

ORIGINAL RESEARCH—EDUCATION

Sexual Counseling for Women in the Context of Physical Diseases— A Teaching Model for Physicians

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ABSTRACT

Introduction. Chronic medical conditions are frequently associated with sexual difficulties and problems, which are often underreported and underdiagnosed. Patients may feel that sexual problems in the context of disease are not important enough to be mentioned to their physicians, and physicians may feel uncomfortable and sometimes incompetent. Furthermore, the diagnostic criteria of Diagnostic and Statistical Manual of Mental Disorders-IV and International Classification of Diseases-10 are focused on the phenomenology of the sexual response without any specificity regarding diseases.

Aim. To facilitate access for patients and physicians, we wanted to develop a tool for assessment and discussion of sexual problems in the context of disease. This tool should be broadly applicable, easy to use and learn for nonmental health professionals.

Main Outcome Measures. Content analysis with respect to the integration of general sexological and disease-specific dimensions. Formulation of a diagnostic and therapeutic algorithm that can be used as a teaching tool.

Methods. Based on our experience as a liaison-consultation sexological division of the university hospital of Basel, we analyzed the sexological diagnostic workup performed with the following group of female patients: women with benign gynecologic conditions; women with incontinence; oncological patients (mammary carcinoma, genital carcinoma); neurological patients (multiple sclerosis, spine injury, Parkinson's); patients with metabolic and endocrine disorders (diabetes, metabolic syndrome, polycystic ovarian syndrome); and patients with mental health disorders (depression, anxiety disorder, schizophrenia). We extracted the commonly used steps in the workup to construct a tool with easy-to-remember elements, which would help the physician to evaluate patients' sexual problems and plan for referral or therapy.

Results. We could differentiate three diagnostic dimensions. The first were person-related preexisting factors, such as sexual satisfaction and function, age, body image, and general well-being. The second were the disease-specific implications, which could be summarized under the 8 Ds: Danger, Destruction, Disfigurement, Disability and pain, Dysfunction, Dysregulation, Disease load, and Drugs. The third was the patient's and partner's general response to the disease determined by affective response, coping style, body image impact, and changes in relationship dynamics.

Conclusion. Sexual problems are frequent in many clinical conditions, but are not yet a routine part of diagnostic workup and therapeutic planning. We have developed a tool to help physicians in different clinical settings to evaluate sexual problems of the female patients with specific clinical conditions in order to facilitate access to recognition and possible treatment. **Bitzer J, Platano G, Tschudin S, and Alder J. Sexual counseling for women in the context of physical diseases—A teaching model for physicians. J Sex Med 2007;4:29–37.**

Key Words. Sexual Dysfunction; Physical Diseases; Pathogenetic Model; Diagnostic Workup; Training Module

Introduction

Sexologists working in a liaison setting in which they are asked to care for inpatients and outpatients of various medical disciplines are confronted with several challenges.

The first challenge is related to patients' and physicians' concepts about the importance of sexuality in the context of disease.

We know from the literature that the prevalence of sexual problems in the context of disease is high, frequently underdiagnosed, and untreated [1]. This seems due to the implicit concept that disease has something to do with survival and self-preservation, and that sexuality comes somehow in the second line, when the disease problem is resolved [2]. This concept ignores the fact that many diseases have a chronic course, and that in real life there is not an either disease-centered or sexuality-centered approach. Both dimensions go together as integral part of our patients' lives, and it is a patient-centered approach that takes this global dimension of health and sexuality into account.

The second challenge refers to classification of sexual dysfunction, which refers to two main goals: (i) description of the dysfunction; and (ii) identification of aetiopathogenetic factors and therefore consideration of contextual factors. Definition of women's sexual dysfunction has undergone important revisions in the past years as recommended by the International Committee that was sponsored by the American Urological Association Foundation [3,4]. This classification proposes subtypes of arousal disorders that separate an absence of subjective arousal from all types of sexual stimulation, from an absence of subjective arousal when the only stimulus is genital. In addition, persistent genital arousal disorder has been suggested as a new arousal disorder. Sexology as a discipline implicitly refers to human sexual behavior of healthy individuals, and sexual counseling and therapy deals with sexual dysfunctions described in the International Classification of Diseases under the heading of F 52, which explicitly states that the dysfunction cannot be entirely explained by a physical disease [5].

