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CHRONICALLY ILL WOMEN AND MEN AT VARIOUS STAGES OF THE LIFE-CYCLE WHAT ASPECTS OF SEXUAL ILL-HEALTH ARE THEY CONFRONTED WITH?

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The physical evidence of a chronic disease is often quite specific--damage to one organ or subtle changes in the chemical messengers of the body. The psychological impact of an illness is broad, however, altering many aspects of a person's lifestyle. In the past five to ten years, the relationship between illness and sexuality has received increasing attention. Now that behavioral medicine and sex therapy have come of age as specialities, an area of health care combining both approaches has emerged--the prevention and treatment of sexual problems in men and women who are chronically ill.

We see sexual health as one important aspect of physical, social, and mental well-being. Sexuality is one of the most fundamental ways that humans share intimacy. Chronic illness, by interfering with a person's vitality, physical attractiveness, genital function, and social interactions, may create distance in relationships. Major diseases remind each of us that death is a solitary experience. To remain a sexual person, then, is to affirm life and one's connection with others.

Unfortunately, sexual health remains a neglected area of care in most medical settings.

Sexual Health

As clinicians, we tend to focus on sexual pathology, but we also need to have a concept of sexual health. Such a model provides a goal for our interventions and reminds us to assess individuals' or couples' strengths and resources, even in the midst of crisis counseling. The World Health Organization's definition of sexual health fits these requirements:

> Sexual health is the integration of the somatic,

> emotional, intellectual, and social aspects in ways that are positively enriching and that will enhance personality, communication, and love.

Sexual health care then becomes the process of facilitating sexual health, through primary and secondary prevention and through intervention when problems occur. Perhaps the most important message we can convey is to maintain a balanced perspective in dealing with sexuality. Too much energy has been wasted on attempts to pigeonhole sexual problems as "organic" vs. "psychogenic"--especially when the patient is already labelled as chronically ill. No matter what risk factors are present for sexual dysfunction, as clinicians we must identify the psychological, physiological, relationship, and social systems threads that weave together to create the pattern we finally observe.

Perhaps a model of sexual health could not have been well-defined until the years after World War II. Not only has sexuality become a less taboo topic, but the rising standards of living in industrialized countries, the loosening of bonds with the extended family, effective contraception, and the modern view of marriage as based on love rather than on economic concerns have combined to make sexuality a focus of tremendous emotional energy. Within this context, the risk that a major illness will impair sexual function becomes more threatening than it was in any previous historical period.

An Integrative Model of Sexual Health Care

To help patients attain sexual health, the caregiver needs a way to integrate these various aspects of functioning. Our model of sexual health care resembles the biopsychosocial model of medical illness proposed by Engel (1977, 1980). The biopsychosocial model unites scientific and clinical approaches to patient care by viewing a disease as the outcome of interactions within a system. The system includes macroscopic components such as family and society as well as microscopic elements like cells and molecules. In contrast, the traditional medical model assumes that a specific disease agent acts in linear fashion to produce a diseased person.

Figure 1 illustrates the integrative model using the example of a 45-year-old woman who could no longer reach orgasm after a hysterectomy and bilateral oophorectomy for benign fibroid tumors. Her sexual problem is depicted as a kind of "blob" to emphasize that the symptom looks different depending on the observer's orientation. Taking a biological perspective, represented as a circle, reveals that the sudden decrease in circulating estrogen after surgery produced frequent hot flushes and severe vaginal dryness, interfering with the patient's desire for sex and enjoyment of intercourse.

A psychological viewpoint i.e., the triangle, allows us to

see that the patient feared her hysterectomy had left her "half a woman." She also had a history of phobic reactions, for example a fear of driving over bridges.

Social factors include the perceptions of the spouse, the family of origin, and society. The patient's husband believed myths that hysterectomy impairs a woman's sexuality. The patient had also recently discovered that her husband was having an extra-marital affair. She grew up in a family that valued women for their fertility, but was only able to bear one child. The hysterectomy was a reminder of her failure. Societal attitudes also contributed to the problem since she was bombarded with messages from the media that sexuality is the province only of the young and beautiful.

Each of these factors is important in its own right, yet all interact together to create the symptom picture. The arrows from factor to problem are bidirectional, since a sexual anxiety will impact in turn on the biological, psychological, and social spheres of our patient's life.

To create a treatment plan for the problem we also must consider the influence of timing. The patient's individual time frame is shaped by her age, her sexual history, and the recent revelation of her husband's affair. Historical time also sets the scene, including society's sexual attitudes and the types of help currently available for a sexual dysfunction.

