Altering related to the aspects of sexuality...

ALTERATIONS RELATED TO THE ASPECTS OF SEXUALITY IN SPINAL CORD INJURED PATIENTS: INTEGRATIVE REVIEW

ABSTRACT

Objective: to analyze studies concerning alterations related to the aspects of sexuality in spinal cord injured patients. Method: this study is an integrative review of articles in English, Portuguese, and Spanish published between January of 2002 and January of 2013 in the LILACS, Web of Science, PubMed, and EMBASE databases with the descriptors: spinal cord traumas, sexuality, questionnaires, nursing diagnosis, and the research guiding question<< What are the available scientific evidences about alterations related to the aspects of sexuality in spinal cord injured patients? >> To respond to the proposed objective three categories of responses were created based on the physical, psychological, and social aspects involving human sexuality. Results: Among the 20 selected articles, the main change related to sexuality in the physical aspect was excitement; self-image concern in the psychological aspect; and difficulty in dealing with the culture of society in the social aspect. Conclusion: it is necessary to broaden thematic studies to integrate this dimension into the assistance to human beings. Descriptors: Spinal Cord Traumas; Sexuality; Questionnaires; Nursing Diagnosis.

RESUMO

Objetivo: analisar estudos relativos às alterações relacionadas aos aspectos da sexualidade no lesado medular. Método: revisão integrativa, de artigos em inglês, português e espanhol, publicados entre janeiro/2002 e janeiro/2013, nas bases de dados LILACS, Web of Science, PubMed e EMBASE, com os descritores: traumas da medula espinhal, sexualidade, questionários, diagnóstico de enfermagem, e a questão de pesquisa<< Quais as evidências científicas disponíveis sobre as alterações relacionadas aos aspectos da sexualidade do lesado medular? >> Para responder ao objetivo proposto foram criadas três categorias de respostas baseadas nos aspectos físico, psicológico e social, que envolvem a sexualidade humana. Resultados: dos 20 artigos selecionados, a principal alteração relacionada à sexualidade no aspecto físico foi na excitação; no psicológico foi a preocupação com a autoimagem; e, no social, a dificuldade em lidar com a cultura da sociedade. Conclusão: é necessário ampliar estudos sobre a temática para que essa dimensão seja integrada à assistência ao ser humano. Descritores: Traumatismos da Medula Espinal; Sexualidade; Questionários; Diagnóstico de Enfermagem.

RESUMEN

Objetivo: analizar estudios relativos a las alteraciones relacionadas a los aspectos de la sexualidad en el lesionado medular. Metodología: revisión de artículos en inglés, portugués y español, publicados entre enero/2002 y enero/2013, en la base de datos LILACS, Web of Science, PubMed e EMBASE, con los siguientes descritores: traumatismos en la médula espinal, sexualidad, cuestionarios, diagnóstico de enfermería, con el tema de investigación “Cuáles evidencias científicas disponibles sobre los cambios relacionados con los aspectos de la sexualidad del lesionado medular?” Para responder lo objetivo propuesto fueron creadas tres categorías de respuestas basadas en los aspectos físicos, psicológicos y social, que involucran la sexualidad humana. Resultados: de los 20 artículos seleccionados, el cambio principal respecto a la sexualidad en el aspecto físico fue en la excitaicón; en el psicológico fue la preocupación por la autoimagen; y en el social, la dificultad para lidiar con la cultura de la sociedad. Conclusión: se necesita aumentar los estudios sobre la temática de modo que esa dimensión se integre a la asistencia al ser humano. Descriptores: Traumatismos de la Médula Espinal; Sexualidad; Cuestionarios; Diagnósticos de Enfermería.
INTRODUCTION

The nurse is present in various scenarios of health assistance, whether in the pre-hospital care, emergency care, in-hospital, rehabilitation, and health promotion or prevention. The spinal cord injured patient passes through all those moments of assistance, and one of the health team members following him, is often the nurse.

