







## Sexuality of elders with dementia: social representation of nursing students\*

Sexualidade de idosos com demência: representações sociais de estudantes de enfermagem

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### ABSTRACT

**Objective:** to learn about the social representation of nursing students about the sexuality of elders with dementia. **Methods:** qualitative study, based on the Theory of Social Representations, developed with 20 Nursing Graduation students from a Brazilian higher education institution. Data was collected through a focal group, processed in the software IRAMUTEQ and analyzed using a Descending Hierarchical Classification. **Results:** four semantic classes emerged: Sexuality as a right, The theme was insufficient in graduation, Meanings attributed to sexuality, and Care from the perspective of students. **Conclusion:** the study showed that the nursing students investigated had polysemic representations about the sexuality of elders with dementia, among which discriminatory and stigmatizing conceptions stood out, socially constructed and anchored in common sense.

**Descriptors:** Health of the Elderly; Mental Health; Dementia; Students, Nursing.

### RESUMO

**Objetivo:** apreender as representações sociais de estudantes de enfermagem acerca da sexualidade de idosos com demência. **Métodos:** estudo qualitativo, fundamentado na Teoria das Representações Sociais, desenvolvido com 20 estudantes de Graduação em Enfermagem de uma instituição de ensino superior brasileira. Os dados foram coletados por meio de grupo focal, processados no *software* IRAMUTEQ e analisados por Classificação Hierárquica Descendente. **Resultados:** emergiram quatro classes semânticas: A sexualidade como um direito, Temática insuficiente na graduação, Significados atribuídos à sexualidade e O cuidado na perspectiva de estudantes. **Conclusão:** o estudo demonstrou que os estudantes de enfermagem investigados possuíam representações polissêmicas sobre a sexualidade de idosos demenciados, em que se destacaram concepções discriminatórias e estigmatizantes, ancoradas no senso comum e construídas socialmente.

**Descritores:** Saúde do Idoso; Saúde Mental; Demência; Estudantes de Enfermagem.

## Introduction

Population aging is a universal phenomenon that has been taking place increasingly fast<sup>(1)</sup> due to changes in the health profile of the elderly. Consequently, with the increase in the number of elders, the number of chronic-degenerative diseases, such as dementias, also increases. Dementia is a syndrome characterized by memory impairment, associated to alterations in one or more cognitive functions, which reflects in physical and mental disabilities and makes it more difficult for elders to maintain their sexuality<sup>(2)</sup>.

Scientific evidences show that sexuality and the sexual activity coexist in the healthy elderly population and are important predictors for quality of life<sup>(3)</sup>. However, sexuality and dementia in the elderly have been associated to inadequate behavior. The presence of dementia causes declines in sexual intimacy, an activity which can be replaced by the demonstration of other types of physical intimacy, such as hugs, kisses, and touches<sup>(4)</sup>. Coupled with that, there is a dilemma with regard to the decline of the capacity of making decisions in elders who have dementia and their healthy spouses<sup>(5)</sup>.

In addition, there is a scarcity of studies about sexuality and dementia in elders, since most studies are focused on the inappropriate sexual behavior and in the hyper- or hypossexuality that result from the process of dementia. There are no studies about the perceptions of students and health professionals about the theme<sup>(6-7)</sup>.

Therefore, it is relevant for students and health professionals to learn about the sexuality of elders in the process of dementia, in order to overcome taboos that may exist concerning psychic and physical problems due to the absence of information, discussing about the experience of sexuality as an important practice during the aging process<sup>(8)</sup>.

Considering this perspective, the guiding question of this research was elaborated: What are the representations of nursing students about the sexuality of elders with dementia? Understanding how nursing

students represent this social object will allow to advance the knowledge in the field and subsidize interventions proposed for this age group. This understanding may give workers opportunities, preparing them for a reflective process that can guide actions based on the representation of the subjects and a health care that embraces the needs and peculiarities of these elders in the promotion of an active and satisfactory aging process.

As a result, this study aimed to learn about the social representations of nursing students about the sexuality of elders with dementia.

