A SEXUAL PROFILE OF ADULTS WITH CYSTIC FIBROSIS

The Sexuality and Sexual Concerns
of Adults with Cystic Fibrosis

by

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ABSTRACT

Only in recent years have diagnostic and therapeutic advances lengthened the life expectancy for patients who have cystic fibrosis sufficiently to allow some of them to live into adulthood. Health care professionals have been focusing on survival issues and are only recently beginning to look at quality of life issues, such as sexuality, of these patients. The purpose of the study was to create a sexual profile of adults with cystic fibrosis which would describe their sexuality and sexual concerns.

A questionnaire was developed and sent to all of the adult cystic fibrosis patients (19 years of age and older) in British Columbia (50 patients), all of whom attend the Shaughnessy Hospital Adult CF Clinic in Vancouver. The 62% response rate provided data for the sexual profile which indicated that 90% of the respondents were sexually active. Only a small number of subjects reported sexual difficulties in their relationships. Concerns about the impact of CF on their sexuality included: the effect of the potentially limited lifespan on their relationships, practical considerations such as fatigue and coughing during sexual activity, and poor body image.

A major issue for CF males is that most of them are infertile due to CF. How and when men should be told about this issue was an important question for the CF Clinic staff. Responses indicated that men thought they should find out from either the physician in the pediatric CF clinic or the physician in the adult CF clinic. Furthermore, 100% of the men suggested that this issue be discussed with males before the age of 19 years.

Limitations and recommendations of the research are discussed. A major recommendation is for physicians and other health care professionals in CF clinics to give patients the opportunity to discuss sexual issues.
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CHAPTER I

INTRODUCTION

Chronic illness has a definite impact on people's lives, one aspect of which is their sexuality. This research study focuses on the sexuality of people with a specific chronic illness, cystic fibrosis.

What is Cystic Fibrosis?

Cystic fibrosis (CF) is the most common lethal genetic disease in North America (Cowen, 1984). The basic defect in CF affects primarily the exocrine glands, and most clinical manifestations result from obstruction of organ passages by abnormal mucous secretions. The major clinical findings are recurrent bacterial pulmonary infection (associated with progressive obstructive lung disease) and intestinal malabsorption due to pancreatic malfunction.

Cystic fibrosis is diagnosed by demonstration of an elevated sodium and chloride concentration in the sweat. These findings are considered diagnostic in conjunction with chronic pulmonary disease, exocrine pancreatic insufficiency, or both. A family history of CF is of further diagnostic assistance (Davis, 1983).
What is Sexuality?

The definition of "sexuality" is not as clear and universal as the definition of the other major component of this research, "cystic fibrosis". Authors of literature on the subject of sex often avoid giving definitions. The book, *Fundamentals of Human Sexuality* begins with a chapter entitled, "Fundamental Questions About Human Sexuality" in which "sexuality" is equated with "sexual behaviour", but the term "sexuality" is not clearly defined (Katchadourian, & Lunde, 1972). *Sexuality in Health and Illness* states that "sexuality involves the biologic basis for experiencing sexual pleasure, and is a powerful force in a person's ability to bond to another person" (Woods, 1984). Dr. Mary Calderone (1982), co-founder of the Sex Information and Education Council of the United States provides the following broad and descriptive definition of "sexuality":

Our kind of sexuality is unique to being human, because for us, unlike for other mammals, it involves far more than the sex act and reproduction. It involves who and what we are as male and female, how we get that way, how we feel about it and how we deal with each other about it. It also involves dreams, fantasies and ideals, and gives us pleasure, even laughter. And it involves learning, thinking, planning, postponing, developing moral values and decision-making. (p. ix)

Sexuality is an exquisitely complex phenomenon which consists of the integration of physical, emotional, intellectual, and social aspects of an individual's personality which express maleness or femaleness (Cornelius, Chipouras, Makas, & Daniels, 1982).
Definition of Terms

In this study, the following terminology will be used to discuss "sex".

**Sex** = "the sphere of interpersonal behavior especially between male and female most directly associated with, leading up to, substituting for, or resulting from genital union" (Webster's Third New International Dictionary, 1981, p. 2081).

**Sexuality** = the phenomenon of an individual's maleness or femaleness. The framework used in this study specifically includes: (1) sexual self-view and identity, (2) relationship issues, (3) sexual desire, (4) sexual behaviour, and (5) fertility and reproduction.