The consideration of aetiopathogenetic factors stresses the role of the disease and other contextual factors for the development of the disorder. The impact of physical disease on the patient's sexual experience and behavior is, however, in many diseases, not well studied and understood and, in most cases, it is far from evident whether the sexual problem is completely caused by the disease.

It seems in fact more likely that in the individual patient the problems are only partially conditioned by the pathophysiology of the disease and there is a large amount of modification due to "personal factors" [6,7]. So the basic practical question is: What is the pathogenetic role of the disease and what is the role of the person-related factors in the formation of the sexual dysfunction? It seems that this question has not yet a standardized answer for most clinical situations, and the practice is based on the clinician's personal experience and judgment.

The third challenge comes with the second: Who has the competence to care for the sexual problem? Is it the specialist for the disease (knowing all about pathophysiology and therapeutic implications, but frequently being an alphanumerate in sexual issues), or is it the sexologist (the expert for sexual issues but a lay person with respect to the disease)? Already having the medical knowledge, physicians from many backgrounds could be trained in sexual medicine. The gap between the two disciplines could thereby be bridged.

This question refers to the next one: What do patients expect? How do they react to the involvement of a so-called sex specialist?

Again these questions are not yet well studied, and everybody depends on experience obtained while being on the job.

Considering these challenges, we have tried to develop a training program in "medical sexology," which should function as a practical tool to serve the following purposes:

- To facilitate access for patients and physicians to discuss and assess sexual problems in the context of disease;
- To provide a basic pathogenetic model of understanding sexual problems in the context of specific diseases;
- To establish and define a basic standard diagnostic procedure that is common for different clinical conditions; and
- To establish and define a basic concept of sexotherapeutic options as the common basis for an individualized plan for referral or therapy.

This tool should be simple and easy to learn for different professional groups.

For 8 years we have worked as a liaison-consultation sexological unit for the various medical disciplines of the university hospital of Basel. We received referrals not only from within the hospital, but also from physicians in the Basel region and from other parts of Switzerland. Based on the

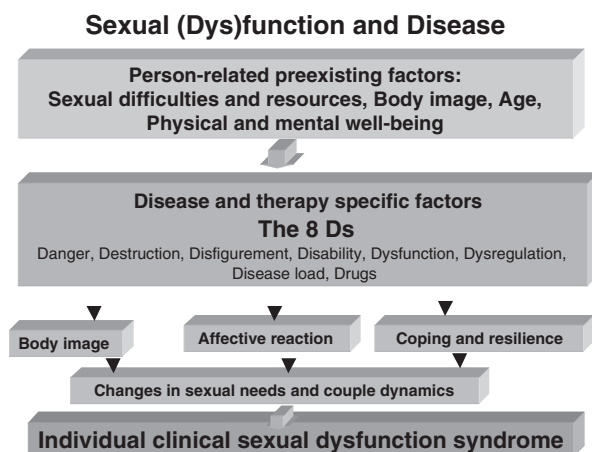


Figure 1 Sexual (dys)function and disease.

experience with 80–100 new patients every year, we analyzed the sexological diagnostic workup and therapeutic interventions performed with the following group of patients:

- Women with benign gynecologic conditions;
- Oncological patients (mammary carcinoma, genital carcinoma);
- Patients with metabolic and cardiovascular disease;
- Neurological patients (multiple sclerosis [MS], spine injury, Parkinson's); and
- Psychiatric patients (depression, anxiety disorder, psychosis).

We then extracted the commonly used steps in the workup under supervision to construct a tool with easy-to-remember elements, which would help the physicians to evaluate the patients' sexual problems and plan for referral or therapy.

We could extract three dimensions, which would interact with each other in the formation of the individual sexual problem of our patients (Figure 1).

The First Dimension: Person-Related Preexisting Factors

Preexisting Sexual Difficulties and Resources

Preexisting sexual difficulties may become evident through the disease process. A diminished interest in sexuality and dissatisfying sexual experiences before the onset of symptoms, diagnosis, and treatment may turn into an openly declared, manifest hypoactive sexual desire disorder [8,9]. The preexisting individual importance attributed to sexuality will influence the impact of a disease on

sexual interest and satisfaction [10,11]. One of the most stable predictors for sexual dysfunction after a potentially distressing event is the subjective satisfaction with the previous sexual experience and behavior [12,13].