## Methods

Qualitative study based on the Theory of Social Representation. Social representations are built from concepts, statements, and experiences of participants, through socially elaborated and shared knowledge. They are responsible to guide behaviors and remodel elements of the environment in which these behaviors take place<sup>(9)</sup>.

The study was carried out in a university center of a capital city in the Northeast of Brazil, counting on the participation of 20 nursing graduation students, who were selected because they were regularly enrolled in the discipline Elderly Health. The students who did not participate in at least one meeting in person were excluded. The discipline is offered by the institution for students in the seventh semester of the nursing graduation course, with a load of 80 hours of class. The syllabus of the subject includes content related to the health-disease process of the aging process<sup>(1)</sup>.

To obtain the data and the intervention, the chosen technique was the focal group, which is used when there is a collective interest in the resolution of problems, making it possible to understand how the perceptions, daily practices, symbolisms, and representations of a certain group are built, making it possible to reflect on a specific theme and change one's opinion about it<sup>(10)</sup>.

The team who worked in this research was

made up of three people: one professor and coordinator, and two graduation students, one of which participated as an observer, while the other offered technical support.

There were three focal groups, from September to October 2016, in a location previously agreed upon by the participants and researchers. Each meeting lasted one hour and thirty minutes. Before the focal groups started, two meetings were carried out, aiming to invite and inform the students about the objectives and the methodology of the research. In these meetings, the students signed the Free and Informed Consent Form and responded to a questionnaire made up of two parts: the first had sociodemographic questions, to characterize the participants with regard to sex, marital status, and age group; the second had open questions aimed at learning the meaning of the theme and the reports of their experiences. The material achieved in these interviews was used to trigger the focal groups regarding its themes. The meetings were recorded through notes and recorded in a digital device. Later, the content was transcribed in its entirety.

The content of the focal groups was grouped in a single corpus of text files and later submitted to a statistical analysis in the software Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires (IRAMUTEQ), which carries out lexical analyses and is frequently used in qualitative researches in the field of health<sup>(11)</sup>.

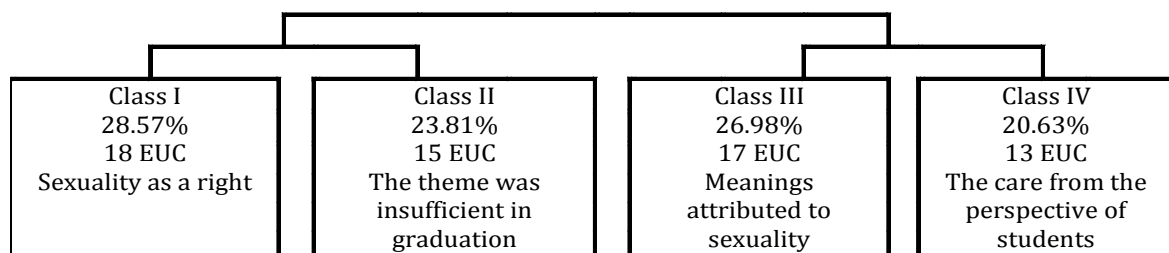
After data was processed in the IRAMUTEQ software, the Descending Hierarchical Classification was

carried out. It classifies all texts based on the vocabulary, which is divided by the frequency of the reduced forms, based on matrixes that cross segments of texts and words (repeated tests  $X^2$ ). This classification made it possible to find the semantic class of text segments that used a similar vocabulary among them, but which had individual particularities<sup>(11)</sup>.

The study was approved by the Research Ethics Committee, under legal opinion No. 1,541,127/2016, in accordance to national and international ethical standards involving human beings. The anonymity of the participants was guaranteed, and their reports were identified by the letter S (student), followed by a number corresponding to the sequence in which the interviews were carried out (S1 to S20).

## Results

From the 20 participants of the study, 17 were single, 18 were from 18 to 23 years old, and 17 were women. Regarding the textual content, the IRAMUTEQ separated the corpus in 99 Elementary Units of Context (EUC), from which 75.6% were used. The textual domains were identified and analyzed using the Descending Hierarchical Classification. Considering the identification of the words with the highest significance (chi-squared values) and the interpretation of the meanings attributed to them, the collective construct was grouped according to the respective meanings and to the social anchoring that was significant for the elaboration of the classes, presented in Figure 1.