**Sexual Issue** = a general term which refers to matters related to "sex".

**Sexual Concern** = a "sexual issue" about which a person expresses some concern.

**Sexual Behaviour** = what people say and do in their pursuit of "sex".

**Sexual Difficulty or Problem** = a specific aspect of a person's "sexual behaviour" to which the person assigns a negative value.

**Intimate Physical Contact (Sexual Activity)** = cuddling, stroking, fondling, kissing, and intercourse. This term was selected and defined for the purposes of this study so that subjects would report on their "sexual behaviour" in broader terms than simply equating sex with intercourse.

**Sexually Active** = having been engaged in sexual intercourse or other forms of stimulation that could lead to climax.

**Sexual Functioning** = the ability of a person to experience the sexual response cycle (the phases of desire, arousal, orgasm, and resolution).
Sexual Dysfunction = a disruption in the sexual response cycle. This term has a more specific definition than "sexual difficulty".

Sexual Profile = a concise description of the "sexuality" and "sexual concerns" of CF adults.

Development of the Research Questions

Sexual issues for chronically ill patients are often overlooked by health care professionals who seem to assume, along with the general public, that sexuality is reserved for those in excellent health (Vemireddi, 1978). Certainly, survival considerations should be paramount. However, people do not cease being sexual because they are ill. Just as patients worry about how illness will affect their longevity and occupational choices, so they are often concerned about how their sexuality will be affected.

Researchers have studied the sexuality and sexual functioning of a variety of different patient populations with chronic illnesses: juvenile rheumatoid arthritis (Herstein, Hill, & Walters, 1977), cancer (Gogan, Kocher, Fine, Foster, & O'Malley, 1979), renal failure (Levy, 1983), multiple sclerosis (Szasz, Paty, & Maurice, 1984), and diabetes (Schmitt & Neubeck, 1985). In the past few years, studies have been done with patients who have a disease which is relatively new to adults: cystic fibrosis.

In the 1940's, the median age of survival for patients with cystic fibrosis was less than 2 years (Davis, 1983). Diagnostic and therapeutic advances have lengthened life expectancy, and the median survival age of CF patients is now 24 years of age (Canadian Cystic Fibrosis Patient Data Registry, 1987). In a study
reported in the annual *Cystic Fibrosis Club Abstracts* in 1985, all of a group of 30 adult patients (over 23 years of age) seemed to follow a regular life style, aided by parents, spouses or other partners (Kulczycki, Schweitzer, & Heller, 1985). Consequently, health care workers are now beginning to take a closer look at the psychosocial adaptation of adults with cystic fibrosis (Boyle, di Sant’Agnese, Sack, Millican, & Kulczycki, 1976; Strauss & Wellisch, 1984).

Although there is some information in the literature about the sexual functioning of adults with CF, in clinical practice, little attention has been focused on sexuality for CF patients. Many people (both hospital staff and patients) feel awkward discussing sexual issues (McKevitt, 1976). For example, CF clinic staff have had difficulty deciding how and when to inform a CF male that he is likely to be infertile. These difficulties in talking about the impact of the disease on sexuality are not surprising since there are many taboos in our society about discussing sexual issues in general. The result is that sexuality has been only minimally addressed by health care professionals, which often leaves patients without much help in dealing with their sexual concerns (Young, 1984).

Dr. E. M. Nakielna, Director of the B.C. Adult Cystic Fibrosis Clinic, confirms that there is currently little attention paid to sexual issues during clinic visits or admissions. The main indicator that some of the patients are sexually active is that they raise questions about birth control. The issue of infertility in males is presented to the male patients by giving them a booklet, *For Adults with Cystic Fibrosis* (Durbach, Nakielna, & O’Loane, 1985), before they are transferred from the Children’s Hospital Clinic to the Adult Clinic at age 18 years. A few have expressed their concerns about infertility during visits to the Adult Clinic.
The literature reports numerous ways in which CF can have an impact on a person's sexuality. The pathophysiologic factors that negatively affect sexual adjustment of these patients include: limited life expectancy, fatigue and malaise, decreased physical capacity, frequent and lengthy hospitalizations for intravenous antibiotic therapy, altered physical appearance (e.g., short stature, deformed chest wall), delayed puberty, sterility in males, reduced fertility in females, and increased risk of maternal and fetal mortality (Seale, Flux, & Rennert, 1985). Furthermore, it is important to consider several disease-related psychosocial factors which affect some CF patients: stigma of chronic illness, conflict with overprotective families who are also struggling to deal with the patient's illness, loss of peers who have died from CF, interpersonal struggles, and role reversal in couples.