Mind-body dualities are not very helpful in assessing sexual problems. Yet physicians are trained to take action and treat the symptom, in contrast to the mental health professional's process orientation (Brown & Zinberg, 1982; Hejl, 1984). Patients have been shaped to follow the doctor's instructions, and may have difficulty taking responsibility for their own recovery as is demanded in psychotherapy. The fast pace of work in many health care settings produces staff overload and burnout, sapping the energy needed to cope with patients' emotions or to collaborate creatively with other disciplines. Although the field of sexology transcends interdisciplinary boundaries, it has not risen above these squabbles.

Sexual problems occur in relationships. Even when a person's only sexual outlet is masturbation, a fantasied partner is usually involved. Sex therapists have espoused the view point that the "patient" is optimally the couple, although individuals or groups can be treated using a sex therapy format.

In medical settings, however, the patient is the patient. When assessing and treating a sexual problem in someone who is chronically ill, the clinician's first task is often to shift the focus from the individual to the dyad.

The Couple Meets the Medical Model

When one partner develops a chronic illness, the anxiety and stress is shared by the other. Yet in most medical settings, little effort is made to involve the family in health care despite growing evidence of their important role in health maintenance and compliance with medical instructions (Doherty & Baird, 1983; Minuchin, Rosman, & Baker, 1978).

Taking a couple approach to chronic illness can be rewarding for clinicians. Since controlling many diseases entails lifestyle changes that affect the whole family, giving the spouse an active role in health care increases the chance that a patient will be compliant. The majority of spouses seen in medical settings are supportive and loving. Getting to know a couple gives the physician, nurse, or other health care provider an enhanced sense of involvement in the family's intimate ties and in their efforts to maintain a high quality of life. The clinician also learns to quickly recognize the distressed couple who will need extra help to meet the challenge of illness. Early intervention with a disturbed family can often prevent turmoil that would otherwise interfere with medical care.

We advocate scheduling periodic couple visits as a routine when treating chronically ill patients If the health care team sees a cross-section of couples, clinicians are less likely to develop a dread that each interaction will be a struggle. Burnout is a risk for the inexperienced clinician who schedules couple visits only when family problems have already disrupted medical care. Crisis sessions reveal families' weaknesses, but do not teach us about their strengths.

<u>The Importance of the Partner in Health Maintenance</u>

A couple's relationship can affect the development and management of a chronic illness in a variety of ways. Simply being married is correlated with better physical and mental health for both men and women (Verbrugge, 1979).

Just being married may not be enough, however. At least for mental health, the quality of the marital relationship is a predictor of better adjustment, especially for women (Gove, Hughes, & Style, 1983). Marital unhappiness or a lack of intimacy is correlated with the severity of derpession within samples of married psychiatric patients (Crowther, 1985; Waring & Patton, 1984). Research in this area is still primitive. Methodological issues include choosing a sample representative of the population at large, using appropriate assessments of mental health, and finding accurate ways to measure the quality of a marital relationship.

In brief, most marriage relationships are a positive force promoting health, but a minority of couples are trapped in a mutually unhealthy lifestyle. Marriages in which one partner is an alcoholic provide a good example. Couple interactions often seem to be a power struggle between two powerless people (Jensen, 1985b). Spouses vacillate between roles of Rescuer, Persecutor, and Victim (Steiner, 1971). When the husband comes home drunk, the wife berates him in her Persecutor mode but then rescues him by getting help from outside the family. If he drops out of treatment, she might return to being the Victim.

Studies of couples with a diabetic spouse illustrate that the ability of the partners to cope with illness is highly predictive of their sexual function (Jensen, 1985a,c). A psychiatrist (SBJ) interviewed 51 couples, giving each a global rating of good, moderate, or poor "disease acceptance." The rating was based on both partners' success in meeting the crisis of the diagnosis, complying with medical instructions, maintaining a supportive social network, and achieving good self-esteem. Emotional reactions to illness, including depression, anxiety, and denial were also included in the judgment. Only 15 percent of couples with good disease acceptance reported a sexual dysfunction, in contrast to 57 percent of those with moderate or poor disease acceptance.

Couples' Strengths in Coping with Illness

Since general coping skills and sexual function are linked in the chronically ill, the clinician treating sexual problems should identify and foster strengths in the relationship that can mitigate the stress of illness. Of course there is no formula for marital happiness. If someone discovers the magic equation, they will be a strong contender for the Nobel Peace Prize. We can, however, provide guidelines for evaluating partners' joint resources.

