.71 (.25)
SCL-90-R DEP	.71 (.36)	.95 (.38)
SCL-90-R-ANX	.45 (.35)	.65 (.35)

Note. SCL-90-R GSI = Symptom Checklist-90-Revised, Global Severity Index; SCL-90-R DEP = Symptom Checklist-90-Revised, Depression Subscale; SCL-90-R ANX = Symptom Checklist-90-Revised, Anxiety Subscale