Given all these possible difficulties, how do these adult CF patients deal with their sexual concerns? Several possibilities exist: (a) they are functioning well sexually and have resolved issues satisfactorily, (b) sexual activity is a low priority for them and they are unaware of sexual issues in general, (c) they have specific sexual concerns but since these have not been addressed by the CF clinic team members, the patients have not felt comfortable talking about their concerns, (d) they have sexual concerns and do talk about them with another person outside the CF clinic setting.

The purpose of this research study is to develop a sexual profile of CF patients characterizing their sexuality, their sexual concerns, and ways in which they deal with these concerns.

The research is focused specifically on answering two questions:

I. What is the sexual profile of adult CF patients in British Columbia? The theoretical model developed to organize the information includes five areas:
(1) sexual self-view and identity

(2) relationship issues

(3) sexual desire

(4) sexual behaviour

(5) fertility and reproduction

II.  a) Do adult CF patients in British Columbia have sexual concerns? An assessment of these concerns would be a first step in helping these patients.

b) If they do have sexual concerns, how do they deal with them, and how can the Adult CF Clinic help these patients with sexual issues?
CHAPTER II

LITERATURE REVIEW

Relevant Frameworks and Models

Two models and one framework dealing with sexuality are reviewed below.

The model described by Dailey (1984) views sexuality as consisting of five integrative aspects. The model developed by Anderson and Wolf (1986) integrates sexual behaviour with chronic physical illness. Szasz’s framework (1986) delineates sexual functioning into seven areas, each of which portrays some aspect of a person’s sexuality and potential limitations due to illness.

Dailey’s Model

Dailey (1984) conceptualized sexuality as containing five overlapping and integrative aspects: Sensuality, Intimacy, Identity, Reproduction, and Sexualization (Figure 1).

Dailey (1984) defines sensuality as the ability to be aware of, in touch with, and acceptance of our bodies in their fullness and richness, and the bodies of others. Body image is described in this model as one of the most dramatic aspects of sensuality. There is further acknowledgement that body image is a special issue for the person who experiences a chronic illness. Also, knowledge of the body’s
Figure 1. Dailey's Model of Sexuality (1984)

Dailey's Model of Sexuality (1984) includes five aspects: Sensuality, Sexualization, Intimacy, Reproduction, and Identity. Sensuality is discussed as an aspect of sexuality, including "skin hunger" or the craving to be touched and caressed.

Intimacy is defined as the need and ability to experience emotional closeness to another person, and to have that closeness reciprocated. Dailey states that risk-taking is a central issue in intimacy, but this theme is not developed further. Effective means of sexual expression are another necessity in achieving intimacy.

The third aspect of sexuality is identity, specifically our discovery of our maleness and femaleness. This includes our sex role socialization in which we become masculine or feminine in our characteristics, thinking and behaviour. Dependency and assertiveness issues in relationships stem from one's identity.

Reproduction is perhaps the most fundamental aspect of sexuality since the species reproduces sexually. The ability or lack of ability to bear children affects a person's sexuality.
Sexualization is defined by Dailey (1984) as the use of our sexuality to influence, control, or manipulate others. Examples given are the withholding of sex in order to make a point with your partner, and verbally attacking your partner's sexual vulnerability.

This model provides a general conceptualization of the various aspects of sexuality. However, there were some aspects of sexuality that were not sufficiently defined and developed to provide a basis for this research study.

Model by Anderson and Wolf

Anderson and Wolf (1986) explain a model which integrates sexual behaviour and chronic illness (Figure 2).

![Diagram of Sexual Behaviour and Chronic Illness by Anderson and Wolf (1986)](image)

Figure 2. Model of Sexual Behaviour and Chronic Illness by Anderson and Wolf (1986)
This model is based on the premise that there is a homeostatic balance between physiological systems and psychological processes in the course of illness and response to treatment. The model takes into account the mutual feedback mechanisms between biological and psychological disease related processes, acknowledging that psychological processes may be either effects or causes of sexual dysfunction. The impact of chronic physical illness on human beings is portrayed through the arrows. The influences from social and cultural forces are depicted as a background for the other interactions.