Health care professionals should become aware of four varieties of tasks that partners in a well-functioning relationship have mastered; allocating marital roles, respecting each others' boundaries, achieving good communication, and agreeing on relationship rules. These couple skills interact to foster a supportive relationship.

The same skills that shape a couple's general relationship, also promote a satisfying sex life.

Allocating Sexual Roles. Many couples give all the responsibility for sexual initiation to one partner, usually the husband. Such a pattern may work well, until one spouse becomes ill.

When men become ill, especially if a sexual dysfunction develops, they often stop initiating sex. Wives, however, may not know how to take over the role of seducer and keep sexual feelings alive. Even when men develop a sexual dysfunction, they continue to take responsibility for sexual initiation, but the frequency often drops radically (Jensen, Meidahl, & Sjögren, 1984). The influence of traditional male sex roles on a couple's sex life becomes even more crucial when we realize that many chronic illnesses seem to cause greater physiological impairment of men's sexual function than of women's.

Diseases that limit mobility or disturb bowel or bladder function can lead to extreme role confusion when the healthy spouse must switch from caretaker to lover, helping with catheter care at one moment and caressing the next. Some couples delegate as little physical caretaking as possible to the healthy spouse. When roles must be mixed, however, sexual attraction and mutual respect can help both partners transcend the embarrassment.

Sexual Communication. An illness often interrupts a couple's sexual routine. For twenty or thirty years they have made love the same way. Communication became almost superfluous. Now they must accommodate to a new set of rules, and the ability to share emotions and preferences, verbally and nonverbally, becomes crucial. No two partners will always be in the mood for sex at the same time or always prefer the same types of sexual stimulation. Asking for a new caress, however, means risking rejection. In the optimal relationship, each partner can communicate a sexual desire but does not always expect it to be granted.

Respecting Sexual Boundaries. When couples disagree about the variety or frequency of sexual activity they must arrive at some compromise. What feels like comfortable intimacy to one partner is overwhelming to the other. Couples function best when they regard sex as one way of being close, but not the only way. Otherwise, an illness that interferes with sexual function can precipitate a panic. If the wife is ill, the husband may continue to demand sex as a way of maintaining a sense of con-

tact with her. She complies, feeling it is her duty as a wife, but in fact is passive and distant, making her husband feel more desperate. Conversely a man who conforms to traditional sex-role expectations may withdraw emotionally from his wife if he becomes sexually dysfunctional. Such couples can benefit from counseling on substituting other ways of being close, such as cuddling, sharing a hobby, or having a quiet talk, for some of the missing sexual interactions.

Agreement on Sexual Rules.

When confronted by an illness, couples must re-examine their sexual rules and take a less performance-oriented attitude towards lovemaking. Instead of reacting to a sexual failure by trying and trying again, partners need to create new ways of pleasuring each other. Sexuality can also assume too much importance in life. A sense of humor belongs in the bedroom just as it does in the rest of the house. Playfulness can ease the tension in accommodating lovemaking to the limitations imposed by an illness.

Sex and the Single Patient

We have focused on couples in this chapter because the medical model is built around the individual patient. In fact, single patients may need special attention from the health care team. Patients who live alone lack social support when they develop a chronic illness. Often they hesitate to ask friends or relatives for the kind of intensive help usually provided by a spouse.

Dating relationships are more vulnerable than marriages to the stress of illness. When a full commitment has not been made, it is easy for healthy partners to decide they would prefer someone who is not infertile, disfigured, or in danger of dying in the next few years. Sometimes the patient pushes the dating partner away to avoid risking rejection.

