

# SYSTEMATIC OR INTEGRATIVE REVIEW

## SEXUALITY OF SPOUSE-CAREGIVERS OF DEMENTED OLDER PEOPLE: AN INTEGRATIVE REVIEW OF THE LITERATURE

### SEXUALIDADE DO CÔNJUGE QUE CUIDA DO IDOSO DEMENCIADO: REVISÃO INTEGRATIVA DA LITERATURA

### SEXUALIDAD DEL CÓNJUGE QUE CUIDA AL ANCIANO DEMENTE: REVISIÓN INTEGRADORA DE LA LITERATURA

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Submitted on: 2014/02/20

Approved on: 2015/02/23

## ABSTRACT

This study aimed to identify and analyze the scientific literature addressing the sexuality of spouse-caregivers of older adults with dementia. We searched the Lilacs, Medline, CINAHL and Web of Science databases and identified 208 articles, of which 13 were selected for inclusion in the study. The data were analyzed using content analysis. The results demonstrate that factors related to changes caused by dementia significantly affect couples' frequency of sexual activity, leading to a decline in intimacy. Conversely, an important aspect of sexuality in dementia concerns the substitution of sexual activity for other ways of demonstrating affection and having physical intimacy. We propose that further studies are required to identify more scientifically appropriate approaches, including therapeutic nursing care.

**Keywords:** Sexuality; Caregivers; Aged; Dementia; Health of the Elderly.

## RESUMO

*O presente estudo teve o objetivo de identificar e analisar a produção científica da sexualidade do cônjuge que cuida do idoso em processo demencial. Realizou-se revisão integrativa de artigos científicos indexados nas bases Lilacs, Medline, CINAHL e Web of Science. Dos 208 artigos, 13 foram selecionados. Os dados foram analisados de acordo com a análise de conteúdo. Os resultados demonstraram que fatores relacionados às alterações provocadas pela demência intervêm de maneira significativa na frequência da atividade sexual do casal, levando ao declínio na intimidade. Por outro lado, um importante aspecto da sexualidade na demência está relacionado à substituição da atividade sexual por outros modos de demonstração de afetividade e intimidade física entre os cônjuges. Percebe-se que o campo de estudo acerca da atividade sexual na demência é promissor e indica a necessidade de novas pesquisas, que contribuam para abordagens mais cientificamente adequadas, incluindo aqui o cuidado terapêutico de Enfermagem.*

**Palavras-chave:** Sexualidade; Cuidadores; Idoso; Demência; Saúde do Idoso.

## RESUMEN

*El presente estudio busca identificar y analizar la producción científica sobre la sexualidad del cónyuge que cuida al anciano en el proceso de la demencia. Se realizó una revisión integradora de artículos científicos en las bases Lilacs, Medline, CINAHL y Web of Science. Se seleccionaron trece artículos entre los 208 encontrados. Los datos se analizaron según el análisis de contenido. Los resultados indican que los factores relacionados con los cambios causados por la demencia afectan significativamente la frecuencia de la actividad sexual de la pareja, disminuyendo la intimidad entre ellos. Por otro lado, durante el proceso de la demencia, se observa la sustitución de la actividad sexual por otras maneras de demostración de afecto e intimidad física entre los cónyuges. El campo de estudio relacionado con la actividad sexual en la demencia es prometedor e indica que se requiere efectuar más investigación con miras a incluir la atención terapéutica de Enfermería dentro de un enfoque científico más apropiado.*

**Palabras clave:** Sexualidad; Cuidadores; Anciano; Demencia; Salud del Anciano.

## INTRODUCTION

The aging process is composed of varied and complex interactions between intrinsic and extrinsic factors that are reflected in physiological changes experienced by individuals.<sup>1</sup>

Expressions of sexuality by older people are closely linked to previous experiences and to the mode of perception of biological, social, and psychological changes. The circumstances and emotional feelings that accompany aging may compromise an adult's capacity to develop and maintain an intimate relationship, changing the way in which intimacy is expressed.<sup>2</sup>