The traumatic spinal cord injury occurs when a traumatic event happens such as automobile, motorcycle, and scuba diving accidents, aggression by firearm or a fall, when then a spinal cord trauma occurs, more commonly called spinal cord trauma.7 Thus, the spinal cord injury (SCI) involves, in most cases, single males, ages between 21 and 30 years, residents in urban areas, with middle school level of education. The most compromised body segments are the thoracic, cervical, and lumbar.1, 4,5

The spinal cord injury occurs in 15% to 20% of spinal fractures. These, in turn, are one of the most important causes of morbidity and mortality worldwide leading to high individual and social costs facing the consequences that SCI can cause.6 The number of incidences of spinal cord in Brazil is unknown, and that condition is justified by the fact that a form of notification of these traumas does not exist in Brazil. This scenario brings an uncertain index about the number of cases of spinal cord traumas, as well as the etiology of these traumas.1

SCI is defined as a set of severe neurological signs and symptoms that disable the individual and is characterized by motor and sensory changes with the presence of neuro-vegetative disorders past the vertebral bodies, where the injury occurs.7 SCI is a condition in which the person experiences loss or misuse of bodily structure functions that cause limitations in physical activities.8

The rehabilitation of these patients is important due to the poor quality of life that the injury generates for the patient and his family. Rehabilitation aims to lessen symptoms, improve independence, and place the individual in society providing them with the ability to perform daily activities.4 To rehabilitate an spinal cord injured patient it is necessary to have knowledge on the physical, mental, and social changes that happened to the individual, which demands monitoring by an interdisciplinary team.9

Bone marrow lesions are classified according to the intensity and impairment of motor and sensory functions. When motor and sensory functions are impaired, other body functions that depend on these commands are also undertaken, one of them being the sexual dimension.10

Sexuality is a complex process and inherent in every human being, and goes beyond the concept of a biological behavior, which aims at the differentiation of being male and female. Thus, the sexual act has the meaning of a physiological act, while sexuality is part of the totality of the human being.11

The spinal cord lesion does not lead necessarily to the loss of sexuality, since sexuality is not lost because of an injury or illness. The injury may lead to motor and sensory changes that directly affect the complex neuro-psycho-endocrine-vascular, which leads to an impairment in the sexual response. Nevertheless, any individual can continue being sexual.10

Therefore, the nurse, as an integral part of the health and professional staff, is responsible for the care and rehabilitation of the patient and has an important role towards this issue. Nurses should include in their planning of care the rehabilitation of the patient's sexuality and, for that, carry out interviews and detailed physical examination, before and after the trauma, as well as seek to delve into aspects of sexuality because this aspect should be addressed as a basic human need.

Accordingly, this study seeks to drive the knowledge for nurses about the difficulties encountered by spinal cord injured patients within the sexuality subject, and provide guidance for a planning for care that can help nurses.

OBJECTIVE

- To analyze studies related to alterations in the aspects of sexuality in injured spinal cord patients.

METHOD

The methodological strategy used in this study was an integrative review that allows access to Evidence-Based Practice (EBP) and provide theoretical-practical knowledge on a particular area.

The integrative review of literature is one of the research methods used in the EBP approach and allows the incorporation of evidence into the clinical practice; this method was chosen to conduct this study because it allows the collection and synthesis of results from experimental and non-experimental research about a particular theme or issue, in a systematic and orderly
fashion, contributing to deepening the knowledge of the investigated topic.

The six steps of the integrative review addressed in this study were: identification of the subject and formulation of the research guiding question, sampling or searching the literature, categorization of studies, evaluation of the studies including the integrative review, interpretation of results, and synthesis of the knowledge evidenced in the analyzed articles or presentation of the integrative review.

The guiding question for this study was elaborated using the PICO strategy (P - problem or patient; I - intervention, C - comparison, and O - outcomes) and thus, the guiding question was: What are the available scientific evidence about the alterations related to aspects of sexuality in spinal cord injured patients?

The following online databases were consulted for the study: Latin American and Caribbean Literature in Health Sciences (LILACS), Medical Literature Analysis and Retrieval System (MEDLINE), Elsevier Science (EMBASE), and Web of Science.

The following controlled descriptors for the location of primary studies were selected through the consultation of these vocabularies: Spinal Cord Traumas/Spinal Cord Injuries; Sexuality/Sexuality; Nursing Diagnosis/Nursing Diagnosis; Questionnaires/Questionnaires.