The researcher found the model useful in terms of the integration of sexual behaviour and chronic illness and the recognition of the influence of both physiological and psychological factors. However, the model did not provide the framework of different aspects of sexuality that was desired for this particular research.

**The Szasz Framework**

The perspective on which this framework is based includes three areas of sexual behaviour: (1) "marketing" (how one presents oneself for pair bonding), (2) "courting" (partner selection activities), (3) "doing" (practices that bring about desired experiences).

The Szasz framework has been used in research into the sexual functioning of people who have spinal cord injury (Szasz, 1986) and those with multiple sclerosis (Szasz, Paty, & Maurice, 1984). At the G. F. Strong Rehabilitation Centre in Vancouver, B.C., a variation of this framework is used to guide the assessment and subsequent care for patients who are being rehabilitated due to a number of illnesses or injuries.
The framework describes seven sex-related areas which vary somewhat in scope and definition depending on the specific application. Exploration of these areas with a patient/client helps to portray the person's sexual capabilities and limitations thereby providing the basis for a sexual assessment. One application of Szasz's framework has been with spinal cord injured patients:

Several identifiable areas are useful in defining the sexual consequences of the cord injury:

1. Sexual response status reflects the physiological ability to experience genital sensations, erection, ejaculation, vaginal lubrication, orgasm, pelvic thrusting, and other responses to stimulation.

2. Sexual activity status indicates the available motor functions that might be used for such activities as embracing, caressing, and intercourse.

3. Sexual interest status reveals the degree to which the person wants to be involved in sex activities.

4. Sexual behavior status gives information about availability of partners and the social interaction skills leading to sexual activities.

5. Sex organ status describes the anatomical integrity of the genitalia and the sexual problems caused by urinary drainage apparatus, genitourinary infections, or surgery.

6. Fertility status reveals evidence of the need or ability to procreate or the nature of contraception desired.

7. Sexual self-view status reflects the person's self-evaluation regarding appeal and desirability as a sexual partner. (Szasz, 1986, p. 411)

This last model (Szasz, 1986) is the one that was adapted for use in this research because it was found to be the most appropriate one to answer the research questions. The model was sufficiently developed to allow the researcher scope in describing the various aspects of sexuality of the adult CF population.
Framework Used in This Research Study

Szasz's framework (1986) provides the basis for the current study. Five areas have been selected and modified from the original framework in order to be applicable to the population of CF patients. These five areas of sexual functioning provide the framework for the collection of data which will produce a profile of the subjects in the sample as sexual beings. The five areas are as follows:

1. Sexual Self-View and Identity — how the person views himself/herself as a sexual being. This area will include: what aspects of himself/herself the person feels good about, how "marketable" the person feels he/she is as a partner for a date and as a sex partner, and the impact of CF on the sexual aspect of life.

2. Relationship Issues — a description of what each person's partner relationships are like and what issues cause upset in these relationships. This area includes the person's description of his/her relationship in terms of sharing, loving, communication, and security.

3. Sexual Desire = amount of desire for sexual activity (feelings of wanting to engage in sexual behaviours). No differentiation is made between frequency and intensity of desire. Subjects are also asked about what things stimulate their sexual interest.

4. Sexual Behaviour = the various sexual acts in which the person engages on
his/her own and with partners. This includes the sexual response brought about by these sexual activities. Incidence of common sexual dysfunctions is described here.

5. Fertility and Reproduction = the extent to which one is able to procreate and the physiological and psychological ramifications of this ability. This area includes how the person feels about and copes with issues related to fertility, birth control, pregnancy, and childbirth.

Studies on Sexual Functioning in Patients with Cystic Fibrosis

Studies on sexual functioning in adult patients with CF are limited. In the past five years, two articles have been published reporting research done at the Cleveland Cystic Fibrosis Center on sexual function in CF adults.