Current demographic trends reveal shifts in the health profile of the population due to the high prevalence of chronic degenerative diseases such as dementia, which results in progressive physical and mental disability and may cause difficulties for the maintenance of sexuality among older couples.<sup>3</sup>

With the worsening of cognitive losses, spouse-caregivers of older adults with dementia have to face many adjustments in order to compensate and adapt to the situation. When viable alternatives are not found or the family's skills and resources are insufficient to enable this adaptation, there is a strong tendency to family dissolution and personal disorganization, with negative consequences to the maintenance of care as well as to the emotional well-being and sexuality of the couple.

Thus, it is important that nurses also devote meaningful attention to the sexuality of spouse-caregivers of older adults with dementia, especially through the exchange of information and provision of support to deal with health problems that interfere with the development of one's own sexuality or with the issue of sexual contact with their demented partners.<sup>4</sup> In addition, nurses should identify the real needs of these caregivers and help them through this process of transition of social roles.

Given the above and considering the relevance of this topic to the fields of health and nursing, this study aimed to identify and analyze the scientific literature on sexuality of spouse-caregivers of older adults with dementia

## METHODS

This paper is an integrative literature review, a form of research that seeks to critically evaluate and synthesize representative literature on particular topic in a systematic way. The following steps were taken: selection of guiding questions; search of databases and selection of the literature based on inclusion and exclusion criteria; development of a tool for the extraction of relevant information from the selected sources; critical analysis of the selected studies; data interpretation; and presentation of results.<sup>5</sup>

We defined the following guiding question: considering national and international studies, what is the scientific production on sexuality of spouse-caregivers of older adults with dementia?

We searched the following databases: Latin American and Caribbean Health Sciences (LILACS); Virtual Health Library; Medical Literature Analysis and Retrieval System Online (MEDLINE); United States National Library of Medicine / National Institutes of Health; Cumulative Index to Nursing and Allied Health Literature (CINAHL); Web of Science; and the CAPES (Brazilian Higher Education Coordination Agency) journals portal.

Keywords in Portuguese were selected from the DeCS thesaurus (Health Sciences Descriptors, DeCS terms). English language databases were searched using the corresponding keywords selected from MeSH (Medical Subjects Headings) and CINAHL headings. The terms used were: "*Sexuality*," "*Dementia*," "*Caregiver*" and "*Aged*". It was necessary to add the English keyword "*Elderly*" to allow the identification of a larger number of articles. The use of the keyword "*spouse*" returned no additional results. We searched the database Web of Science using the same descriptors mentioned above. For all databases, the Boolean operators "*and*" and "*or*" were utilized.

The databases were searched from April to July 2014. This review comprised articles published until November 2013. Inclusion criteria were: original and review articles published in Portuguese, English, Spanish or French, with no publication cut-off date. We excluded letters to the editor, opinion articles, case studies, studies conducted with institutionalized older people, studies with no clear methodology, and studies which could not be accessed in full (online or in-print).

After reading all titles and abstracts, two reviewers selected the articles that were to be read in full. In order to organize the data found in the articles, we used a self-elaborated form containing the following items: article identification, authors' names, journal where the article has been published, year of publication, Qualis/CAPES, impact factor, methodological characteristics and main results found.

Qualis is a scoring system used by CAPES to stratify journals according to their quality. The classification of journals is carried out within their respective assessment areas and is annually updated. Journals are classified into 8 quality strata: A1 (highest quality); A2; B1; B2; B3; B4; B5; and C (lowest quality).<sup>6</sup>

The impact factor is a parameter based on the mean number of times that papers in a particular journal are cited by all journals. It is used to evaluate the relative importance of a journal in a given field. The higher the value, the more recognition it receives from the academic community.<sup>6</sup>

The evidence was appraised and leveled according to the method proposed by Melnyk and Fineout-Overholt<sup>7</sup>: Level I - evidence derived from a systematic review or meta-analysis of randomized controlled trials or clinical practice guidelines based on randomized controlled trials; Level II - Evidence derived from at least one well-designed, randomized control trial; Level III - Evidence derived from well-de-

signed clinical trials without randomization; Level IV - Evidence derived from well-designed cohort and case-control studies; Level V - Evidence derived from a systematic review of descriptive and qualitative studies.; Level VI - Evidence derived from a single descriptive or qualitative study; Level VII - Evidence derived from opinions of respected authorities or reports of expert committees.

