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Relationship Satisfaction and Emotional Language in Frontotemporal Dementia and Alzheimer's Disease Patients and Spousal Caregivers

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Abstract

We studied the impact of two types of dementia on marital satisfaction and on the emotional language spouses use during conflictive marital interactions. Fifteen frontotemporal dementia (FTD) and 16 Alzheimer's disease (AD) patient-caregiver couples, as well as 21 control couples, discussed a relationship problem in a laboratory setting. Marital satisfaction was assessed via questionnaire, and emotion language was quantified using text analysis. FTD couples reported lower marital satisfaction than AD and control couples. During the interactions, FTD and AD caregivers used significantly more negative emotion words than their patient spouses (no spousal differences were found in control couples). FTD caregivers also used more negative words than AD caregivers and controls. We interpret these findings as reflecting challenges that the behavioral changes in FTD create for maintaining a healthy marital bond.

Keywords

frontotemporal dementia; Alzheimer's disease; marital satisfaction; emotional language

INTRODUCTION

Caregiving for dementia patients is typically provided by their spouses;^{1,2} thus, understanding the effects of dementia on marriage is particularly important. Existing research on these marriages has focused on Alzheimer's disease (AD) and has relied largely on caregiver reports of relationship qualities. This research indicates that dementia creates a number of difficulties for caregiver spouses, including deterioration in relationship quality, lower relationship satisfaction, and decreased emotional and physical intimacy.^{3–6} The AD literature consistently identifies the behavioral symptoms of dementia (e.g., agitation, apathy, disinhibition, loss of insight, wandering) as key contributors to greater perceived caregiver burden^{2,7–11} and lower relationship satisfaction.^{3,12}

Given the impact of behavioral symptoms, we would expect differences in relationship quality between patient-caregiver couples to be associated with varying degrees of behavioral disturbance. While the primary impairments in AD are cognitive, in frontotemporal dementia (FTD), the primary deficits are behavioral, manifested in striking social, emotional, and

personality changes.^{13–24} Behavioral changes do occur in AD, but they often appear much later in the course of the illness.^{25–27} In contrast, behavioral changes in FTD occur early,^{28, 29} distinguishing these patients from those with AD and vascular dementia.³⁰ Studies comparing caregiving in AD and FTD find that FTD caregivers experience a greater degree of general burden, stress, and depression, and feel less satisfied in their caregiving roles than AD caregivers, despite comparable levels of functional impairment between FTD and AD patients.^{31–35} To our knowledge, no previous studies have compared the quality of the marriage and the nature of marital interaction between these two diseases.

In the present study we examined marital satisfaction and marital interaction in AD and FTD couples. Marital satisfaction was assessed using a standard questionnaire.³⁶ Observational studies of marital interaction have been rare in the dementia literature.^{but see 37} To obtain an ecologically valid, dynamic snapshot of the interactions of patient-caregiver couples, we utilized a marital interaction paradigm that we have used extensively with non-patient couples in which spouses discuss and try to resolve a relationship conflict.³⁸ We applied a text analysis methodology³⁹ to transcripts of these discussions to assess positive and negative emotional language used by patients and caregivers during the interactions. This approach to assessing emotional language is based on the assumption that the words that appear in natural, spontaneous language reflect underlying psychological states and are less prone to the biases of self-report than questionnaire measures.⁴⁰ Text analysis of emotional language has been used with a number of different kinds of interacting dyads^{41,42} including interactions of married couples.^{43,44}

Given the generally stressful nature of caring for a dementia patient, we hypothesized that caregivers of both AD and FTD patients would report lower marital satisfaction and use more negative emotional language and less positive emotional language than controls. Because behavioral symptoms are strongly associated with decreased relationship satisfaction for caregivers³ and because FTD patients are more likely to show such symptoms than AD patients,³⁰ we hypothesized that FTD caregivers would have lower marital satisfaction, would use more negative emotional language and less positive emotional language than AD caregivers.

Because FTD patients have a dramatic lack of awareness of their disease^{45–47} and a proclivity to inflate positive traits and underreport negative ones,⁴⁸ we hypothesized that FTD patients would show a positive bias on our measures (i.e., higher marital satisfaction, less negative and more positive emotional language than both their spouses and AD patients). Given AD patients' tendencies to minimize marital problems compared to their spouses,^{49,50} we hypothesized that AD patients would also show a positive bias on our measures compared to their spouses.