**Figure 1** – Thematic dendrogram of the classes generated by the IRAMUTEQ through the Descending Hierarchical Classification. Teresina, PI Brazil, 2016

In the dendrogram, the Descending Hierarchical Classification and the reports made it clear that it was necessary to learn about the sexuality of the elders. Classes I and II were related to the right of the elders with dementia to experience sexuality and to increase the knowledge of the students about the theme. Classes III and IV were associated to the meanings of sexuality and to the care from the perspective students.

Class I was related to the social representations that recognizes that sexuality is an important activity in the life of the elderly person, being a physiological, basic, and emotional need in the aging process: *There is no right age for sexuality (S1). A vision of health, in all ages it's important and it needs to be seen naturally, since it does no harm to the elder, it's normal (S3). All human beings have the right to a sex life, considering that there are many ways in which the elder express their sexuality, we should respect and guide these elders in a health way, be them healthy or with dementia (S12).*

In class II, elements emerged that were representative of the importance of adequately training professionals to care and manage the sexuality of elders with dementia: *Having knowledge about this theme is important, since the population of elders is growing, whether with dementia or not, we need to educate ourselves (S2). It is very important for the elder to have knowledge about the theme, so we will know how to provide a good assistance (S20).*

Students referred to failures and difficulties in their academic formation, highlighting shortcomings and the lack of themes regarding the sexuality of elderly people. This pushes away the possibility of offering integral care and is reflective of the need of basic investments in educational strategies that can fill in these gaps: *Promoting basic knowledge about this subject in the graduation, with a discipline targeted at the theme (S16). The graduation does not present the theme, since this theme was seldom discussed (S17). The lack of information, a theme that was not addressed much, I think I'll have many difficulties, I think it should be discussed more (S18). This part should be discussed more, this theme should be explored with seminaries and lectures during graduation (S19). More*

*time in the field and internships and more proximity (S20).*

Class III expressed two representations based on common-sense information about the sexuality of elders with dementia. The first attributed meanings to the importance of love and of affective relations between elders. The second referred to the stigma and to a stereotype of a reductive and fragmented vision of sexuality: *It is really important in the life of the elder to work with sexuality, since they need love and care, everyone needs, needs hugs, kisses (S7). Elders do not have sexual lives, it is necessary to inform them about the risks to which they are exposed and try to educate them about sexuality (S1). If when we are healthy we are exposed to sexually transmitted diseases, imagine when we have mental problems and elders do not have sex, if they do, it's weird (S12).*

In class IV, students brought forth representations related to nursing care with regard to situations in which there were manifestations of sexuality. Their statements showed unpreparedness and fear of dealing with these situations: *Evaluate what type of behavior the elder has and then would have a dialog, letting the elder express their feelings openly (S08). To me it would be difficult, I wouldn't know how to act, I would need to experience this up close (S14).*

Believing that sexuality in elders with dementia is a problem prejudices the care that needs to be provided. The prevention of sexually transmitted diseases was found to be a strategy of care, showing negative representations based on limited knowledge: *It is important to know how to act and guide them so the elder is not harmed, to guide them to prevent diseases (S20). I would try to know more about how this happens and guide the prevention of diseases (S21).*

In addition, it was found that the statements analyzed showed stigmas, as they represented sexuality as a synonym of sexual act, which should not be practiced or experienced by people with mental health problems: *Acting with understanding and patience, I would explain that I have a family and a spouse and I could not become affectively involved with another person (S18). In most cases, when an elder has an intense libido, people associate it to madness, and it's true (S13).*

## Discussion

The main limitations of this study are related to the qualitative methodological approach and to the alignment to the theoretical analysis proposed. This is a research carried out in a single higher education institution, restricted to investigate a population that is limited in its size, which makes it impossible to generalize the results. Also, the absence of studies about the representations and/or perceptions of nursing students about the phenomenon investigated restricted the comparative discussions with other results and was another limitation of the research.