We critically interpreted the articles using content analysis. The authors discussed the results of the analyses and achieved a final consensus on the content of the review. The information used in this paper was freely available on the internet and did not require ethical secrecy.

## RESULTS

15 articles met the inclusion criteria and were analyzed. Seven (46.7%) articles were found in MEDLINE, three (20%) in Lilacs, three (20%) in CINAHL and two (13.3%) in the Web of Science. Two of the 15 articles found in full were discarded because they were a letter to the editor and an opinion article.

Publication sources included several different journals in the fields of psychogeriatrics, geriatric neuropsychiatry and mental health (6 articles; 46.1%); and clinical practice (seven articles; 53.9%), involving sexuality and disability. Only two (15.4%) journals had been published in the field of nursing. Nurses were identified as the authors of four (30.7%) articles. Nine (69.3%)

papers had been written by other health professionals (physicians, psychologists and sociologists).

With regard to the year of publication, one article was published in each of the following years: 1997, 2002, 2008, 2009, and 2012. Two articles were published in each of the following years: 1998, 2005, 2010, and 2013. No articles meeting the inclusion criteria were published between 1999 and 2001; 2003 and 2004; 2006 and 2007; or during 2011. As for the country of publication, five articles (38.5%) were published in the UK; five (38.5%) in the USA, two (15.4%) in Brazil, and one (7.7%) in France.

Most articles (11; 84.59%) were published in English. One article (15.41%) was published in Portuguese and one (15.41%) in French. Eleven articles (84.6%) were original articles, and two (15.4%) were reviews.

Table 1 shows the studies' characteristics with respect to journal of publication, title, number per journal, Qualis/CAPES, impact factor and year of publication.

Table 2 summarizes the main findings of each paper that met the inclusion criteria of this review.

## DISCUSSION

The articles reviewed here have investigated aspects such as: overload; gender and daily care; triggering factors for changes in sexual activity; physical and emotional health; sexual satisfaction; changes in sexual actions; and health professionals' approach.

Table 1 - Studies' characteristics with regard to journal of publication, title, Qualis/CAPES, impact factor, level of evidence, and year of publication (n = 13). Rio de Janeiro, RJ, Brazil, 2014

Journal / Article	Publication	Qualis	Impact factor	Level of Evidence	Year
<b>International Journal of Geriatric Psychiatry</b>	01	B1	3.086	-	-
Article 1: Sexual relationships in married dementia sufferers	-	-	-	IV	1997
<b>Sexuality and Disability</b>	04	B2	0.862	-	-
Article 2: Affection and sexuality in the presence of Alzheimer's disease: a longitudinal study	-	-	-	II	1998
Article 3: Sexuality and intimacy in Alzheimer's patients and their partners	-	-	-	VI	1998
Article 4: Decline in satisfaction with physical intimacy predict caregiver perceptions of overall relationship loss: a study of elderly caregiving spousal dyads	-	-	-	IV	2005
Article 5: Sexual satisfaction in dementia: perspectives of patients and spouses	-	-	-	IV	2010
<b>International Psychogeriatrics</b>	02	A2	1.892	-	-
Article 6: Spouse caregivers perceptions of influence of dementia on marriage	-	-	-	II	2002
Article 7: The impact of dementia and mild memory impairment (MMI) on intimacy and sexuality in spousal relationships	-	-	-	VI	2010
<b>Psychology Neuropsychiatry Vieil</b>	01	*	0.397	-	-
Article 8: Sexualité et démences	-	-	-	VI	2005
<b>International Journal of Clinical Practice</b>	01	B1	2.538	-	-
Article 9: The influence of caregiver burden on sexual intimacy and marital satisfaction in couples with an Alzheimer spouse	-	-	-	II	2008