METHODS

Participants

Overview—Participants were 52 male-female couples recruited by the Memory and Aging Center (MAC) at the University of California, San Francisco as part of a larger study of neurodegenerative diseases. In each couple, one member was either a dementia patient (diagnosed with FTD or AD) or a neurologically healthy control. The other member was the patient or control's spouse or domestic partner (there was one domestic partnership in each of the three groups; the remainder were marriages). Group sizes, mean ages, and sex distribution are reported in Table 1.

Recruitment and diagnostic process—Dementia patients were recruited from the pool of referrals to the MAC and had to meet research criteria for either FTD¹⁸ or probable AD.⁵¹ Patients were diagnosed by trained MAC staff through a review of data from neurological assessments, clinical interviews, case histories, neuropsychological tests, and brain imaging.

AD patients tend to be older than FTD patients, thus, to equalize age, we recruited early-onset AD patients. Control couples were recruited from the local community via advertisements and word-of-mouth and were neurologically and psychiatrically healthy as determined by a complete evaluation at the MAC.

All patients and controls were required to have a spouse or partner willing to participate. In the remainder of this paper, members of control couples are identified as either the “control patient,” to refer to patient analogs or the “control caregiver” to refer to caregiver analogs.

Measures

Dementia severity—The Clinical Dementia Rating Scale (CDR)⁵² was administered by trained MAC staff. The CDR includes a structured interview administered to caregivers that assesses six domains of daily functioning. The CDR is widely used as a measure of dementia severity, with higher scores indicating greater impairment. The CDR box score was computed by summing the subscores for each of the six domains⁵³ (scores range from 0 to 18).

Marital satisfaction—The Locke-Wallace Marital Adjustment Scale³⁶ was administered to both partners of each couple. (One couple in the FTD group and another in the control group did not complete the Locke-Wallace questionnaire for unknown reasons.) The Locke-Wallace is a well-established self-report measure of marital satisfaction containing 15 items, e.g., “When disagreements arise, they usually result in (a) husband giving in, (b) wife giving in, (c) agreement by mutual give and take.” Scores range from 2 to 158, with higher scores indicating greater marital satisfaction. Scores of 100 or above are generally considered to indicate satisfied couples, with scores below 100 indicating dissatisfied couples.

Procedure

General procedure—Participants in the present study were evaluated at the University of California, Berkeley using a comprehensive battery of tasks assessing emotional functioning. 54 One of these tasks, a social interaction task³⁸ (described below) was used to assess emotional language.

Social interaction task—Couples participated in a 15-minute conversation about an area of conflict in their relationship. The pair chose the conversation topic in advance with the guidance of an experimenter. The conversation was preceded by a five-minute silent baseline period. Couples were seated in chairs facing each other. Each participant wore a small microphone attached to the shirt collar to record speech. Audio and video recordings of the interaction were made; however, for the present study, only the audio recording was used.

Data Reduction

Text analysis—From the audio recording of each interaction, a verbatim transcript was prepared according to common transcription standards.⁵⁵ The transcripts were analyzed using a text analysis program (Oedipus Text) written by one of the authors (R.W.L.). The program compared each word in the transcript against a dictionary of emotion words and assigned it to a discrete emotion category (described below). It then presented the word in its context (the preceding sentence, the sentence it occurred in, and the following sentence) to a trained coder, blind to diagnostic grouping, who determined whether the word was in fact used in an emotional way. This context-coding was done to avoid counting non-emotional homonyms (e.g., “what do you *mean*,”) and phrases (e.g., “I’m *afraid* I don’t understand”).

Emotion word dictionary—Inclusion of words in the emotion dictionary was based on a number of studies of the emotional lexicon.^{56–58} This composite list consisted exclusively of words that met the criteria for an emotion state as defined by Ortony et al.⁵⁷ (e.g., happy, angry,

sad, elated, passionate, relieved), and did *not* include emotion-related words that do not refer to emotional states per se (e.g., baffled, abandoned, tingly). There were approximately 1500 emotion words in the dictionary (approximately 300 word roots, plus all possible variations) in two superordinate valence categories: positive and negative. These categories were derived from 27 subordinate discrete categories of emotion⁴⁴ as follows: 12 categories (amusement, excitement, general positive emotion, interest, joy, love-general, love-parental, love-romantic, pride, relaxation, relief, satisfaction) were collapsed into the positive emotion category; and 15 categories (anger, anxiety, apathy, contempt, disgust, embarrassment, envy, fear, general negative emotion, grief, guilt, jealousy, pain, sadness, shame) were collapsed into the negative emotion category.