The inclusion criteria for the present integrative review were studies published in the databases mentioned above, in Portuguese, English, and Spanish, in which physiological, psychological, and social alterations that involve sexuality identified in adults in spinal cord injured patients are depicted between January of 2002 and 2013. The exclusion criteria were those studies which did not cover spinal cord injury along with sexuality and were undergoing preclinical or secondary studies, such as narrative review, integrative review, systematic review, clinical guidelines, and studies with the descriptor Physiological Sexual dysfunction because the search was for physiological, psychological, and social alterations describing only satisfaction or dissatisfaction with sex life.

The guiding research question and selection criteria used for this review were used to select the studies. Firstly, careful reading of titles and abstracts was performed before selecting those that related to the guiding question. Second, the selected studies were read in full before the final article selection.

This bibliographical survey occurred in the period from July of 2012 to January of 2013 and was performed independently by three different researchers to ensure the selection of all articles that could answer our guiding question.

A total of 60,239 articles that refer to the subject were found in the above-mentioned databases. After the reading of titles and abstracts by the independent researchers and application of the inclusion and exclusion criteria, 43 articles were selected for complete reading.

After careful reading of these 43 articles in full to select those that would be part of this integrative review, 20 articles were included in this study. To illustrate the search results a flow chart with the steps of the integrative review is presented showing: guiding question, selection of articles, inclusion criteria, and extraction of articles included in the integrative review (Figure I).
An instrument that better\textsuperscript{16-17} tended to the objectives proposed in this study was used to identify and categorize the articles. The instrument includes the following parts: identification - complete reference and databases; Goals - goal, guiding research question and hypothesis; Methodological characteristics - qualitative and quantitative study design (studies with primary and secondary data), sample (characteristics, inclusion and exclusion criteria), data collection technique (description of type of...
instrument, which ones were used, validation, duration of the study), and data analysis (descriptive or statistics); Results - analysis, description, and limitations; and Conclusion - conclusion (description and recommendations).

Three categories of responses based on the physical, psychological, and social aspects that involve human sexuality were created to respond the proposed objective.¹⁸

RESULTS

Twenty studies were included for analysis in this integrative review; seven were selected from the LILACS database, seven from PUBMED, and six from EMBASE. Articles from the Web of Science database were repeated articles from other databases and were excluded.

The years of publication ranged from 2004 to 2011. The years with the higher number of publications were 2005 and 2008, with four studies in each year, followed by the years 2006 and 2011, with three and two publications, respectively. The journals, in which the subject sexuality in spinal cord injured patients was mostly published, during the cited period, were the international journals Spinal Cord and Sexuality and Disability, with four articles in each journal. The countries that most produced studies on the subject were Brazil, with six studies, and USA, with three, followed by Spain, Sweden, and India, with two, and Finland, Sweden, Switzerland, Italy, and Malaysia, with just one study in each country.

Thirteen of the analyzed studies used a quantitative approach including eight with a non-experimental descriptive correlational design, one with an experimental clinical assay, and four with a quasi-experimental design with non-equivalent control group.

Three out of the seven studies with qualitative approach used a narrative approach, one was a case study, and three used phenomenology. Thus, the methodological characteristics that mostly surfaced in this analysis were those of quantitative approach with non-experimental descriptive correlational design. The sample size ranged from 1 to 959 participants. The structured and validated instruments, specific to sexuality, that were widely used were Female Sexual Function Index (FSFI) and International Index of Erectile Function (IIEFS), applied in two studies (one study used these two instruments and another used only Female Sexual Function Index (FSFI). Another instrument found in only one study was the

Spinal Cord Women Questionnaire (SCIWQ), which evaluates the health-related quality of life in injured spinal cord patients and has an item that deals with sexuality. However, it has not been validated in Brazil yet. One study created a specific instrument with 64 questions about sexual practices after trauma and quality of life, applied to both men and women. Two other studies used scales of functionality, however, did not use any structured instrument in relation to sexuality. The other 14 studies did not use structured instruments and built their own instruments.

In relation to the objectives of the analyzed studies, ten evaluated alterations in sexuality of spinal cord injured patients, while five examined the sexual issues pointed out by the patient, two analyzed the experience of spinal cord injured patients facing sexuality, two evaluated the knowledge of spinal cord injured patients about sexuality, and one raised the possible nursing diagnoses in spinal cord injured patients with Sexual Dysfunction being one of the diagnoses. Taking this into account, we chose to add this study to the integrative analysis because the authors collected the main alterations in spinal cord injured patients, and some related to sexuality.