The purpose of the first study, by Levine and Stern (1982), was to determine whether or not it was possible for CF patients to have normal sex lives (i.e., heterosexual intercourse on a regular basis). The researchers also looked for characteristic sexual difficulties and the effects of physical deterioration. They used a structured one-hour interview followed by a detailed questionnaire to investigate the sexual functioning of 30 married CF patients who were categorized into three groups according to the severity of the illness. These married patients (19 females and 11 males) accounted for 20% of the total population of CF adults over the age of 19 years who were patients in the clinic.
On the basis of the data collected, the couples were assigned to one of four groups: a problematic (eleven couples), good sexual relationship (six couples), minor sexual problems (four couples), and serious sexual problems (nine couples). The serious sexual problems were all manifested as decreased desire, although they had different causes. Five of the nine problems were attributed to CF. The data further indicated that no objective measure of disease severity could be used to predict the quality of sexual functioning. It was concluded that severe disease made serious sexual problems due to physical illness more likely, though not inevitable. It was also pointed out that "many patients with severe sexual impairments had mild forms of the disease" (p. 426).

The results demonstrated that a normal sex life is possible for a couple in which one partner has CF. However, the disease does have an impact on their sexual lives. Infertility was reported to be a major source of anguish for most patients. Dyspnea (breathing difficulty) during sexual activity and the psychosocial consequences of chronic illness were mentioned. Although the researchers point out that very little has been written on the effects of chronic pulmonary disease, they recommend that all of these patients be encouraged to discuss their sexual problems with a health professional since sexual counselling or specific medical therapy may prove useful.

The second Cleveland study compared the sexual adaptation of 48 single young CF adults to a comparably aged single group without chronic disease (Coffman, Levine, Althof, & Stern, 1984). The data gathered demonstrates that although there was no significant relationship between the severity of disease and sexual health, CF does play a role in producing primary or secondary psychogenic sexual dysfunctions. Deficiency of sexual desire was the most common sexual problem;
other problems were not specified. A particularly noteworthy finding is that "men with CF appear to fare far better socially and sexually than their female counterparts" (Coffman et al., 1984, p. 417). Single female patients with CF began dating later, dated less often, felt less attractive, had less sexual desire, and had more sexual problems than did physically healthy female subjects.

From the results of the two Cleveland studies, it appears that CF patients may have sexual difficulties related to: (1) personal and relationship factors that can apply to any individuals regardless of whether they have a disease, (2) stresses related to having a chronic, fatal disease, and (3) factors associated with CF. The paucity of research in this area can be explained by the fact that it has only been in recent years that an appreciable number of CF patients have been living into adulthood.

**Sexuality and Chronic Illness**

Literature on sex and serious illness indicates that although some people have little or no interest in sexual activity or find it burdensome or boring, a large number of patients are interested in sexual expression (Zilbergeld, 1979). For these people, sexual expression is essential to their sense of well-being. Sexual interaction may be a way for them to be close with their partners at a time when much in their lives is bleak, and it can help patients feel good about themselves. So often, both the patient and partner are deprived of this potential joy and sense of well-being. The patients are often depressed, afraid, confused, and perhaps angry about their chronic illness. All of these feelings can interfere with sexual interest and functioning.
The importance of sexuality to chronically ill people has been demonstrated in research done with cancer patients (Bullard, 1981). Results showed that although 75% of the cancer patients studied reported decreased frequency of sexual activities due to the physical deterioration of their disease, 70% of them reported that sexual activities had become somewhat more, or much more, important. The conclusions of this study state:

Paradoxically, then, at a time when nondisabled couples and individuals appear to be increasingly complaining of lowered sexual drive or interest or are voluntarily choosing a celibate life-style (Kaplan, 1979), we have observed people severely debilitated by a disability or disease who retain a strong desire to be sexually active and to have their sexuality affirmed and validated by others. (Bullard, p. 173)

It is important for health care professionals to realize that sexual dysfunctions are not necessarily caused by a person's illness. Especially in cases of sexual disinterest, one often assumes that this is due to the fatigue and depression accompanying the illness. Szasz and associates describe a case of a 42-year-old woman with multiple sclerosis who was referred for sexual therapy because of her complete sexual disinterest over 10 years. After taking and assessing the patient's sexual history, it was discovered that the sexual disinterest was in fact part of a premenstrual syndrome. Progesterone suppositories were prescribed and were effective in dealing with the cyclical depression and the sexual disinterest so that the couple could resume their sexual practices of over 10 years before. For this woman, sexual disinterest was not a result of her chronic illness, MS, but rather of an unrelated physical problem, premenstrual syndrome. This case illustrates that a direct cause and effect relationship between the person's illness and the sexual dysfunction cannot be taken for granted.
Many people equate sexual functioning and self-esteem. Therefore it often happens that the person who achieves a level of sexual functioning and self-esteem that is personally satisfying, usually develops the self confidence and assertiveness necessary to form meaningful relationships, to develop work ability, and to be otherwise productive. On the other hand, those who feel discouraged about their sexuality may become disabled in other respects (Bullard, 1981).