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Journal / Article	Publication	Qualis	Impact factor	Level of Evidence	Year
<b>Aging &amp; Mental Health</b>	01	A2	1.781	-	-
Article 10: Gender differences in sexual behaviors of AD patients and their relationship to spousal caregiver well-being	-	-	-	IV	2012
<b>Revista de Psiquiatria Clínica</b>	01	B1	0.89	-	-
Article 11: Sexual satisfaction in dementia	-	-	-	VI	2013
<b>Journal of Gerontological Nursing</b>	01	*	0.62	-	-
Article 12: Influence of cognitive decline on sexuality	-	-	-	VI	2013
<b>Journal of Aging Studies</b>	01	A1	1.227	-	-
Article 13: Living and loving with dementia: negotiating spousal and caregiver identity through narrative	-	-	-	IV	2009

\*No Qualis/CAPES classification.  
Source: prepared by the authors.

Table 2 - Distribution of articles published on sexuality of spouse-caregivers of older people with dementia between 1997 and 2013. Rio de Janeiro, RJ, Brazil, 2014

Author(s)	Journal	Country/Year	Main findings
Simonelli C, et al <sup>8</sup>	International Journal of Clinical Practice	United Kingdom (2008)	Sexuality, love, companionship and intimacy continue to be important elements in the lives of older people and dementia patients. The most common sexual disorder reported by spouses of patients with dementia was sexual indifference, which was associated with apathy and blunted affect. In nursing homes or long-term care facilities, the expression of sexuality by people with dementia and having to deal with inappropriate sexual expressions are sources of concern for the nursing staff, the other residents and the families. The provision of information on sex and dementia, as well as the use of a psychobehavioral approach may help families and caregivers reduce their tension.
Davies HD, et al <sup>9</sup>	International Psychogeriatrics	United Kingdom (2010)	Alzheimer dementia can affect marital relationships. Couples may experience change in roles, loss of companionship, difficulties with communication. Moreover, spouses of AD patient may feel a progressively heavier burden. An open atmosphere with regard to sexual issues could encourage caregivers to talk with professionals in case problems arise. An integrative approach is needed to meet the requests and needs of these people. Direct questions about sexual functioning should be asked during routine evaluation in order to reveal any difficulties experienced in this area by the couple.
Nogueira MML, Brasil D, De Souza MFB, Santos RL, Dourado MCN <sup>10</sup>	Revista de Psiquiatria Clínica	Brazil (2013)	The burden of care and the change of roles in the marital relationship were considered to be the main causes for the decline of sexual activity. Factors associated with sexual dissatisfaction included: erectile dysfunction in patients and spouses; patient's ability or capacity to consent to intercourse; and problems related to the age and (physical and emotional) health of the spouse and/or patient.
Hayes J, Boylstein C, Zimmerman MK <sup>11</sup>	Journal of Aging Studies	USA (2009)	13 men and 15 women whose spouses had Alzheimer's disease and related dementias. The intensive interviews confirmed that identity change on the part of sick spouses had important implications for intimacy, although not always in adverse ways. Most caregivers reported decrease in intimacy as a result of the disease. Many men and women believed that they would maintain close relationships with their spouses while they were alive. Wives were more open to talk about intimate changes in their marital lives than husbands.
Dourado M, Finamore C, Barroso MF, Santos R, Laks J <sup>12</sup>	Sexuality and Disability USA	Brazil (2010)	36 elderly patients with possible or probable Alzheimer's disease (22 men and 14 women) and their spouses. 15 patients were in the initial phase of the disease and 21 patients had moderate Alzheimer's disease. Six assessment instruments (MMSE; CDR; ASPID; Cornell Scale for Depression in Dementia; Questionnaire on Sexual Experience and Satisfaction; Zarit) and semi-structured interviews with patients and their spouses were used to collect data. Both the patients and their spouses reported sexual dissatisfaction due to erectile dysfunction, and lack of sexual desire by the woman. There was a positive relationship between sexual satisfaction and caregiver burden. Men associated sexual dissatisfaction with sadness. Women expressed feelings related to the loss of intimacy and the increased anxiety.
Ballard CG, et al <sup>13</sup>	International Journal of Geriatric Psychiatry	United Kingdom (1997)	40 caregivers participated in the study. Nine (22.5%) continued to have sexual intercourse. 12 (38.7%) caregivers who were no longer sexually active reported being dissatisfied with the lack of sexual intercourse. Male caregivers were more likely to maintain sexual activity. Dissatisfaction with the lack of intercourse was significantly associated with the diagnosis of vascular dementia.

