

The influence of caregiver burden on sexual intimacy and marital satisfaction in couples with an Alzheimer spouse

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SUMMARY

Objective: This study investigates affective and sexual dimensions in partners involved as caregivers of Alzheimer dementia (AD) subjects. A negative correlation between burden of the caregiver and sexual-affective quality of life was assumed. **Design and methods:** Hundred participants with AD partner (33 male, 67 female), aged between 55 and 85 years were recruited and data were collected from the Caregiver Burden Inventory scale and a semi-structured interview that included demographic information, medical history, relationship and sexual satisfaction, and current sexual function. AD group was compared with a control group (CG) (N = 100) matched for age, sex, education and marital status on measures of the semi-structured interview. Data were analysed using frequency count, univariate analysis (chi-squared and ANOVA) and bivariate correlation. **Results:** The findings revealed that mean burden level was 31.59 (SD 19.51). A difference between experimental and CGs was found for sexual and affective marital satisfaction ($p < 0.05$). The same variables showed a rather negative correlation with total burden levels ($r = -0.374$, $p < 0.001$; $r = -0.448$, $p < 0.001$).

What's known

Alzheimer dementia and the global impairment of intellectual function, as well as its physiological correlates, have strong influence on the quality of life with the consequent need of assistance which could determine a high burden level in the caregiver. The attendant cognitive changes that occur in the Alzheimer patient present many, often conflicting, challenges to a couple's sexual functioning.

What's new

Alzheimer dementia can cause changes in sexual intimacy and marital satisfaction. The subjective perception of burden by spouse caregivers is higher in women than in men and it is related to the AD severity of their partners. Affective and sexual satisfaction are negatively correlated with burden degree, the higher the burden and the lesser the satisfaction. Caregivers and control group did not differ concerning the presence of sexual dysfunctions, but caregivers who were more stressed had sex less frequently.

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The authors have declared that they have no interests which may be perceived as posing a conflict of interest or bias.

Introduction

Dementia is a disorder that deteriorates patients' cognitive, social, functional abilities and self-care skills leading to significant losses in their quality of life (1–4). Dementia is the main cause of disability among the elderly people, with the consequent need for continual assistance which often affects the patient's family (5–8). Alzheimer dementia (AD) is one of the commonest causes of dementia (9) characterised by a progressive loss of cognitive and functional capacities; behavioural disturbances are prevalent throughout the course of the disease and can be a cause of the patient's poor quality of life and caregiver's distress (8,10,11). Many authors reported that a good relationship between patient and caregiver has a positive effect on the evolution of dementia (12) and can also alleviate some behavioural disturbances (13).

Caregiving is 'based on a reverence for life and the belief that human being have the innate right to

function to their highest level of mental and physical capacity. The major mission of caregiving is to promote independence by maintaining the person's most functional state – physically, intellectually, emotionally and spiritually' (14, pp.13).

One psychosocial response to caregiving is perceived as a burden and it has most often been conceptualised in terms of caregiver burden (8,12,15,16). It results from the 'physical, psychological, emotional, social and financial problems experienced by families caring for impaired older adults' (17, pp. 253).

Strong positive correlations exist between caregiving and psychological distress (18,19) and between distress and reported health problems (20,21). Yet, caregiver burden is correlated with the level of depression and a negative quality of life and, differently from chronic disorders other than AD, increased with the worsening of patients' disability (22). These problems include all areas of their lives, not least of which is sexual functioning (10), which is strictly linked with depression as well.

Despite these difficulties, many caregivers try to maintain an intimate relationship with their partner because they find sexuality to be a source of support, reassurance and a means of coping with their partner's invalidating illness (10,23). Furthermore, some caregivers believe that in spite of some changes that occur in sexuality, it remains a positive part of life with the partner.

The aim of this research is to investigate affective and sexual dimensions in partners involved as caregivers of AD patients. A negative correlation between burden of the caregiver and sexual-affective quality of life was assumed, despite the fact that AD seems to have little impact on whether the couple continues to have intercourse when compared with the general ageing population.

Literature review

Duffy (24) provided data on how AD affects intimate relationships. Of $n = 38$ husband and wife caregivers, close to 80% perceived a change in their emotional relationship to the AD spouse, characterising the relationship in non-sexual terms as the illness progressed; a similar percentage experienced a change in sexual intimacy with a gradual decline in interest most commonly reported.

Wright (25) reported similar finding for sexual activities of AD couples, but based on cross-sectional data, found that expression of affection was not significantly different for AD couples ($n = 30$) with respect to healthy couples ($n = 17$).

Davies et al. (10) indicate that older adults with dementing illnesses experience deleterious changes in sexual functioning that can affect their quality of life. However, few healthcare professionals ask older adults about their sexual functioning.