Age

The majority of studies indicate a decline in the frequency of sexual activity with age. Cross-sectional studies also show a decline in women's sexual functioning with increasing age. There is general agreement in the literature that with age there is a decline in desire and sexual interest, and some studies show that the frequency with which women experience orgasm also declines with age [14].

Body Image

Body image describes the inner representation of the body with respect to cognitive and emotional attributions. It is a changing inner working model, being constantly adapted to internal and external information about the body.

Body image has an impact on sexual motivation, contact, and sexual behavior, as well as sexual satisfaction [15,16].

General Physical and Psychological Well-Being or Morbidity

General well-being is an empirically proven predictor for sexual function. General well-being refers to a global evaluative feeling and thought, summarizing physical, mental, and social perceptions and interpretations [17].

It is evident that preexisting complaints and subclinical disturbances of general well-being and physical fitness may have an impact on the development of sexual dysfunction in the context of disease [18].

The Second Dimension: Disease-Specific Factors

These are factors that are directly linked to the disease itself.

They comprise eight different entities, which for didactic reasons can be summarized under the 8 Ds.

Danger (Threat) to Life of the Disease

Diseases differ in their danger or threat to the patient's life and survival. This is most prominent in cardiovascular and oncologic conditions. The intensity of this threat has an impact on the patient's outlook on life and his or her objectives

and values. Sexuality may lose importance or disappear for a time period as a need behind the primary objective to survive [19,20].

Destruction

Diseases and their therapies differ in the degree of direct destruction of organs related to human sexuality where the destruction has a morphologic effect on sexual function. Examples are the cancers of the female and male genital organs, such as vulvar, vaginal, uterine, and ovarian cancers [21,22].

Disfigurement

Diseases and their therapies may have different impacts on the body surface and thus lead to visible changes that may be experienced by patients or other persons as disfigurement, thus having a possible negative impact on sexuality. This may occur on the one hand after surgical interventions because of certain forms of cancer, and also after chemotherapy (hair loss, skin changes, etc.) [23,24].

Disability and Pain

Diseases may lead to a dramatic decrease in mobility and to chronic pain and thus impair sexual function. This is especially true for chronic rheumatic and neurological diseases [25,26].

Dysfunction

Dysfunction describes the direct impact of disease on the neuromuscular and neurovascular elements of the sexual response. These mechanisms are very prominent in neurological diseases, such as MS, spinal cord injuries, etc. [27,28]. Other causes for dysfunction can be surgery, radiation, and removal of hormone-producing organs.

Dysregulation

Dysregulation refers to the influence of certain diseases on the central nervous regulation of the sexual response cycle. It is known that hypothalamic sexual centers are connected to central nervous neurotransmitter pathways and may be therefore influenced by disturbances of dopaminergic, serotonergic, adrenergic, and gabaergic action. An example of this are the disturbances occurring in patients with Parkinson's disease, dementia, and various psychiatric diseases [29,30].

Disease Load

Diseases are frequently accompanied by clinical conditions not being a separate disease but a part

of the disease itself. Some of these conditions have a direct impact on sexuality, such as urine or stool incontinence, anus praeter, etc. [31,32].

Drugs

The treatment of most diseases includes pharmacotherapy, which through its action may have various impacts on sexual function. The mechanisms can be divided into central nervous and peripheral nervous, neurovascular and neuromotor, and endocrine and local [33,34].

The Third Dimension: The Individual's (and the Partner's) Reaction to the Disease

Affective Response

Anxiety and depression are well-known pathogenic factors in sexual medicine. Anxiety and depression may lead to diminished sexual desire and arousal and enhance avoidant behavior, which may lead to distancing and isolation between the partners. Patients may develop subclinical disturbances that manifest themselves primarily in the domain of sexuality [35–37].

Influence on Body Image

Most physical diseases impact on the patient's feelings about his or her body and may modify the inner representations of the body, which is called the body image. Negative inner representations may aggravate patients' tendencies to withdraw from sexuality [38,39].

Coping Strategies

There is immense literature on how patients cope with diseases and on how these coping mechanisms have an influence on the disease-related quality of life. Cognitive, emotional, and behavioral coping elements can be distinguished from each other and comprise a large spectrum of possible responses. Patients who give up, lose hope, withdraw, catastrophize, focus on negative thoughts, and are depressed and anxious will have a greater risk to suffer from sexual difficulties or will withdraw from sexuality on the whole [40,41].