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Table 2 - Distribution of articles published on sexuality of spouse-caregivers of older people with dementia between 1997 and 2013. Rio de Janeiro, RJ, Brazil, 2014

Author(s)	Journal	Country/Year	Main findings
Eloniemi-Sulkava U, et al <sup>14</sup>	International Psychogeriatrics	United Kingdom (2002)	Older adults remain sexually active. Dementing illnesses can cause changes in sexual functioning that can have detrimental effects on the couple and their quality of life if left untreated. Cultural taboos, personal beliefs, and inadequate training contributed to the lack of existing help. Health care providers should ask simple questions during a routine evaluation. Leaders of Alzheimer's support groups are in a position to make particularly important contributions by enhancing their knowledge about and comfort with discussion of sexual intimacy and Alzheimer's disease. It is important to provide a safe, private and supportive environment to allow the expression of sexuality in the context of long-term home care. Health care professionals can also improve their ability to assess and help with sexual dysfunction and concerns by reading, attending workshops and symposia, or taking a seminar in sexuality and aging. Becoming aware of personal biases and beliefs that impact professional practice is essential.
Davies HD, Sridhar SB, Newkirk LA, Beaudreau AS, O'Hara R <sup>15</sup>	Aging & Mental Health	United Kingdom (2012)	Most couples who dealt with Alzheimer's dementia reported having intimate sexual contact, indicating its importance in the relationship. Female caregivers reported higher levels of stress and depressive symptoms than male caregivers. Satisfaction with intimacy was significantly associated with lower levels of stress and depressive symptoms in caregivers. Gender-specific therapies to address patient sexual difficulties and caregiver well-being could potentially maintain or improve the marital relationship.
Wright LK <sup>16</sup>	Sexuality and Disability	USA (1998)	Affection and sexuality were investigated in a longitudinal study with two groups of couples. Affectional expressions were not different for the two groups prior to illness onset but declined significantly for the AD group five years into the illness trajectory. Affection remained stable for the well group. Affection increased significantly after placing the sick spouse in a nursing home, and several couples continued at the same or higher levels of sexual intimacy.
Svetlik D, Dooley WK, Weiner MF, Williamson GM, Walters AS <sup>17</sup>	Sexuality and Disability	USA (2005)	136 spouse-caregivers of older adults with physical and/or cognitive disabilities. Older caregivers and those with more cognitively impaired spouses evaluated their own physical health less favorably. The only significant predictor of declines in satisfaction was providing more care; the only significant predictor of more perceived relationship loss was greater decline in satisfaction with opportunities for affectionate physical contact and sexual intimacy.
Davies DH, Zeiss AM, Shea EA, Tinklenberg JR <sup>18</sup>	Sexuality and Disability	USA (1998)	Older adults remain sexually active.
Derouesné C <sup>19</sup>	Psychology Neuropsychiatry Vieil	France (2005)	25 caregivers (60%) reported that demented patients showed at least one negative sexual behavior change during the course of dementia; seven male patients (24%) manifested the need for sex as a constant behavioral symptom; 10% of caregivers reported at least one positive sexual behavior change. Dementia did not significantly affect the general atmosphere of the marriage; 19 couples (46%) continued to have sex. After five years this number dropped to 15 couples (41%), and, after seven years, to seven couples (28%).
Robinson KM, Davis SJ <sup>20</sup>	Journal of Gerontological Nursing	USA (2013)	Literature review with eight original studies (1990-2013). The data were divided into two categories: sexual intercourse among married individuals with dementia (2 articles); and hypersexuality and inappropriate sexual behavior (6 articles). The articles included in the first category have already been summarized in this Table (articles 1 and 9). In the second category, the authors investigated the concepts of hypersexuality, the prevalence of hypersexuality in dementia, sex predilection, and found that hypersexuality occurs with advancing disease, regardless of the type of dementia.