Despite these limitations, the analyses of this group can contribute to give support to intervention strategies in the nursing graduation courses, making it possible to unite health and education by bringing together theoretical and practical elements about the knowledge of nursing as related to mental health and to elderly health, thus reproducing the education of professionals that is based on integral care.

When considering the reports of the participants of this study, the genesis of a field of representation about the social object "sexuality of elders with dementia" was noted, showing that the objectification of this subject was anchored by many meanings, according to which few represented it as something complex, from which other emotions and behaviors that are not reduced to the sexual act are a part of. These representations find support in literature, since, obviously, sexuality also involves the sexual act<sup>(12)</sup>, and elders continue to have desires that are similar to those they had when younger. However, they have limitations due to physiological and, sometimes, pathological changes that make intimate relations more difficult<sup>(12-13)</sup>.

However, elders discover other pleasures, adapt to their new condition and find a way to live<sup>(14-15)</sup>. A study about the social representations of sexuality among elders showed that aspects such as "the love, respect, and caring are the principal elements

that structure and organize the social representation of sexuality in the elderly, sex appears as a peripheral element, being evoked frequently, but not promptly enunciated, denoting itself as not representative to the most important aspect for the elder"<sup>(16:580)</sup>.

Although literature shows sexuality as a basic human need in the lives of elders<sup>(3,7)</sup>, the processes of stigmatization and discrimination associated to this phenomenon persist in society, showing a symbolic and stigmatized representation that serve as a building block for the popular idea according to which elders are asexual, which also was true for the students who participated in this research.

The negative opinions and attitudes of the society, the students, and the health workers with regard to the sexuality of elders going through a dementia process can interfere in the health care being provided, showing that professionals, in general, feel unsafe with regard to what to do, but recognize that it is necessary to intervene. The interventions may be threatening and punitive, denying the sexuality of the elder who is being cared for<sup>(17-18)</sup>.

This study revealed that the negative social representations about the sexuality of elders with dementia are related to both the academic formation, during graduation, and to the professional exercise. As a result, this theme must be included in the education of nurses, considering that, during the graduation there are no spaces to reflect upon the care regarding the sexuality of the subject<sup>(1)</sup>.

The biggest the knowledge of health professionals about sexuality and dementia, the more positive will be the attitudes of these professionals<sup>(19-20)</sup>. However, there is a scarcity of training programs, as well as an absence of disciplines that address the health of elders in the context of sexuality and dementia<sup>(10)</sup>. The disciplines currently offered are based on a biomedical perspective<sup>(1)</sup>. However, in the professional education, in the conception of health, in the biopsychosocial dimension, ethical, social, and cultural aspects must be considered, as well as the relationship with



the multiprofessional team<sup>(1)</sup>.

Finally, this study stands out as an innovative one, as it addresses the social representations of the sexuality of elders with dementia in the context of the education of nursing students. The discussion of this theme in the formation of nurses offers the possibility of deconstructing and reconstructing socially established concepts and values, making it possible for nursing students to acquire scientific knowledge about the impact that dementia has in the elderly and their families, in different dimensions, to contribute for the development of evidence-based practices<sup>(5)</sup>.

## Conclusion

The social representation of nursing students about the sexuality of elders with dementia, presented in this study, revealed the beliefs, interpretations, and the network of symbolisms constructed to explain the social object. The representations were shown through discriminatory and stigmatizing conceptions, meaning that changes must take place in the conceptions of the participants with regard to this object, to make possible an integral health care, that enables an active and satisfactory aging process.

## Collaborations

Moreira WC contributed for the conception and for the project, data analysis and interpretation, article writing, in the relevant critical review of the intellectual content and the final approval of the version to be published. Fontinele VC collaborated with the project, the writing of the article, and the approval of the final version to be published. Nóbrega MPSS took part in the relevant critical review of the intellectual content. Amorim FCM, Carvalho CMS and Almeida CAPL aided in the project, in the relevant critical review of the intellectual content, and in the final approval of the version to be published.

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