As for the aspects involving sexuality, physiological aspects were found in 19 studies, however, only 12 of them investigated about the main changes in sexuality in the subject with SCI. The other seven studies analyzed and included in this review had in its results aspects of sexuality that answered our guiding question. In this category, subcategories were created describing changes in each phase of the sexual response cycle.

At the stage of desire, which is in the first stage of the sexual response cycle, six studies evidenced that decreased sex drive occurred in these individuals after SCI. Five out of these six studies, showed more than 50% of the sample referring to this alteration, while one study showed that only 13% of the sample had decreased sexual desire.

Among these five studies with more than 50% of the sample stating alterations in the desire phase, three investigated men and women, one investigated women only, and one investigated only men; in the latter study, men showed more desire reduction than women.¹⁹, 20, 22, 23, 36

In these three studies composed of men and women, only one with 63 participants identified that 31% of women showed worsening desire after the trauma.²²
According to a study carried out only with women, 51% reported that there was a decrease in the importance of sex in their lives after the trauma, yet, 54% pointed out that the reduced sexual desire that occurred after the SCI was justified by the loss of mobility, fecal and urinary incontinence, pain, sense of shame in the body, inability to achieve orgasm, feelings of not being attractive, medication, lack of a partner, fatigue, depressed mood, many preliminaries before the sexual act, low self-esteem, and concerns. On the other hand, 51% stated being very satisfied with their sex life after SCI.²¹

At the excitement stage, which is in the second stage of the sexual response cycle, only one study cited explicitly alterations referring that 50% of its sample felt excitement sometimes as opposed to the 12% who never felt excitement after SCI. Vaginal lubrication was addressed in this study, which is inserted in the stage of excitement, with 19% responding that it was maintained after the trauma; 31% responded sometimes, and 31% responded that never had vaginal lubrication after SCI. In men, 57.5% reported that they always feel excitement, and 8.5% never feel. In the erection phase, 15% usually have an erection in contrast to 49% who never experienced an erection after SCI. This sample was composed of 47 men and 16 women.²²

Out of the 20 analyzed studies, eight reported difficulties with erection (men) and lack of vaginal lubrication (in women) as alterations in excitement. Although these studies did not explain these were problems in the excitement phase, this difficulty was verified.²⁹ 20 23

Among these studies, three showed statistical analyses indicating more than half of the investigated population with this alteration, however, the other studies only mentioned this difficulty. ²¹ 23 28

During orgasm, considered the last phase of the sexual response cycle, eight studies addressed this issue in the 20 analyzed studies. Among these, one results in difficulty or absence of orgasm after SCI²², three reported difficulties in having an orgasm¹⁹ 26 30, two reported never having an orgasm after SCI²⁸ 39, and two reported difficulty of ejaculation after the SCI.²⁵ 3¹

Thirteen out of the 20 analyzed articles addressed psychological changes that alter sexuality in the SCI patient. ¹ 20 22 23 26 28 30 6

No study addressed only the psychological aspects of the patient, but reported on psychological aspects related to physical aspects.

Two studies narrated that SCI patients have low self-esteem ¹ ²³ 3 5 and five showed concerns with self-image that causes discomfort to the partner or to find someone to have a relationship. ¹ ² 26 3 10 Three studies showed that maturity on the part of the partner can also contribute to a satisfactory sexual relationship, by learning about the new condition. ¹ 2 8 3 1

Four other studies pointed out the lack of collaboration by the partner in relation to the adaptation and new forms of sexual intercourse. ¹ 23 3 10 Three studies found in the subject’s speeches issues such as lack of communication, difficulty speaking about the subject with the family - due to lack of openness - and also lack of support from health professionals to talk about the subject and resolve their doubts. ¹ 2 8 3 4

Four studies reported the manifestation of fear, loss of self-confidence, anxiety, and depression, which become a consequence in the lack of desire for another person, or even insecurity in initiating sexual intercourse after SCI.²² 26 3 3 6

Researchers also show that the subjects have difficulty finding partners after the trauma because they are mostly young age adults. ³ 0