\*No Qualis/CAPES classification.

Source: prepared by the authors.

Caregiver overload has been described in many studies and its effects on sexual activity and intimacy should also be discussed. Dementia leads to a decline in sexual intimacy, due to the burden of daily caring, especially among female spouse-caregivers.<sup>8,12</sup>

Gender had a direct influence on sexual satisfaction or dissatisfaction.<sup>10</sup> Female spouses reported less desire to have sex and difficulties finding the time to have sex due to daily caregiving their demented partners.<sup>11</sup> Association with self-reported symptoms of

stress and depression is higher among women, even when the degree of dementia is mild.<sup>8,10,13,14</sup> The loss of reciprocity in the course of the disease leads to higher levels of anxiety and psychological distress in female spouses, when compared to male spouses, and women also show lower levels of sexual satisfaction.<sup>15</sup>

The frequency and type of intimate relationship do not significantly differ between genders. There is a high percentage of reports referring to the initial stage of intimate phys-

ical activity. Nevertheless, this percentage drops significantly when it comes to actual sexual intercourse.<sup>15</sup> Factors related to changes caused by dementia interfere significantly with the frequency of sexual activity between demented patients and their partners, leading to a decline in intimacy.<sup>12,16,17</sup> Spouses report noticing that sexual intercourse becomes less important to their partners after disease onset. They become more self-centered and less flexible, and exhibit decreased verbal expression and personality changes such as stiffness, apathy, and impaired emotional control.<sup>9,14</sup>

Couples who had a stable and functional relationship before the diagnosis of dementia reported significant changes in affective expressions with the onset of memory impairment. This was related to the patient's loss of ability to make decisions and to changes in spousal roles (with the spouse assuming a parental role), changes that negatively affected their intimate engagement in both emotional and sexual dimensions of the relationship.<sup>9,12</sup> In other couples, the effects of the disease seem to be even greater. Already-existing communication problems between partners can be especially observed in the early stages of the disease.<sup>9,10</sup>

Memory problems and decline in decision making ability can interfere with intimacy, with no significant difference between dementias.<sup>8,9</sup> In more advanced stages of dementia, trouble remembering the proper sequence of steps of sexual intercourse or the steps already undertaken leads patients to have little involvement with their partners, due to distraction or loss of arousal, or even due to the exacerbation of sexual activity.<sup>10,15</sup> Delirium or confusion in more advanced stages of Alzheimer's disease (AD) may cause concern and embarrassment to caregivers who try to have sexual contact with their spouses, because their conduct may be interpreted as sexual abuse.<sup>18-20</sup>

The lack of sexual activity was also attributed to the occurrence of erectile dysfunction in patients and spouses, as well as to problems related to the age and health.<sup>10,12,19</sup> It is reasonable to suspect that the likelihood of sexual dysfunction may be greater in male patients with AD than in similar-aged healthy men. About 50% of men reported that the time of onset of erectile dysfunction was concurrent with the emergence of the first clear disease symptoms, and that the dysfunction was not associated with medications or physical problems.<sup>18</sup>