Recently, many studies focused the attention on marital relationship and dementia (22,26). In the research conducted by Eloniemi-Sulkava et al. (27) 25 (60%) of the caregivers interviewed reported that the demented patient had shown at least one negative sexual behavioural change during the course of dementia. Despite this, they found that dementia did not significantly affect the general atmosphere of the marriage.

Methods

Population

Participants consisted of two groups of 100 subjects each, recruited from three Geriatric Centres of Rome, Italy. The 'AD group' comprised 33 male and 67 female spouse caregivers of patients who had received a diagnosis of AD from the 'Alzheimer's

evaluative unit' of each centre; the majority of them were in early to middle phases of the illness.

The control group (CG) comprised subjects matched, with the AD group, for age, sex, education and marital status. Their spouses had no cognitive impairment but in some cases had common medical ageing problems.

Caregivers were interviewed on patients' clinical visit days while CG were interviewed during a regular checkup. The demographic and clinical characteristics of the patients had been referred by the caregivers and are listed in Table 1, while demographic characteristics of caregivers were listed in Table 2 with Caregiver Burden Inventory (CBI) scores too. After we gave the participants a complete description of our study we obtained their written informed consent to participate.

Measures

Demographic, affective and sexual variables were assessed by a semi-structured interview developed by the study group of Clinical Sexology Institute of Rome (ISC) after a detailed review of literature. In particular, affective and sexual variables were measured with response options ranging from one (not at all) to five (totally). Caregiver burden was evaluated by CBI (28) a multiple-choice questionnaire with five burden dimensions.

Time-dependent burden

Time-dependent burden (T/dep-B), or objective burden, evaluates the burden because of restriction on the caregiver's personal time. Because persons with AD often lose the ability to perform the activities of daily living, caregivers devote time and energy to helping them with daily tasks.

Developmental burden

Developmental burden (Dev-B), refers to the sense of failure regarding caregiver's hopes and expectations: it describes the caregivers' feelings of being 'off-time' in their development with respect to their

Table 1 Demographic and clinical characteristics of 67 male and 33 female Alzheimer dementia patients

Variable	Value
Age (years), mean \pm SD	74.69 (5.537)
Age of diagnosis, mean \pm SD	71.15 (5.641)
Dementia severity	
Severe	10%
Moderate	52%
Mild	38%

peers. Caregivers see their peers enjoying their later years as they expected, while they experience frustration, anxiety and strain.

Physical burden

Physical burden (Phys-B), describes caregivers' feelings of chronic fatigue and damage to physical health (such as physical stress and somatic disorders).

Social burden

Social burden (Soc-B), reflects conflict of roles concerning caregiver's job or family. They sometimes feel unappreciated and neglected by others and have to limit the time and energy that they invest in relationships or in their jobs.

Emotional burden

Emotional burden (Emot-B), regards any embarrassment or feeling of shame caused by the patient. Caregivers may feel guilty about these socially unacceptable feelings.

Caregiver Burden Inventory quantifies the global burden according to a total score (higher score = higher burden) and evaluates and quantifies different aspects of burden through its subgroups and respective scores.

Statistical analysis

Statistical analysis was carried out using the SPSS program (SPSS 13.0 per Windows, 2005; SPSS Inc.,

Chicago, IL, USA). Categorical data are expressed as percentages, and continuous data as mean and standard deviation. The analysis of variance (one-way ANOVA) was used to study within group differences among caregivers related to their burden score.

Student *t*-test was used to assess sexual and affective satisfaction; a bivariate correlation analysis was used to assess the relationship, in terms of intensity and direction, between burden and both affective and sexual marital satisfaction; moreover categorical variables were analysed with chi-squared (χ^2) test. Statistical significance was set at $p < 0.05$.

Results

The findings revealed that mean burden level was 31.59 (SD 19.51); the majority of the AD group had a moderate degree of burden (56%) while 23% and 21% had low and high degree of burden respectively. Mean scores obtained in the various subdimensions of CBI showed higher values for T/dep-B, Dev-B and Phys-B than Soc-B and Emot-B.

Women carers show higher mean burden score than men carers ($F_{(1,99)} = 4.835, p < 0.05$). Furthermore, a statistical difference for the mean burden score of the caregivers and the AD severity of their partners was found ($F_{(2,97)} = 22.777, p < 0.05$). We did not observe a strong correlation between total burden scores and age; however, our results support the hypothesis that old age could be one of the factors which tends to predict burden.

The AD group and CG revealed a statistical difference concerning the items: 'Are you satisfied with your affective life?' [t -test (198) = -2.170, $p < 0.05$] and 'Are you satisfied with your sexual life?' [t -test (198) = -2.388, $p < 0.05$]. Using Pearson's coefficient, both affective and sexual dimensions show a rather negative correlation with total burden levels at a high level of significance (respectively $r = -.448, p < 0.001$; $r = -.374, p < 0.001$; Figures 1 and 2). Low levels of affective and sexual marital satisfaction are associated with higher burden degree.