Because of low base rates in many of the 27 subordinate categories, we relied on the superordinate valence categories for all analyses. Three variables were computed for each speaker: number of positive words, number of negative words, and total number of words (emotional plus nonemotional) used during the 15-minute conversation. Speakers' total words were used as covariates in all emotional language analyses.

Data Analysis

Analyses were conducted using 3×2 mixed-model analysis of variance (ANOVA) for age and analyses of covariance (ANCOVAs) for marital satisfaction and emotional language. In these analyses, diagnosis (FTD, AD, or control) was treated as a between-subjects factor and partner (caregiver or patient) was treated as a within-subjects factor (reflecting the interdependence of spousal data).⁵⁹ In the ANCOVAs, age and dementia severity were used as covariates (see below). Significant main effects and interactions were followed up with Bonferroni-adjusted pairwise comparisons of the estimated marginal means.

RESULTS

Sex, Age, and Dementia Severity

Before testing our hypotheses, we assessed differences in sex, age, and dementia severity (Table 1). A Fisher's exact test of sex revealed no significant differences in the proportions of caregiver and patient sex across the three groups ($p = .33$).

An ANOVA with age as the dependent variable revealed significant main effects for diagnosis, $F(2,49) = 10.95, p < .001$, and partner, $F(1,49) = 15.39, p < .001$, but no significant Diagnosis \times Partner interaction, $F(2,49) = 0.72, p = .49$. Follow-up tests of the main effects revealed that control couples were significantly older than both FTD ($p < .01$) and AD couples ($p < .001$), but that FTD and AD couples did not differ from each other ($p = 1.00$). Across the sample, caregivers were younger than patients ($p < .001$).

An ANCOVA of dementia severity using the CDR box score as the dependent variable and patient age as a covariate revealed a significant main effect for diagnosis, $F(2,48) = 51.67, p < .001$. Post-hoc comparisons showed all three groups were significantly different from each other. As expected, control patients were less impaired than both FTD and AD patients ($p < .001$). Between the two dementia groups, AD patients showed less impairment than FTD patients ($p < .01$).

Because differences were found both in age and dementia severity, these were used as covariates in all subsequent analyses.

Marital Satisfaction

The ANCOVA for marital satisfaction (controlling for caregiver age, patient age, and CDR¹) revealed a significant main effect for diagnosis, $F(2,44) = 8.57, p < .001$. The main effect for partner, $F(1,44) = 0.48, p = .49$, and the Diagnosis \times Partner interaction, $F(2,44) = 1.20, p = .31$, were not significant. Follow-up comparisons showed that FTD couples were less satisfied than both AD ($p < .001$) and control ($p < .01$) couples. AD and control couples were not significantly different from each other ($p = 1.00$). Adjusted means and standard errors for marital satisfaction are reported in Table 2.

Emotional Language

ANCOVAs were conducted on negative emotion words and positive emotion words, each controlling for CDR and both partners' ages, as well as total words uttered by each speaker. The ANCOVA for negative emotion words revealed a significant main effect for diagnosis, $F(2,44) = 5.02, p < .05$, and a significant Diagnosis \times Partner interaction, $F(2,44) = 9.64, p < .001$, but no significant main effect for partner, $F(1,44) = 0.86, p = .36$. Given the significant interaction, the diagnosis main effect was not interpreted.

The Diagnosis \times Partner interaction was followed up with simple effects tests of the adjusted means. Examining each partner within each diagnostic group, FTD caregivers used more negative emotion words than FTD patients, $F(1,44) = 31.56, p < .001$. AD caregivers also used more negative emotion words than AD patients, $F(1,44) = 4.28, p < .05$, though this difference was no longer significant when the analysis was repeated within the two dementia groups only.^{see note 1 above} There were no significant differences between control caregivers and patients, $F(1,44) = 2.12, p = .15$. Looking at the three diagnoses within each partner, there were significant differences within caregivers, $F(2,44) = 10.70, p < .001$, but not within patients, $F(2,44) = 0.22, p = .81$. FTD caregivers used more negative emotion words than both AD ($p < .001$) and control ($p < .001$) caregivers. AD and control caregivers were not significantly different from each other ($p = .19$).

