

# Chronic disease and sexuality

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## Chronic disease and sexuality

### Abstract

This study explored the level of production and contents of information available within the global context on the approach of sexuality in individuals with chronic disease (CD). The following main themes were identified: sexuality as a human right and fundamental part of health for individuals with CD, factors present in situations of CD that generate alterations in sexuality, and the models for assessment, measurement, and intervention of the phenomenon. Scientific production is scarce and limited on sexuality during CD, with the most part of said production from recent years.

**Key words:** chronic disease; sexuality.

## Enfermedad crónica y sexualidad

### Resumen

Se exploró el nivel de producción y contenido de la información disponible en el contexto mundial sobre el abordaje de la sexualidad en personas con enfermedades crónicas (EC). Se identifican como principales temas: la sexualidad como derecho humano y parte fundamental de la salud para las personas con EC, los factores presentes en las situaciones de EC que generan alteraciones en la sexualidad y los modelos para la valoración, medición e intervención del fenómeno. Es escasa y limitada la producción científica sobre la sexualidad en la EC, siendo la mayor parte de ella de años recientes.

**Palabras clave:** enfermedad crónica; sexualidad.

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## Doença crônica e sexualidade

### Resumo

Se explorou o nível de produção e conteúdo da informação disponível a nível mundial sobre a abordagem da sexualidade em pessoas que cursam com doenças crônicas (EC). Identificam-se como principais temas: a sexualidade como direito humano e parte fundamental da saúde para as pessoas com doença, os fatores presentes nas situações de EC que geram alterações na sexualidade e os modelos para a valoração, medição e intervenção do fenômeno. É escassa e limitada a produção científica sobre a sexualidade na EC, sendo a maior parte dela de anos recentes.

**Palavras chave:** doença crônica; sexualidade.

## Introduction

The World Health Organization reports that in all countries, including the Latin American and Caribbean region, there is a high incidence of chronic disease (CD) in the world with a tendency to continue increasing. Not only are there more individuals affected by CD, but these people are living longer.<sup>1</sup> Also, it is accepted worldwide that sexuality is a human right and a fundamental part of health, besides being a quality-of-life component. In spite of this, voids exist in research and in the clinical practice on sexuality in situations of CD, which is why it was decided to proceed in exploring the production and contents of information available within the global context on the approach of sexuality in individuals with CD.

It is worth pointing out, as suggested by De Santis and Vásquez<sup>2</sup>, that still today multiple limitations exist for research in the field of sexuality and, in that sense, although it tends to increase in number, its results must be carefully assessed before being applied. For this review, a systematic search was carried out in five databases: CINAHL, Ovid, Scielo, Medline, PsycInfo, with a window of observation between 1975 and 2012, under the descriptive terms of sexuality, chronic disease, chronic suffering, combined with assessment, measurement, intervention,

care, models, and programs, with their English translation. Some 93 articles were reported, of which 36 fulfilled inclusion criteria by specifically documenting, reviewing, or representing sexuality in situations of chronic disease with relevance for clinical practice. Once selected, the articles were classified and organized by those reporting models understanding sexuality during CD, sexuality during CD by age, and sexuality during CD by type of disease.

### Models of understanding sexuality during CD

To understand the impact of CD on sexuality and of sexuality during chronicity, Verschuren *et al.*,<sup>3</sup> make, among others, the following observations: 1) Sexual function is assessed according to a response accepted as “normal” under standards of performance within the expected response cycle. 2) Sexual wellbeing is an individual and subjective experience of sexuality that depends on how it is evaluated within the context of individual and social life. 3) Sexual dysfunction and sexual problems can occur at the same time, but happen separately, and 4) Sexual intimacy is an important way of communicating with the partner. The

authors indicate, further, that it is currently evident that a change of paradigm has emerged regarding management of CD, from which the possibility of being alive is not as significant as is the quality of life of people with CD. Within this analysis framework, understanding human sexuality as a quality-of-life component of individuals with CD is quite important. Verschuren *et al.*,<sup>3</sup> proposed a theoretical model to address the topic of sexuality during CD, with two components: the first, admitting human sexuality as a complex phenomenon where biological, psychological, relational, and socio-cultural factors intervene and, the second, accepting that CD is not only characterized by somatic and physical symptoms, but also by psychological stress and psychosocial pressure. That is, in their theoretical proposal, it is clear that CD and sexuality have common factors.