The questions 'Do you feel in love with your partner?' and 'Do you think your partner feels in love

Table 2 Demographic characteristics and CBI scores of 33 male and 67 female of AD group

Variable	Value
Age (years), mean \pm SD	71.71 (5.716)
Young old (< 64 years)	12%
Middle old (65–74 years)	52%
Old old (> 75 years)	36%
Education	
Primary	64%
Secondary	28%
Degree	8%
CBI, mean \pm SD	31.59 (19.515)
CBI subscale, mean \pm SD	
T/dep-B	9.08 (6.344)
Dev-B	8.16 (6.734)
Phys-B	8.31 (6.037)
Soc-B	2.30 (2.532)
Emot-B	2.34 (2.825)

AD, Alzheimer dementia; CBI, Caregiver Burden Inventory; T/dep-B, time-dependent burden; Dev-B, developmental burden; Phys-B, physical burden; Soc-B, social burden; Emot-B, emotional burden.

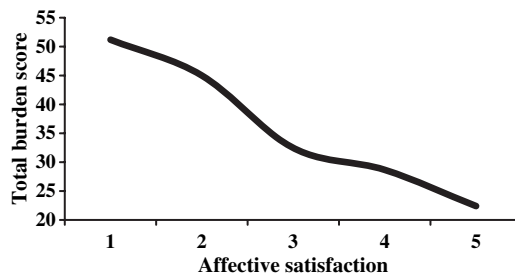


Figure 1 Total burden score and affective satisfaction

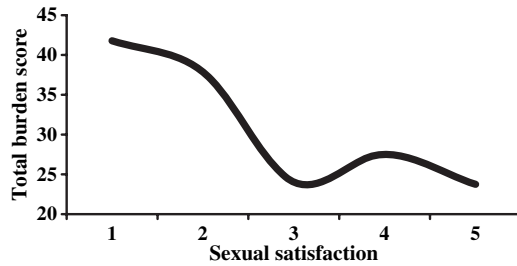


Figure 2 Total burden score and sexual satisfaction

with you?' did not show any differences between the two groups. However, in the AD group, a statistical difference between men and women, referring to perception of the change in affective relationship brought on by Alzheimer disease, was found [χ^2 (2, $N = 100$) = 6.197, $p < 0.05$] (Figure 3).

A statistical difference between AD group and CG for sexual intercourse frequency was found using Mann-Whitney test ($U = 4131.5$, $z = -2.239$ and $p < 0.05$): compared with control group, more subjects in the AD group declared never to have sex and far fewer subjects indicated to have sex weekly, as it is clearly visible in Figure 4. Despite this, we did not observe any statistical difference, between AD group and CG, in item regarding sexual intercourse quality satisfaction. At last, the male caregivers had more sexual intercourse than female caregivers [χ^2 (3, $N = 100$) = 7.883, $p < 0.05$]. Moreover, a statistical difference in mean burden score was observed: data show that caregivers with lower burden degree have more sexual intercourse 'weekly' [χ^2 (12, $N = 100$) = 15.081, $p < 0.05$] or 'monthly' [χ^2 (19, $N = 100$) = 17.710, $p < 0.05$] than caregivers with higher

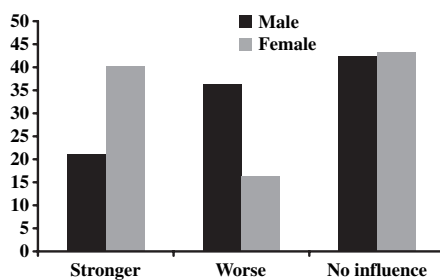


Figure 3 Alzheimer dementia influence on affective relationship

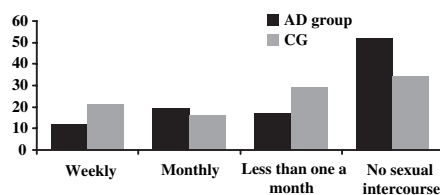


Figure 4 Sexual intercourse frequency

burden degree, using Duncan test. Our findings did not reveal any statistical difference between AD group and CG concerning sexual dysfunctions.

Discussion

In agreement with literature, the data of this study support the conclusion that compared with normal ageing, affection and sexuality are different when a spouse has AD (10,27,29).

The mean burden score of the study group of caregivers is 31.59 (SD 19.51), similar to that of another Italian study conducted by Marvardi et al. (8) (32.5, SD 18), but different from that of the study conducted by Novak and Guest (28) on a Canadian population (22.14, SD 16.3).