The ANCOVA for positive emotion words revealed no significant main effects for diagnosis, $F(2,44) = 0.26, p = .77$, or partner, $F(1,44) = 0.07, p = .79$, and no Diagnosis \times Partner interaction, $F(2,44) = 0.10, p = .90$. Adjusted means and standard errors for emotional language are reported in Table 2.

DISCUSSION

Prior research has found that caregiving for a spouse with dementia takes a toll on marital satisfaction. In the present study, we extended this work by examining marital satisfaction and the use of emotional language and by including both AD and FTD patient-caregiver couples.

As hypothesized, we found that FTD couples had lower levels of marital satisfaction than AD and control couples. We believe this finding reflects the fact that the behavioral and emotional symptoms of FTD (e.g., apathy, disinhibition, lack of empathy) are particularly destructive for the marital bond. We had also hypothesized that dementia patients would report higher levels of marital satisfaction than caregiving spouses. We found no evidence of this for either patient group. If we assume that the caregiving spouse's rating of marital satisfaction is accurate, then FTD patients may be more aware of relationship quality than they are in other interpersonal domains such as personality change⁴⁸ and awareness of others' emotions.²⁴ We did not find

¹Because of the floor effect for control patients' CDR scores, the analyses for marital satisfaction and emotional language were repeated comparing FTD and AD only, controlling for dementia severity (along with all other covariates included in the original analyses). The secondary analyses revealed the same pattern of differences between the two dementia groups as found when all three groups were included.

evidence supporting the observation that AD patients minimize marital problems compared to their spouses.^{49,50} However, in the population we studied, marital satisfaction was relatively high in AD couples. Thus, there may not have been a great deal of dissatisfaction for AD patients to minimize.

As hypothesized, FTD caregivers used more negative emotional language than AD and control caregivers during a social interaction. Within dementia couples, caregivers – particularly FTD caregivers – used more negative words than their patient spouses, but no such differences were found for control couples. Importantly, these differences were found after controlling for dementia severity. Negative emotion has been strongly associated with poor marital outcomes in studies of non-patient couples at all ages.^{60,61} Thus, these findings involving negative emotional language provide a new window onto the difficulties that FTD causes for the marriage.

Our hypothesis that we would find a lack of positive emotional language in FTD couples was not supported. This may reflect the marital interaction task we used, which focused on an area of marital conflict and, thus, does not elicit a great deal of positive emotion.⁶⁰ The question of whether there are deficits in positive emotional language in dementia couples could be profitably revisited in a future study using a discussion topic that is more conducive to the expression of positive emotion.

Taking the marital satisfaction and emotional language findings together, the lower marital satisfaction reported by both spouses and the greater use of negative emotional language by caregiving spouses in FTD couples underscores the profound impact that FTD has on the marriage. The discrepancy between marital satisfaction and emotional language in the FTD patients (i.e., they report lower marital satisfaction but do not use greater negative emotional language) points to one of the subtle challenges of dealing with FTD patients. In these patients, declines in cognitive, social, and emotional functioning may proceed at different rates,^{17,19,20,62,63} resulting in inconsistencies that are disturbing for their partners (e.g., accurate assessment of marital distress that is not reflected in the use of negative emotional language).

The burden associated with caring for a family member with AD has been extensively documented^{2,64,65} and clearly is extremely taxing for caregivers. However, our finding that AD couples reported similar levels of marital satisfaction and used similar amounts of negative emotional language to control couples suggests that AD may burden, but not erode, the marital relationship. This conclusion is further supported by the mean marital satisfaction scores in AD couples (adjusted mean = 117.92), which are in the range indicative of satisfied marriages, compared to those of FTD couples (adjusted mean = 88.22), which are in the range indicative of dissatisfied marriages.

Why might this be? We believe that when a loved one loses the ability to be empathic and to connect emotionally, as in FTD,^{18,24} caregivers are likely to become frustrated, hurt, and angry, and that relationship satisfaction will decline. In contrast, when a loved one starts to forget things and forget people and becomes increasingly confused, but still maintains the ability to be empathic and to connect emotionally, as in AD,⁶⁶ caregivers are likely to experience sadness and grief, combined with more positive emotions such as affection, sympathy, and love. Consistent with this, despite caregiving stress and burden, AD caregivers have reported feeling as close, if not closer, to their patient spouses than before the illness.^{3,6}