A common disorder reported by spouses of patients with dementia is sexual indifference. It is manifested by reduction of patient's participation in sexual activity, passivity, active rejection and feelings of disgust. Conversely, hypersexuality is reported as a heterogeneous and ill-defined behavior.<sup>20</sup> It is necessary to differentiate between increasing sexual demands and inappropriate behavior, as they may arise from psychological issues, from the need for physical contact and intimacy, from low self-esteem or from cognitive demands, such as identifica-

tion disorders, forgetfulness of social conventions, stimulatory/disinhibitory effects of some drugs (antidepressants and antipsychotics/benzodiazepines), association with alcohol use, and erotic stimulation by the media.<sup>19</sup>

Male spouses who kept having sex with their demented partners reported being interested in maintaining this relationship. They would, however, leave their wives alone if they showed no pleasure or interest in sex.<sup>11,13</sup> When the healthy partner is a male, the couple often maintains sexual activity, with only minor changes in comparison to previous sexual activity and satisfaction. Disease of female partners has a much smaller effect on sexual activity patterns.<sup>11,18,20</sup>

The physical and emotional health of patients and their spouses is directly related to sexual activity.<sup>16</sup> Cessation of intercourse in women is attributed to the physical condition of the male partner. Other reasons account for the reduction in sexual interest in older people diagnosed with AD: medical conditions, reduced libido, depression, anxiety, fatigue, partner's (body) image changes, incontinence, poor personal hygiene and interpersonal difficulties.<sup>10,15,19</sup>

Having an active sex life was not associated with patients' sex and age, but rather with good physical health condition and low rates of depression in spouses.<sup>19</sup> Caregiver experience of a greater deterioration of the relationship was particularly associated with more patient symptoms of mood/apathy than with cognitive impairment.<sup>10</sup> The primary effect of depression on sexuality is reduced sexual interest or desire. Depression also can affect physiological response to stimulation - erection in men and lubrication in women.<sup>10,15</sup> It is unclear whether satisfaction with intimacy improves the well-being of caregivers or whether the reduction of depression and stress levels increases the caregiver's ability to engage in intercourse or have more satisfaction with intimacy. The levels of perceived stress and depressive symptoms, however, were lower in couples who had a strong emotional connection with each other before the onset of the disease.<sup>15,19</sup>

With regard to health care providers, it is essential that they: receive training focusing on sexual-related issues and approach techniques, and including conceptual aspects and specifics in case of cognitive problems; provide differentiated care to couples in case of a diagnosis of dementia, especially if they have sex-related questions; and consider the consequences experienced by the couple during the course of the disease.<sup>18,20</sup> In addition, paying close attention to the self-reports of dementia patients about their satisfaction can contribute to better understanding and evaluating couples' well-being and quality of life.<sup>20</sup> Finally, health care providers should inform the couple about changes in sexuality that accompany disease progression.<sup>18</sup> They must create an environment of trust and privacy.<sup>18,19</sup>

## CONCLUSION

Sexual activity in dementia is greatly influenced by the burden that arises from caregiving. Sexual satisfaction or dissatisfaction is directly affected by gender issues. Factors related to changes caused by dementia significantly affect couples' frequency of sexual activity, leading to a decline in intimacy.

Memory problems and progressive disability to make decisions interfere with intimacy, resulting in little involvement with the partner or hypersexuality. Erectile dysfunction contributes to the lack of sexual relationships between patients and their spouses, as well as sexual indifference, which is manifested as passive behavior and active rejection.

On the other hand, dementia may have less impact on the lives of couples when they continue to have sex with each other. Sexually active patients show a more favorable disease evolution, i.e., sex can be a balance factor for a closer emotional understanding between couple members. Given the many barriers imposed by the disease and its evolution, an important aspect of sexuality in dementia concerns the substitution of sexual activity for other ways of demonstrating affection and having physical intimacy.

Sexual activity in dementia is a promising field of study. Further studies are needed to investigate more scientifically appropriate approaches, including therapeutic nursing care.

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