Changes in the Couple's Dynamic Interaction

Diseases may lead to a change in the individual's sexual needs and may thus modify the preexisting balance of exchange between the couple. Patients may sometimes express an increased need of tenderness and nongenital physical closeness, and

sometimes need to feel that they are desired and that the partner is taking an active positively aggressive role in sex. Also the partner may experience difficulties in moving from the caretaker role to that of the sexual partner. He might assume that the unwell woman does not want to be sexual or even feel inadequate (e.g., at coping with responsibilities the unwell woman used to do, or at being able to relieve her pain and suffering) such that the partner's sexuality changes. The individual importance of sexuality may change and create a chronic incongruence and conflict [42–44].

The Basic Diagnostic Pathway

Taking the model into account, we defined the following diagnostic steps. Please refer to the Appendices 1–3.

Taking the information from the three dimensions together, a comprehensive medical sexological diagnosis can be formulated, which will be used as the basis for the therapeutic planning.

Therapeutic Plan

Physicians without special training in sexology should have a basic notion of the therapeutic possibilities for their patients with sexual difficulties in the context of disease [45,46].

Basic Sexual Counseling

The contents of this general session should be the following:

- Information and education about the sexual problem, its medical name, and prevalence;
- Information and education about the biological, psychological, and social factors contributing to the problem along the line of the diagnostic pathway explaining general predisposing and maintaining factors and disease-specific factors using the 8 Ds;
- Education about possible gender differences in response to disease, stress, and sexual difficulties;
- Discussion of the individual's and the couple's concept of sexuality and love; and
- Discussion of possible new definitions and orientations and new needs with respect to love and sexuality.

For many patients in the clinical setting, this psychoeducational intervention not only is helpful, but may be sufficient as a first step and basic sexological care.

Individualized Sexological Treatment

There are basically two groups of therapeutic options which physicians should have knowledge about [47,48]:

1. Medical interventions. These include hormones, analgesics, antidepressants, spasmolytics, changing drugs, surgery and possibly investigational use of PDE5-inhibitors, and dopamine agonists.
2. Psychological interventions. These include supportive psychotherapy, interpersonal psychotherapy, couple therapy, coping counseling, and specific sex therapy (sensate focus, sexual aids, etc.).

Patients should be informed about the efficacy, possible side effects, and risks of these interventions in relation to their individual problems. They can then take an informed decision regarding specific treatment options, which usually need a multidisciplinary approach with close collaboration between the attending physician and the therapist trained in sexology. This collaboration is enhanced and facilitated by a common understanding of the patient's sexual problems. The educational model described above aims at creating this common understanding and should lay the ground for multidisciplinary care.

Discussion

Patients with chronic diseases and sexual problems are at risk to fall between the cracks. The physicians in charge of the management of their disease(s) do not frequently consider themselves as responsible for sexual health issues, and the professionals in the field of sexual health, on the other hand, either do not have access to these patients or lack disease-specific expertise. It seems that only in selected multidisciplinary rehabilitation teams are patients offered sexual medical care, leaving it more to chance than to an elaborate concept whether patients' sexual health is addressed and eventually cared for [49].

It seems therefore mandatory that common diagnostic and therapeutic pathways are elaborated, which connect different professionals in this complicated field of mind/body interaction characteristic of human sexuality [50].

On a primary care level, different teaching modules with diagnostic and therapeutic algorithms have been developed. These instruments focus on the descriptive accuracy of sexual symp-

toms such as hypoactive sexual desire disorder, arousal disorder, pain disorder, etc. [5].

Regarding the pathogenetic contributing factors, it seems that the biopsychosocial model with predisposing, precipitating, and maintaining biological, psychological, and social factors is the most widely used in teaching and practice [51].

The role of a defined disease is in general hard to determine on an evidence-based knowledge and is frequently left to clinical judgment and/or multidisciplinary evaluation, because the empirical basis for the disease-specific impact on sexual identity, function, and sexual relationship, especially in women, is rather limited and studies are hard to perform. The mostly used theoretical framework seems to be given in the concept of sexual rehabilitation [49]. In this concept, the disease-related impairments of sexual function are described especially for malignant and neurological disorders on the basis of clinical experience and individual reporting of patients.