The model proposed by Verschuren *et al.*, indicated that upon estimating the relationship between CD and sexuality we must bear in mind the subject's age, health condition, progress of the CD, and type of disability, given that by being sudden it requires immediate adaptation to the situation, but a progressive CD requires continuous adaptation to limitations generated by the disease. In this sense, the impact has to do with the moment in life the CD appears, so that if the individuals are not sexually active, they generally learn to live with the limitation characteristic of CD, unlike those who are sexually active because they must adapt to an additional loss. Chronic disease can have a psychological effect on patients or their partners, affecting self-image and self-esteem, it may alter the bodily image due to negative changes in appearance, or due to loss of functionality; this leads to a negative self-perception in the sense of being less attractive and, eventually, to rejecting sexual activity.<sup>3</sup>

There is increasing evidence on how psychological aspects (individuality, coping style, and interpretation of external stress factors) can modulate psychological responses like immunity, inflammation, and endocrine and neurological processes. The psychological repercussion of a disease can, thereby, inversely affect the physiology.<sup>3</sup>

Kralik *et al.*,<sup>4</sup> studied 81 middle-age women with chronic disease to describe how they experience their sexuality and how it is altered by the CD. For them, sexuality involved desires, appearance, expression, and sexual feelings; some aspects of their lives they recognize as of the affectation with CD. Their findings include an experience of sexuality under the situation of CD with a changing body, awareness of the needs of others, and a particular way of communicating it. They conclude that upon revising the cultural construction of female sexuality and how it is affected by CD, its impact on their lives is understood as something much more than symptoms. It is fundamental, therefore, to understand the experience of having a CD with sensitivity on how it affects quality of life and specifically sexual wellbeing.

### **Impact of CD on the couple's relationship**

Verschuren *et al.*<sup>3</sup> indicated that CD affects importantly the couple's relationship, in part due to the psychological effect of the individual who is ill on the partner. This has a bi-directional influence. Sexual and marital relationships are different, although they are frequently associated. According to the same authors, the impact of CD can serve as a source of individual growth or as a source of stress for the partner. For example, chronic pain and breast cancer affect the quality of the relationship. When the partner is the caregiver, the sense of peer is lost and disparities emerge that are negative in the relationship. Communication and social skills, which permit solving problems and managing conflict impact upon the relationship. Caring for a loved one affects time and freedom, which gives the sense of a limited life and can generate serious problems for the couple and separate them even more –although it can eventually bring them closer. Generally, the caregiver hides desires and emotions from the receptor and ends up feeling desolate and alone; many feel and express pride for how their partners (receptors) assume the disease, with patience and courage. According to researchers, marriage is a protective factor for men but not for women. These findings

have been confirmed in hemodialysis patients and in patients with multiple sclerosis.<sup>3</sup> Soubhi, Fortin, and Hudon,<sup>5</sup> in a study conducted with 7547 adult Canadian partners with one or more chronic diseases, identified that both for women as for males, the perception of conflicts with the partner was associated to a negative perception of mental health and greater distress. In synthesis, CD affects the couple's life, but living as a couple also affects the evolution and quality of life of an individual with CD.

## **Sexuality during chronic disease according to age**

### **Sexuality in children and adolescents with CD.**

Finnegan<sup>6</sup> indicates that children learn about gender and sexuality through a socialization process; understanding that process is important to support their sexual health during chronic disease. Socialization permits children to gradually learn roles, values, and social standards associated to multiple factors like physical and psychological health, social development through direct teaching, imitation, modeling, experimenting, and information. Silence, as a way of maintaining innocence and preventing early sexual activity is no more than a myth.