Limitations and Future Directions

As noted earlier, the present study expanded on the existing literature on dementia and marriage by measuring both marital satisfaction and the use of emotional language during marital interaction and by including two kinds of dementia. Because we examined relationship

satisfaction and the use of emotional language at a particular moment in time, however, we were limited in our ability to characterize the longitudinal relationship and interactions between increasing dementia severity and changes in the marriage.⁶⁷ Further, our dementia couples were recruited from a tertiary care specialty clinic; thus, we do not know if our results would generalize to dementia patients and caregivers in the population at large.^{68,69}

Our findings of differences in marital satisfaction and negative emotional language in FTD and AD couples point to the importance of considering interventions that target the difficulties specific to each form of dementia. Dementia caregiver intervention research has made great strides in developing theoretical models, testing a range of therapeutic approaches, and demonstrating successful burden reduction in a number of domains.⁶⁵ However, the bulk of this research has been focused exclusively on AD caregivers. Future work is needed that includes FTD patients and their caregivers and that takes into account the particular difficulties that FTD symptoms create for relationships.

Conclusion

This study underscores the profound challenges that FTD creates for couples, highlighting the lowered relationship satisfaction and increased negative emotional language associated with the disease. Caring for a loved one suffering from a neurodegenerative illness is difficult and painful regardless of the particular disease. Providing this care in FTD, when the patient begins to lose the capacity for emotional responsivity, empathy, self-awareness, and social appropriateness, may be particularly damaging to the marital bond.

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Table 1

Age, Sex, and Dementia Severity

Group	N	Age		Sex		Patient CDR box score	
		Caregiver	Patient	Couple	adj mean (SE)	Caregiver	Patient
FTD couples	15	56.90 (7.60)	60.37 (6.09)	58.64 (1.53)	13/2	2/13	6.93 (0.51)
AD couples	16	54.02 (7.03)	59.28 (5.28)	56.65 (1.48)	10/6	6/10	4.56 ^e ** (0.50)
Control couples ^b	21	64.03 (6.60)	66.58 (7.88)	65.30 ^c ***, <i>d</i> ** (1.30)	15/6	6/15	-0.09 ^f *** (0.45)
adj mean (SE)							
Total	52	58.31 (0.99)	62.08^e*** (0.93)	60.19 (0.83)	38/14	14/38	3.80 (0.27)

FTD = frontotemporal dementia; AD = Alzheimer's disease; SD = standard deviation; adj = adjusted; SE = standard error; F = female; M = male; CDR = Clinical Dementia Rating Scale.

^aCorrected for patient age.

^bFor controls, the "patient" was the member of the couple who participated in the larger study being conducted through the UCSF MAC and UC Berkeley, as a patient analog; the "caregiver" was the member of the couple who participated in a subset of study tasks, as a caregiver analog. Unless otherwise noted, analyses reporting on "patients" include control patient analogs and analyses reporting on "caregivers" include control caregiver analogs.

^cControl couples > AD couples

^dControl couples > FTD couples

^ePatients > caregivers

^fControls < FTD & AD

^gAD < FTD

** $p < .01$,

*** $p < .001$

Table 2

Marital Satisfaction and Emotional Language

Group	Marital satisfaction			Emotional language					
	Locke-Wallace			Negative			Positive		
	N	adj mean ^a (SE)	Couple	N	Caregiver	Patient	N	Caregiver	Patient
FTD	14	78.53 (8.75)	97.90 (9.07)	88.22 ^{c***,d**} (6.72)	15	13.74 ^{e***,f***} (1.79)	4.20 (1.55)	16.60 (3.62)	12.94 (2.14)
AD	16	117.71 (6.17)	118.13 (6.39)	117.92 (4.74)	16	5.598 [*] (1.26)	3.13 (1.09)	15.23 (2.54)	10.77 (1.50)
CTL	20	126.91 (7.95)	121.34 (8.24)	124.12 (6.11)	21	1.06 (1.65)	3.33 (1.42)	16.02 (3.32)	9.55 (1.96)

Grp = group; FTD = frontotemporal dementia; AD = Alzheimer's disease; CTL = control; adj = adjusted; SE = standard error.

^aCorrected for age and CDR box score.

^bCorrected for age, total words and CDR box score.

^cFTD < AD

^dFTD < control

^eFTD caregivers > FTD patients

^fFTD caregivers > AD & control caregivers

^gAD caregivers > AD patients

* $p < .05$,

** $p < .01$,

*** $p < .001$