Impact of CF on Sexuality

Physiological Issues Related to Reproduction

For Men:

One of the implications of CF for men is infertility. Over ninety-five percent of males with CF are infertile due to inadequate development of the vas deferens, epididymis, and seminal vesicles (di Sant'Agnese & Davis, 1979). Two mechanisms have been proposed to account for the structural abnormalities of the epididymis and vas deferens. One possibility is a developmental anomaly occurring in the fetus during differentiation of these structures from the Wolffian duct (Denning, Sommers, & Quigley, 1968). The second possible mechanism is that the vas deferens withers, fails to develop, or becomes atrophic after blockage by abnormal secretions. The question has not yet been resolved, and it may be that both processes occur in some individuals (Seale, Flux, & Rennert, 1985). In either case, although spermatogenesis is normal, the sperm are not transported out of the epididymis and are not present in the ejaculate (Davis, 1983).

The infertile man with CF typically has small ejaculate volume, usually less that 2 ml. and frequently less that 1 ml. This may make it difficult to do studies
other than sperm counts. However, some authorities recommend that fructose content be documented to confirm obstructive azospermia (Lloyd–Still, 1983).

Fertility has been reported in a few CF males, some of whom had a late onset of symptoms (Blanck, 1976). Therefore semen analysis with sperm count and ejaculate volume measurement should be mandatory in all postpubescent males before counselling (di Sant'Agnese & Davis, 1979). The literature suggests that sperm analysis be done on CF males when sexual maturation is reached and before intercourse has begun (Lloyd–Still, 1983).

For many men, fertility may be central to their sexual self-concept; i.e., their gender identity may not be "real" unless it involves reproductive capacity. In addition to feeling personally diminished, men occasionally report feeling that they have less to offer a partner. For couples who wish to raise children, adoption or artificial insemination of the wife are alternatives.

For Women:

Although the reproductive tract of CF females is structurally normal, infertility is common. It has been estimated that fertility is less than 20 percent of what is observed in a comparable group of unaffected women. This lessened fertility is probably due to the thick, tenacious, desiccated mucous that CF women often have which forms a mechanical barrier to sperm penetration (Fitzpatrick, Rosenstein, & Hubbard, 1984). Another mechanism has been proposed to account for the reduced fertility: some investigators have reported that cervical mucous in CF women was scant, but was qualitatively altered in water and electrolyte composition, which could impede sperm motility (Kopito, Kosasky, & Schwachman, 1973).
CF women may have irregular cycles and women who are more severely ill with CF may have anovulatory cycles. Also, there is probably a higher incidence of chronic cervicitis in women with CF, and repeated courses of antibiotics as well as glucose intolerance predispose patients to vaginal infection (Davis, 1983).

Pregnancy in women with CF is possible, but it may represent a significant risk to both mother and offspring unless the mother's clinical status is excellent. In 1980, Cohen surveyed 129 pregnancies in CF patients and found a higher than expected rate of preterm births and perinatal deaths, and an increased incidence of maternal complications (Fitzpatrick et al., 1984). However, it appears that women with CF fall into two groups with regard to pregnancy (Seale et al., 1985). In the first group, there is little affect on the mother's condition and fetal outcome is good. In the second group, pregnancy appears to be associated with a worsening of the mother's condition which never returns to the pregravid state. Babies born in this latter group are more likely to be small for gestational age or are born preterm. One consistent factor in determining the health of mother and newborn is the pregravid nutritional status and pulmonary status. A 1985 review of research in this area concluded:

Women with cystic fibrosis whose clinical status is good and who have good respiratory function appear to have no severe exacerbation of their symptoms with pregnancy and have normal term infants. (Seale et al., 1985)

Because of the risks of pregnancy and the fact that some women do not want to pass the CF gene on to their children, the effectiveness and risks of various contraceptive methods are of major concern in this group of patients. However, contraception may pose problems for these patients. Barrier methods (condoms or diaphragms) are often the most suitable but they require assiduous compliance. The
intrauterine device may not be suitable for some nulliparous women, and it has been suggested that CF women have an increased risk of infection with IUD use (Hilman, 1981).