For children and adolescents with CD it is quite important, as part of comprehensive care, to consider their sexuality. On the one hand, the situation of CD should not unnecessarily alter sexual development and, on the other hand, normal development of sexuality should not exacerbate CD. It is fitting to be mindful of the possible effects of CD in the sexual health of children by checking to see if there is delayed sexual development, exceedingly restricted relationships, inhibition in sexual function, altered state of health that hinders some expressions of sexuality, or reproductive problems.

Finnegan<sup>6</sup> indicates that barriers should be avoided in offering effective sexual health care of children and adolescents, such as: 1) blocking dialogue when there is a family care approach, 2) insufficient knowledge or lack of ability to

address the theme, 3) not being accepted as valid interlocutors on issues related to sexual wellbeing, 4) fear for the confidentiality of the information, and 5) lack of an appropriate venue to address these types of themes.

Kelton<sup>7</sup> indicates that pediatric nurses must recognize the need to offer sex education to children with CD and to their families. In many cases, nurses know that sexuality is important, but do not address it due to lack of knowledge, because they feel uncomfortable, or because they believe they will make the patient uncomfortable. For adolescents with CD, as with any adolescent, it is necessary to include counseling on birth control, prevention of sexually transmitted diseases, and on drug use. Likewise, schooling must be maintained, inasmuch as possible under regular conditions or adapted if necessary.<sup>8</sup>

From the beginning of the disease, when it is diagnosed, its possible impact on sexuality can be incorporated to caring for the adolescent. In many cases, as the adolescent grows, the parents appreciate the support to air the theme in the family, but nurses do not always have the answer, although they do have the obligation to seek the sources of the information required with the family. Among the conditions that must be managed by nurses working with young individuals with CD is the concept of genotype and phenotype, identification of sex and gender, sexual development during puberty, the importance of sexual feelings and their expression, and reproductive capacity. It is, thereby, important to assess and document an education plan and its implementation and evaluation.<sup>7</sup>

For the purpose of evaluating the impact of CD upon the wellbeing of adolescents, Miauton *et al.*,<sup>9</sup> took a group of Swiss adolescents with CD to describe their behavior (leisure activities, sexuality, risk behaviors) and compare this to youth without CD. The sample evaluated was of 9268 adolescents in school ages between 15 and 20 years. The adolescents with CD reported riskier behaviors by not using the car's safety belt, driving under the influence of alcohol, cigarette and

marihuana smoking, alcohol consumption, and suicide attempt during the last year. The authors state that experimental behaviors are not rare in adolescents with CD and can be explained by the need to assess their consumption and behavior limits. In light of these behaviors, prevention and comprehensive care are quite relevant.

**Sexuality in elderly individuals with CD.** Martínez *et al.*,<sup>10</sup> in their review on sexual activity during old age, indicated some aspects that permit confusing age with CD against sexuality. According to them, during this stage the psychological and physiological need persists of continued sexual practice. The emphasize in that although changes exist characteristic of aging that affect sexuality and can diminish sexual desire and functionality, there is no age during which sexual activity, thoughts about sex, or desire come to an end. The most outstanding changes in the sexual wellbeing or function occur associated to the disease.

Orihuela *et al.*,<sup>11</sup> conducted a study to evaluate sexual knowledge, attitudes, and behaviors in a Latin population. They found diverse opinions on sexuality, with predominance of the criterion according to which it must take place without bearing in mind age, although in some cases it was associated to youthfulness. They indicated that sexual activity and interest is more conserved in men -in women the lack of interest is salient. Among the chronic conditions endured by the group studied and which affected their sexuality were hypertension, osteoarthritis, and diabetes mellitus. The authors recommend preparation on sexuality during this stage to improve the quality of life of these individuals with a broad approach of criteria.