Scholars discussed, the question of foreplay before intercourse with participants in these studies; they mostly complained and reported that this harms the sexual act itself because it takes too long to achieve arousal and they get tired due to their physical condition. ³ 6

Among the 20 studies, only five addressed social issues involving sexuality. ¹ ³ 1 3 4 Four studies reported difficult for acceptance of the condition of the injured spinal cord patient in the society, two studies cited culture issues resulting from difficulty in expressing sexuality and demonstrating having sexual activity in the country were the patients live. Two other studies approached discrimination and prejudice on the part of others who are not SCI individuals, creating situations that cause anxiety, fear, and insecurity that end up interfering with sexuality. ¹ ³ 3 3

Only one study found responses such as lack of employment as a concern affecting sexuality. ³ 3

**DISCUSSION**

This integrative literature review allowed us to identify the main biopsychosocial alterations that spinal cord injured patients...
present, which directly affect sexuality contributing to the generation of external evidence.

The medical area composes the authorship of the majority of the analyzed studies, however, all studies in the LILACS database were conducted by nurses, and only one study was conducted by psychologists in the international journals. The topic researched corroborate the interest from the nursing point of view demonstrating through this integrative review, that spinal cord injured patients have great difficulty in fully exercising their sexual life and require some guidance after the trauma, especially health education focused on this basic human need, which is sexuality.34

In another study, where the nursing diagnoses in spinal cord injured patients were discussed, limitations such as sample number and difficulties in finding nursing records about sexuality were encountered. Research has already demonstrated the poor quality of nursing records and the difficulty in conducting retrospective research in the field of nursing by analyzing medical records; because information is scarce and often do not match the care provided. In addition, it demonstrates that nurses do not talk and guide patients about their sexuality.35

Exceptionally, one study used a methodology in clinical assays and was developed by nurses, published in a Brazilian journal. Despite the good concept that this journal has among Brazilian journals, it is still difficult for nursing professionals to publish in international journals especially on this subject.35

Four studies presented quasi-experimental studies including intervention group composition and control group, with comparisons mainly between a group presenting SCI and another not presenting it.26, 27, 28,29

The literature still does not present specific instruments for this population; however, generic instruments that capture alterations in spinal cord injured patients in a satisfactory manner are used. A similar view is presented in this integrative review, in which most articles did not use specific instruments on sexuality and, much less, were validated for the population with spinal cord injury.

The instrument Female Sexual Function Index (FSFI) was employed in two international studies conducted by physicians; this instrument aims to assess sexual function of women in general. It is an instrument with six sub-scales that evaluate desire, arousal, lubrication, orgasm, satisfaction, and pain. It works with Likert-type scales with affirmations from 0 to 5 points, varying from 2 to 36 points, defining that the higher the value the better sexual function.

Another instrument was the International Index of Erectile Function (IIEFS) used in one study among the 20 analyzed studies. This instrument is a self-response questionnaire widely used in the evaluation of male sexual function, which has 15 items with five categories of sexual function: Erectile Function (6 items), Orgasmic Function (2 items), Sexual Desire (2 items), Coitus Satisfaction (3 items), and Overall Satisfaction (2 items).

The studies demonstrated that the age of subjects ranged from 18 to 70 years, with a predominance of young-adults, suggesting that spinal cord injuries affect younger people victims of car accidents.

In this integrative review, six studies addressed aspects of sexuality in men with SCI, seven addressed only aspects of female sexuality, and the others approached it in both sexes. Non-traumatic spinal cord lesions reach more young adult men than women, however, in the context of sexuality, female aspects are more covered because of the ease of communication with women and because female instruments are used more often.1, 30,34

Although women have preserved sexual functions, and pass through the three phases of the sexual response cycle, they still have major concerns with their sexuality in the psychological and social context and require extensive rehabilitation programs about their sex life.31

The analysis of the 20 selected articles allowed the observation that spinal cord injured patients have active sex life after the injury and feel satisfied with the sexual act because most of them were injured after 18 years of age when they were already sexually active. However, those who had the trauma before they started their sex life feel less satisfied and present more sexual dysfunctions.20

Another important factor is that spinal cord injured patients who have active sex life, have decreased numbers of sex relations compared to the times before trauma, a fact explained by desire, arousal, and orgasm difficulties.20,28

One of the problems encountered is female “blame” for feeling pleasure in sexual intercourse, either in those with SCI or without, i.e., even before the injury these women had sexual relations only for
reproduction purposes. After the injury, many of them became sterile, which leads to a decrease in sexual activity and the presence of trauma at the time of sexual intercourse.  