Oral contraceptives may cause pulmonary exacerbation, aggravate or even cause polypoid cervicitis, and are associated with hepatic and thrombogenic dysfunction (Lloyd-Still, 1983). In 1974, Dooley published a report suggesting that the use of oral contraceptive pills by women with CF may be associated with marked deterioration in pulmonary status. A subsequent study done in 1984, on ten CF patients who were using oral contraceptives, did not show any evidence of significant deterioration in lung function or an increase in acute pulmonary exacerbations during the six month follow-up period (Fitzpatrick et al.). In current practice, oral contraceptives are used by patients with CF, in as low a dosage as possible, and with close gynecologic and pulmonary follow-up.

The spectrum of potential problems related to reproduction for females with CF is expanding as the survival age is extended. It is now known that CF women have an increased tendency to develop endocervical polyps and ovarian cysts (Hilman, 1981).

**Psychosocial Issues**

Several studies in recent years have looked at the psychological adjustment of adults with CF. In 1984, results of research on a group of 226 patients with CF, all over the age of 16 years, were reported. Findings showed that a high degree of autonomous function and separation from parents is achieved by most patients. The study also confirmed previous reports that about 85 percent of adults with CF are involved with school, career, or household chores. In general, CF patients appear to
make satisfactory adjustments to productive adult roles. Not surprisingly, increased emotional difficulty has been noted with advancing age and illness (Cowen, 1984).

Psychological testing of adults with CF has revealed average or above average intellectual ability and perceptual motor function despite frequently poor oxygenation (Strauss & Wellisch, 1981). Occupational successes of these patients are impressive: most patients with CF work or attend school until shortly before their deaths (Davis, 1983). Marital adjustment has also been found to be very positive. Di Sant'Agnese and Davis (1979) reported that although marriages of CF patients are inevitably stressed by chronic disease, infertility of the partner with CF, and separations for hospitalizations, 80% of the marriages studied were intact.

Most patients with CF must learn to live with feelings of being different, which are exacerbated by the fact that they are frequently sick and may be expecting deterioration. Having a chronic illness limits one's marketability (being a viable candidate for dating and sexual involvement) on the social scene, and also affects how desirable one is perceived as being as a potential mate. The hindrance of knowing one has a decreased life span may affect the mating process and the planning of a family. The ever-present potential for deterioration in health and necessary hospitalizations may inhibit the development of intimate relationships. A group of researchers studied twenty-seven CF patients and found that interpersonal relations were strained and patients had a sense of isolation and of having few friends (Boyle, di Sant'Agnese, Sack, Millican, & Kuleczycki, 1976). Furthermore, the sexual desire of these patients may be decreased due to chronic fatigue and feelings of malaise.

Boyle et al. (1976) studied 27 patients with CF aged 13 to 30 years. Findings showed that altered physical appearance was significant, and patients were acutely
aware of looking different from others of their age group. Body image affects one's self-esteem and consequently influences one's own feelings of being sexually desirable. Patients are forced to confront the realization that they do not meet the cultural standard of sexual desirability (even more so than the many healthy individuals who do not match the media image of desirability). Many adults with CF are underweight which may negatively affect their self-esteem, particularly for men whose sense of masculinity may be tied in with having the societally approved substance of a man. Body image may be further altered by clubbing of the fingers which is nearly universal among patients with CF.

Delayed puberty in both sexes may inhibit sexual development. Adolescents with CF often lag behind their peers in physical maturation, and this can influence the establishment of male–female relationships and dating. A study done in 1981 on 27 adolescents (aged 12–16 years) with CF reported that the teenagers "appeared to be immature and only two had friends of the opposite sex" (Bywater, 1981, p. 538). Relationships may be further hampered by the reaction of others to the patient's frequent coughing and expectorating of mucus. The need for physiotherapy, for enzymes with meals, and for frequent hospitalizations all influence how the adolescent fits in with his/her peer group.