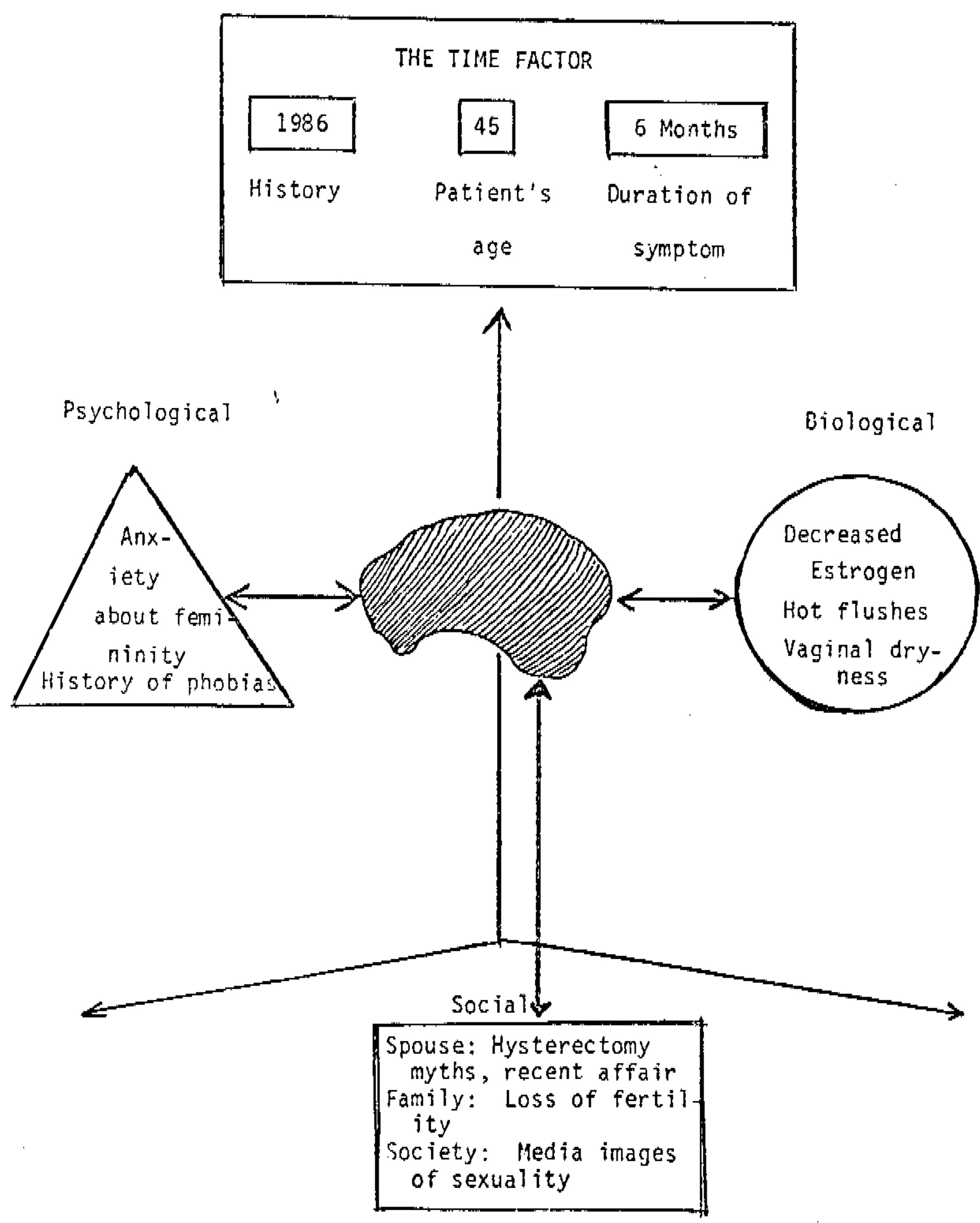
Some illnesses leave a public disfigurement that impacts on potential dating partners at the moment of meeting. Single men and women who have facial scars, have lost a limb, or have obvious neurologic impairment are often reluctant to try to meet new people. It takes courage and solid sense of self-esteem to face rejection with equanimity.

Other consequences of illness are private, but nevertheless affect developing love relationships. When does one tell a date about a mastectomy, an ostomy, infertility, or a sexual dysfunction? If divulged too early in a relationship, such information may prevent the partner from coming to value the patient enough to overlook imperfection. If left until too late, however, the disclosure may be such a shock that it provokes anger and a sense of betrayal. No easy answer exists.

The single patient is also less likely to request help for these sexual concerns. A man or woman may fear that the health care team disapproves of sex before marriage or sees the patient as asexual. Patients who are homosexual may be even more private about their sex lives, especially with the recent resurgence of homophobia since the AIDS epidemic. Thus the sensitive clinician must make an extra effort to assess sexual concerns in unmarried patients.

This paper is based on and elaborated from our textbook:
Leslie R Schover & Søren Buus Jensen:
Sexuality and Chronic Illness. Comprehensive Assessment and Treatment. Guilford Press, New York (september 1987).

Figure 1. The Integrative Model Applied to a Problem of Inorgasmia



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