Similarly to the results of Marvardi et al. (8), our findings suggest that distress caused to caregivers by the condition of their partners influenced T/dep-B, Dev-B and Phys-B. This is true especially for women, who show higher mean burden score than men. This fact might be linked to some factors: first, the gender role of both men and women. In particular, women often show a strong tendency towards caregiving within the couple especially when a chronic illness occurs, but are more psychologically and physically distressed than men caregivers. This was true despite their ability to maintain a sense of emotional closeness with their partner and thus still perceive some sense of marital satisfaction (8,30). Second, although all spouse caregivers were the primary carers of AD patients, male caregivers (25 subjects of 33) more frequently than female declared, during the interview, to resort to nurses or other family members for coping with the daily care of their AD partner.

A statistical difference for the mean burden score of the caregivers group and the AD severity of their partners was found. Caregivers of partners who have been diagnosed a severe degree AD report higher total burden scores. This might be linked to an increase in the distress of the caregivers because of a progressive accumulation of the attendance load connected to Alzheimer's behaviour and cognitive disturbances (11,31). Degenerative nature of AD has a negative influence on affective and sexual marital satisfaction. The correlation between burden scores and these two dimensions indicates that low levels of affective/sexual satisfaction are associated with higher burden degree.

Concerning sexuality, AD group showed more subjects who have no sexual intercourse and far fewer subjects indicated to have sex weekly. Our findings show that caregivers with higher burden degree have less sexual intercourse; probably, it can

be due to the kind of stress perceived by caregivers, particularly by women. No differences between AD group and CG as regards the feelings of love of one partner towards the other were found, but men and women differ significantly in their perception of the change in affective relationship brought on by AD. The perception of a worse affective marital satisfaction after AD onset was more common in men than in women (36.4% vs. 16.4%). While, the perception of a stronger affective marital satisfaction after AD onset was more common in women than in men (40.3% vs. 21.2%). These data suggest that some gender-specific effects could occur. Also, male caregivers of AD group had more sexual intercourse than female caregivers. When a dementing illness is present, it is likely that female carers will lose interest in sex, believing that sex should have a very low priority or that attending to their own sexual needs is somehow wrong and inappropriate (32). So, they can shift their attention to the affective and care aspects of the marriage relationship. On the other hand, they can also acquire greater power in the relationship and become capable of rejecting undesired sexual advances. It is expected, instead, that male carers will continue to desire sex, even if changes in sexual behaviours could be experienced as stressful. The attendance load because of caregiving and some kind of adjustment in the daily life related to their partner's impairment, can be the reason why they felt their affective relationship had worsened.

Conclusion

Alzheimer dementia can affect marital relationships and the couples may experience change in roles, loss of companionship, difficulties with communication and spouses of AD patient may feel a progressive heavier burden (8,33). However, there are also some positive aspects in the marriage after the onset of dementia, that do not strongly affect the general atmosphere especially regards affective life, as some studies support (10,27).

An open atmosphere with regard to sexual issues could encourage caregivers to talk with professionals in case problems arise. The caregivers interviewed indicated that no healthcare professionals had asked about sexuality or disseminated information about potential problems with sexuality because of cognitive disorders. Sometimes, cultural values, personal beliefs and inadequate training provide obstacles for clinicians to address confidently their patient's sexual needs, but some of caregivers interviewed declared that they would like to speak on this matter with a specialist. For this reason, to better address the challenges created by AD, it is important for the physi-

cians to inform about different aspects of chronic illness, including also sexuality.

The medical team should include a psychologist as quality of life extends beyond the medical sphere, and sexual activity in healthy relationships help people to stay in good physical condition and helps to reduce physical and psychological stress (34). Many studies have focused on high quality marriages which lead people to have a lower risk of developing health problems (20,21,35,36).

Many health professionals do agree that AD patients have a right to sexual expression. However, many clinicians work with the common assumption that if sexual concerns are important to the patient, the patient will initiate discussion about them, while at the same time, many patients similarly think that if the professional is open to discussion and has the professional training and ability to help with sexual problems, then the professional will lead the discussion and inquiry. Unfortunately, such common attitudes may serve to continue a silent avoidance of sexual concerns (37).

Then, it is important that healthcare professionals become comfortable in dealing with sexual problems (37,38), and aware of personal biases and prejudices. An integrative approach (37) is necessary to accede to people's requests and needs, including questions about sexual functioning during a routine assessment which will permit the couple to raise any difficulties they have in this area.

Further investigations are needed to extend the current findings; particularly, we need to explore and find out which kind of specific support or counselling might have a significant effect to reduce patient and caregiver stress. Only evidence-based interventions could help clinicians to improve couples' quality of life. We hope intervention studies, covering also the sexual aspects, will soon be carried out.

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