### **Sexuality during specific chronic diseases**

**Chronic hormonal diseases.** These diseases have direct impact on an individual's sexual function and wellbeing. Although physiological hormone decrease does not seem to affect sexual desire, sexual dysfunction does affect it. Documentation exists on the effects of hypogonadism, testosterone replacement therapies, high levels

of prolactinemia (associated to low testosterone and ovarian dysfunction), indicated that these are associated to low sexual interest in both genders and in men with erectile dysfunction, alteration or lack of ejaculation.<sup>12</sup> Also, diabetes mellitus is indirectly related because of its complications and psychological effects to altered sexuality. Damages in small vessels or peripheral nerves may interfere with sexual functionality; in men loss of desire may be present, along with erection problems and problems with ejaculation and orgasm. In women sexual dysfunction may appear due to the same cause; however, it does not seem that the capacity to have an orgasm is related to diabetes. Nevertheless, vaginal infection is more frequent in diabetic women and that explains the slightly higher dyspareunia in them than in healthy women. Additionally, with sexual dysfunction we also see insecurity, rejection of the disease, and low self-esteem.

Whitehouse<sup>13</sup> indicates that research on the effect of diabetes on sexuality is specially limited to the elderly population, where the effects of health are confused with those from the aging process. Longitudinal studies available are not sufficient to analyze the changes. Also, controls may have been biased because groups with similar characteristics in good state of health are not used; rather, with different pathologies or levels of diabetes. There was also no homogeneity in the methodologies or revision of the treatments of the diabetic women or the complications generated by diabetes. In said sense, we suggest performing a comprehensive assessment that includes the aspect of sexuality, directly and respectfully inquiring, to obtain the required information, especially among older women.

**Chronic renal diseases.** Coelho-Marques *et al.*,<sup>14</sup> studied 86 healthy women 18 years of age and older and 38 women in dialysis to examine their quality of life, including their sexual health. They found not only quality of life deteriorated and especially in the environmental and physical components of women in dialysis, but also a decline in sexual function. Curiously, the decline in sexuality was not associated to the quality of

life reported. Sathvik *et al.*,<sup>15</sup> carried out a study with 75 patients in hemodialysis to observe their quality of life. As a measurement tool, the researchers employed the WHOQOL-BREF questionnaire that includes a view on sexuality. Most of the patients studied, especially men, were not satisfied with their sexual life, admitting lower interest or lack of interest for it. Similar findings were reported by Rosas *et al.*,<sup>16</sup> in groups of men and women in dialysis.

Lew-Starowicz and Gellert<sup>17</sup> revised the relationship between sexuality and quality of life in 112 patients in hemodialysis. Their findings confirm that sexual dysfunction is related to depression and anxiety, which generates an important negative impact on dialysis patients. The authors indicated that the theme is relevant in their quality of life and frequently underestimated by therapists. Rosenkranz *et al.*,<sup>18</sup> looked at rehabilitation and satisfaction with quality of life of adult patients who had renal problems since very early age. With a sample of 39 young adult patients between 18 and 43 years of age, 13 of them in dialysis and 26 successfully transplanted, they found that the general level of satisfaction with life was significantly reduced. The patients were less satisfied in the relationship with their partners, sexuality, and their family life.

**Genitourinary diseases.** Schultheiss<sup>19</sup> reports in individuals with chronic prostatitis altered quality of life and wellbeing associated to a disorder of sexuality. Among the symptoms of male urogenital infection are: erectile dysfunction, premature ejaculation, and painful ejaculation. Chronic prostatitis is the second most frequent cause of premature ejaculation. The author suggests studying prostatitis as a possible cause of sexual dysfunction prior to medicating to solve it. Withmore,<sup>20</sup> indicated that interstitial cystitis is a chronic vesicle condition characterized by increased urinary frequency and urgency, suprapubic pain, and dyspareunia, and that it causes sexual pain in women, which is why this diagnosis must be considered.

**Neurological diseases.** Borisoff *et al.*,<sup>21</sup> studied sexuality in individuals with spinal cord trauma;

indicating that research has been aimed at male erection and fertility, when in reality pleasure and orgasm are the highest priorities for recovery. They propose the sensory substitution approach as a possible path, although still unexplored, in individuals with these alterations. Pentland *et al.*,<sup>22</sup> studied women from 31 to 70 years of age with spinal cord transection in Canada to see how they confront their situation within diverse aspects of their daily lives. The authors identified great sense of loneliness, a perception that many of their needs are not kept in mind by health personnel. The most common concerns were of gynecological/sexual type, aspects of the bladder and fecal continence.