A difference in male and female concerns regarding sexuality was observed. Women with SCI have much more interest in knowing about their fertility after the trauma and have a concept of sexuality that goes beyond the physical conception of the word “sexual” than men; men care about their physical aspect of how ejaculation and erection will be affected after injury.  

Human sexuality is an integral part of the total personality of people and suffers strong influence of factors such as self-esteem, self-image, and self-concept influencing the way the individual view, respect, and understands self. All these aspects interfere in the exercise of sexuality. Thus, the paraplegic man suffers several changes after the trauma, among them, the valuation of romanticism, increasing vanity, creativity, increased communicability, increased observation and also, increased concern about his wife’s sexual satisfaction. Changes in reducing anger, increasing amiability, sincerity, sensitivity, companionship, emotional neediness, insecurity, and friendship bonds were observed among social relations.  

The changes demonstrated in the referred study are justified because after the trauma men realize the confrontation between his sex life before and after the injury and believe that their previous experience and the way they lived his sex life after the injury testify against his physical condition, evidenced in the issue of masculinity, strong gender, taking the sexual act as only a form of pleasure. Therefore, they need to reposition themselves in life and value their unique experience, reinventing their sexuality and masculinity.  

The 20 analyzed studies demonstrated that the level of lesion can interfere with sexual satisfaction, but it has no influence on this satisfaction if it is complete or incomplete.  

Thematic scholars argue that sex life remains after injury, with less frequency, studies have treated sexuality only as a clinical dysfunction, and research have demonstrated that sexuality suffers more influence from psychological and social than physiological factors. Thus, the physical rehabilitation deserves to be revisited in the treatment of spinal cord injured patients, essentially, in the area of sexuality.  

Only two studies mentioned that sexual satisfaction decreased after SCI in 29 male individuals and also report that sexual satisfaction gradually increases over the months corroborating the findings of another study only with men.  

It is known that women have more difficulties returning to their sexual activity after SCI than men, however, when they start their sexual activity they feel more satisfied than men.  

The lack of treatments, rehabilitation, and programs that offer educational activities about sexuality in this new condition of life was evidenced in all studies denoting that health professionals still lack information about what and when to guide these patients.  

A “taboo” on the topic of sexuality is still prevalent, which interferes directly in the care provided to patients in need of assistance on this basic human need. A literature review on the theme of sexuality in women undergoing radical mastectomy evaluated the perception of these women about their body image and sexuality. One of the limitations of that study was the low incidence of articles describing sexuality, justified by the authors by the context of sexuality being an obstacle for publication and the fear from researchers and interviewees in establishing a dialogue on this subject.  

**CONCLUSION**  

The elaboration of this integrative literature review allowed us to find evidence related to alterations in adult spinal cord injured patients in relation to their sexuality after the trauma.  

The studies are still preliminary in the use of instruments that identify characteristics of sexuality in this specific population. The main scientific evidences found in this integrative review related to aspects of sexuality in spinal cord injured patients were the physiological aspects such as excitement (erection in men and lack of vaginal lubrication in women) and the difficulty to achieve orgasm during intercourse with regards to the responses of the sexual cycle; we also found evidences on psychological factors that, similarly, altered sexuality in spinal cord injured patients such as concern about self-image, “blame” on the part of women, and lack of manhood on the part of men.  

Finally, other observed alterations with fewer incidences, in the analyzed studies, were on the social aspect such as difficulty of acceptance of these patients on the part of society. Thus, it is necessary to expand studies on sexuality of spinal cord injured patients, mainly concerning sexual satisfaction in these individuals so that this
dimension is integrated into the assistance to the human being.

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Alterations related to the aspects of sexuality...


Submission: 2013/08/22
Accepted: 2013/10/10
Publishing: 2014/02/01

Corresponding Address
Eliane Nepomuceno.
Endereço: Bela Vista, 589
Bairro Monte Alegre
CEP: 14051-070 – Ribeirão Preto (SP), Brazil