In our model, we have tried to combine the above-described three elements: descriptive sexological diagnosis, biopsychosocial model with predisposing, precipitating, and maintaining factors, and disease-specific factors. By means of this combination, we want to avoid that neither biomedical nor psychosocial factors are omitted or underrepresented in the diagnostic workup [51]. At the same time, we were concerned to create a common language that could be understood and adopted by both professional groups, medical specialists and specialists in sexual counseling and therapy. We are now teaching the model to residents in different medical specialties, clinical psychologists, and sex counselors, and we have started a study in which we want to assess the acceptability and interdisciplinary usefulness of the model viewed by the professionals and the change in care and referral for sexual health problems among the patients of our university hospital.

Conclusions

Women with chronic diseases are frequently experiencing sexual problems and dysfunctions. Sexual counseling and therapy are until now not part of the routine care of medically ill patients. One reason for this is the lack of a concept of disease including the sexual dimension shared by medical specialists and sexologists, and the lack of a common diagnostic and

therapeutic algorithm, which would allow evaluation in the clinical setting and provide the basis for further sexological care or referral. We have developed a teaching tool for physicians, which integrates sexological knowledge and skills, and disease-specific effects on sexual function in a comprehensive model of understanding, providing a diagnostic pathway and therapeutic decision aid.

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Appendix 1

Dimension 1 Person-related Preexisting Factors

Ask actively about the actual sexual experience by giving a general introduction:

- In many patients the disease or the treatment you are having impacts on their sexuality. How is your experience?

Help the patient to describe the sexual problem in terms of desire, arousal, orgasm, pain, and general satisfaction.

- Did or do you observe any change in your sexual desire or interest, in sexual fantasies or activities?
- Do you have difficulties in getting sexually aroused?
- Does the vagina not feel wet enough?
- Do you have difficulties to experience an orgasm?

- Do you feel pain during intercourse or masturbation?

Ask questions regarding the specific disease and its impact on the patient's sexuality, e.g.,

- Do you have difficulties with continence?
- Do you have difficulties moving into a position for intercourse?
- Do you have difficulties stimulating yourself or your partner due to your arthritis?
- Do you have difficulties now with breast stimulations since your surgery/radiation?

Assess the preexisting characteristics of the patient's sexual experience and behavior and body image with the following questions:

- How would you rate the importance of sexuality in your life before the onset of the disease?
- How would you rate your enjoyment of sexuality at that time?
- Did you experience any of the following sexual difficulties (loss of interest, difficulty to reach orgasm, arousal difficulty, etc.)?

Assess the preexisting level of physical and psychological well-being:

- What diseases did you suffer from before the onset of the actual illness?
- How would you rate your physical and psychological well-being before?

Appendix 2

Dimension 2 Disease-specific Factors

Assess the disease-specific impact on sexuality following the 8D mnemogram:

- Danger (Threat):

How does the patient experience the threat of the disease to her or his life?

- Destruction:

Does the disease or treatment have a direct impact on the integrity of sexual organs?

- Disfigurement

Does the disease lead to a change in the body's outer appearance with a possible negative emotional impact?

- Disability and pain

Is the disease causing chronic pain and motor disability which may impact on the patient's capacity to enjoy the bodily expression of her sexuality?

- Dysfunction

Does the disease lead to an impairment of the sensomotor and sensovegetative innervation of the physiological processes involved in the human sexual response?

- Dysregulation

Does the pathophysiology of the disease have an impact on the neurobiological and neuroendocrine processes involved in the central or peripheral regulation of the sexual response cycle?

- Disease load

Is the disease accompanied by an impairment of intimate physical mechanisms like micturition and defecation?

- Drugs

What is the impact of the drugs used for the treatment of the disease?

Appendix 3

Dimension 3 Patient's and Partner's Response

Assess the patient's and partner's response to the disease:

- How would you describe your actual state of mind (mood)?
- What are the greatest difficulties you encounter in living with the disease?
- How do you cope and what are the things that help you in confronting the disease?
- What was and is your partner's reaction to the disease?
- Have you observed a change with respect to your sexual needs?
- What about your partner? Have you observed a change in your partner's sexual needs (Giacomo)?
- Have you observed a change with respect to your self-image?
- Have your feelings for your partner currently changed?