Kralik *et al.*,<sup>23</sup> in a study with nine women with multiple sclerosis as informants, sought to understand the construction of sexuality and the impact of a changing body. Their conceptual framework was self-identity as of how the patients felt as sexual beings, how they experienced their bodies, their sexual activity, and how others reacted against them. It is interesting that in the construction of the theory product of the study that the cultural, educational, social, religious components, as well as the family context impacted upon the female capacity to model the experience of the disease amid the elections available to seek living under normality amid the disease.

**Chronic pain.** Ambler *et al.*,<sup>24</sup> in a study of 237 patients from a chronic pain management program, found that 100% of them reported diminished sexual activity associated to the pain they endured. Weijmar *et al.*,<sup>25</sup> introduced some guides constructed with international experts to assess and manage chronic dyspareunia under the understanding that 15% of the women who suffered from it, did not understand it well and, in that sense, did not manage it well. The authors suggest that difficulty exists in differentiating it from vaginismus.

**Inflammatory intestinal disease.** Several authors, who have studied the relationship between inflammatory intestinal diseases and sexual

dysfunction, coincide in stating that little research is available to support clinical management although the alteration is frequently documented.<sup>26-29</sup> Andrews *et al.*,<sup>30</sup> studied patients with Crohn's disease and ulcerative colitis, considered long-lasting diseases that affect importantly the quality of life, which must comprise the psychological burden, collateral effects of the disorder, maintenance of therapies and compliance level, smoking habit, sexuality, fertility, family planning and pregnancy, and anemia or iron deficiency. The researchers indicated that up to 75% of the women and 44% of the men report problems. In men, erectile dysfunction resulted fluctuating in relation to the exacerbation of the disease. Interestingly, it is reported, as in prior studies, that depression is most associated in both genders to altered sexuality. Special consideration is given to patients operated because they were most affected than the rest for fear or fecal urgency, flatus and fatigue that can influence or interrupt the sexual relationship.

**Cardiovascular diseases.** Corona *et al.*,<sup>31</sup> based on a study conducted on 1687 patients, indicated that erectile dysfunction due to genital low blood flow is associated to cardiovascular disease. In that sense, erectile dysfunction may not only indicate existing cardiovascular problems, but also an important warning of a bigger cardiovascular event.

According to Verschuren *et al.*<sup>3</sup> vascular diseases have direct, indirect and iatrogenic impact on the sexuality of individuals. Regarding the direct impact, it is evident sexual function given that in cardiovascular diseases, in many cases, sexual dysfunction occurs due to insufficient irrigation of the genital region because of atheromatosis. Dysfunction of the penis and vaginal atrophy are associated to the lack of sufficient irrigation. During the cerebrovascular event (CVE) there are vascular antecedents and after the CVE function and desire tend to diminish. Very few patients have reported satisfaction with their sexual lives after a CVE. During untreated hypertension, erectile dysfunction occurs with almost double the frequency against controls without the disease.

With respect to the direct impact, researchers<sup>3</sup> state that, regarding sexual function, physical complications like pain, loss of muscle strength, spasms, sensitivity disorders, and urinary incontinence affect sexuality. Likewise, sexuality is affected by associated psychological changes, like loss of control, impulsiveness, fear, dependence, fear of failure, or lack of trust. With respect to sexual wellbeing, the authors state that, after a cardiac or cerebrovascular event, fear remains that such will be repeated; some 75 to 80% of the subjects diminish or interrupt their sexual activity. In terms of iatrogenic effects, many antihypertensive drugs negatively affect sexual activity. The medication for conditions associated to medications acting on serotonin inhibitors, serotonins, and antiepileptic substances may have concurrent effects or additive negative effects in sexual function.<sup>3</sup>

Kazemi-Saleh *et al.*<sup>32</sup> indicate that in patients with chronic disease, fear is one of the important causes to evade the sexual relationship, which affects importantly the quality of life. In their study with 87 patients with coronary disease, they examined the differences between those having and those not having sexual fear. Of these patients, they found that 29 expressed fear and, consequently, lower frequency of sexual relations. Associated to the finding were: age, socioeconomic level, educational level, smoking, history of myocardial infarction. Among the modifiable factors that generate fear and which must be considered in these patients, we have the marital relationship and depressive symptoms.

**Rheumatic diseases.** Xibillé-Friedmann *et al.*,<sup>33</sup> studied a group of independent women during their daily lives with rheumatic disease including lupus Erythematosus, rheumatic arthritis, and psoriatic arthritis. They indicate that these diseases are frequently accompanied by dysfunction and depression. Their effect on sexuality, as in other diseases, has not been widely studied. These patients had a more altered perception of their sexuality than the control group with which they were compared, with tendency to depression and low self-esteem.

**Lung disease.** Vincent and Singh<sup>34</sup> state that sexual expression is an important part of the individual's identity and even so it is not widely addressed by the healthcare team. They state that therapists should consider if poor sexual health bears a direct effect on their patient's quality of life by performing an adequate and comprehensive assessment. They suggest incorporating into said assessment aspects like age, spirituality, relationships, roles they play and other social components, physical aspects and emotional aspects, as well as capacity to understand. As a consideration of particular interest in patients with lung disease, they suggest revising energy conservation to advise these patients to be mindful of the temperature of the site, the time of day, comfort, position and support from the partner. They further state that it is necessary to be aware of one's own sexual health to work in this field.

**Cancer.** Huber *et al.*,<sup>35</sup> reviewed experiences of sexuality and intimacy in women with breast cancer, indicating that these are determinant factors of quality of life. Theirs, as do other studies, reflects that in spite of awareness of its importance, many therapists do not address the issue with their patients. To open communication settings, said therapists must give relevance to the theme and recognize the impact of the cancer treatment within that context.

**Mental disease.** McCann and Clark<sup>36</sup>, in their phenomenological study with nine young adults with schizophrenia, argue that this is a complex and chronic disease, of high impact upon quality of life and that, additionally, it is perceived as a catastrophic event that alters lives, affects relationships with others, and whose medications alter bodily perception and – consequently – their expression of sexuality. The authors state that in spite of limitations to generalize a study of this type, nurses must be trained for holistic care of patients with schizophrenia, which demands understanding the corporeity experienced by the patient with the disease and the support from social relationships, as well as the effects

of antipsychotic substances and adherence to treatment. Higgins *et al.*,<sup>37</sup> in a literature review from 1980 to 2005, report that, although serious limitations were noted in the literature reviewed on education and sexuality in patients with mental disease, there are high-risk sexual behaviors in individuals with severe mental disease, which among others, places them in danger of having sexually transmitted diseases. It is evident that educational programs address sexually transmitted diseases, including HIV, along with negotiation and acquisition of skills in the use of condoms. However, it is also noted that in severe diseases it is difficult to heed the information and manage to modify the behavior based on said information.

## Conclusion

Sexuality during chronic disease is described in the literature due to the high impact it generates on the patient's quality of life. The literature analysis permits noting that most of the publications have been generated in recent years. When comparing the studies found with the volume of literature on chronicity and sexuality, it may be said that, globally, that scientific production on sexuality in these situations is scarce and limited. Different studies make it evident that alterations in sexuality have a high impact on the quality of life of individuals with chronic disease. Alterations occur due to dysfunction and due to loss of sexual wellbeing in which the conditions surrounding the experiences of the individuals often plays a preponderant role. Although models are reported to assess, measure, and understand the phenomenon, there is almost an absolute lack of reports related to intervention and care. The lack of research is notable on this theme in individuals with chronic disease and sexually diverse. Lastly, awareness is required from the team of therapists on the importance of this phenomenon to consolidate care models and comprehensive intervention proposals that include approaching sexuality in individuals with chronic disease.

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