Parents of a chronically ill child may respond by being overprotective, which will likely inhibit the child’s development of autonomy. Boyle et al. (1976) reported that the young adults they studied were often overprotected by their mothers, while the fathers were typically withdrawn and unavailable. It is not surprising then that relationships with the opposite sex and expressions of sexuality are discouraged. There may be subtle messages transmitting the parents' fears that their child will not be a normal, marketable, social being. The sexual scripting from parents to
child may be especially negative if the parents believe that the individual cannot really function as a normal person particularly with respect to the development of relationships. It is common even for parents of healthy children to discourage sexual expression and ensure as long as possible that their children are not sexual. This likely stems from the myth that "sex equals intercourse", so that if children are sexual then they will have intercourse. These difficulties, experienced by parents in dealing with the sexuality of their children, often result in inhibition of the usual sexual exploration of childhood and adolescence. Certainly, if the impact of parents on healthy children can be so inhibiting, then such tendencies will likely be more exacerbated when the child is chronically ill.

There are many myths in our society about what sexual behaviour should be (Zilbergeld, 1978). Such myths may be very destructive even if they are illogical, and they are at the root of many of the sexual problems that people have today. "All of us have learned that sex is for the young, the healthy, and the agile, and further that sex should be spontaneous and passionate with no room for special considerations or needs" (Zilbergeld, 1979, p. 239). We tend to dichotomize people into two groups — healthy ("normal") and unhealthy ("abnormal") — and think that sex is for the normal people. Not surprisingly, it may be difficult for people with a chronic illness to believe themselves capable of sex. Zilbergeld (1979) believes that people can bypass these myths and enjoy expressing themselves sexually if they gain insight into the destructive nature of the myths and attain some autonomy.

The increased dependence of a person with a chronic illness can affect his/her partner relationships. If the patient is a male, there may be some role reversal in the couple unit, and the female partner may have additional responsibilities (Cowen,
Corey, Simmons, Keenan, Robertson, & Levison, 1984). The amount of stress created by such a situation will depend upon how the couple deal with this issue.

CF patients do have sexual needs and concerns depending on their developmental stage of life. Adolescent patients are often slow to develop secondary sex characteristics, and in females menarche is often delayed or absent (Stern, Boat, Doershuk, Tucker, Miller, & Matthews, 1977). Young, unmarried patients may be concerned about their appearance and about finding sexual and marital partners. Married adults may have concerns about their ability to have children and about their life expectancy.

The person with CF is likely to confront mortality earlier than the general population. Dealing with death and dying is a complex area which has been written about at length in the medical literature. Certainly, this process has a profound impact upon all aspects of the CF adult’s life (Strauss, & Wellisch, 1981). The potentially limited lifespan of these adults is likely to affect their relationships, families, family planning, the sexual aspect of their lives, and a host of other areas.

Although most of the psychosocial issues described over the previous pages will apply to many CF patients, only a few of the issues may apply to those CF adults who are only mildly affected by CF. However, all of the numerous ramifications of CF are potential triggers for depression. The patient may feel helpless and angry about the loss of health, about impaired hopes for the future, and about the many problems associated with his/her illness. When depression results, this in turn affects self-image, intimate relationships, and sexual functioning. A vicious cycle can develop, and getting out of it can be a real struggle. Depression can lead to sexual problems, which in turn cause a loss of sexual desire and an increase in anxiety. This heightened anxiety can often serve to intensify depression (Dailey,
Dec. 1984). In one study of young adults with cystic fibrosis (Boyle et al., 1976), it was determined that all patients used the mechanisms of denial and avoidance to deal with their illness. However, these defenses were found to break down at times, particularly as decreasing physical capacity was noted in the patient.

In summary, there are numerous ways in which cystic fibrosis can have an impact on a person's sexuality. Not only are there physiological reasons for this impact, but many psychosocial issues arise with respect to an individual's functioning as an interactive, sexual being.

The Responsibility of Health Professionals

It has been said by a researcher in the field of sexuality of chronically ill patients (Bullard, 1981) that "individuals with physical disabilities and chronic medical conditions who have arrived at a comfortable and enjoyable sense of their sexuality have often done so in spite of, rather than because of, their experience in the health-care and educational systems" (p. 170). Bullard describes the body of research that suggests that sexuality continues to be an important issue for many patients, even those for whom death is thought to be the overriding concern. In a study examining four case histories of patients with chronic renal disease, it was found that patients saw sexuality as one aspect of comprehensive health care and thought that it should be included in the treatment plan (Wagner & Wagner, 1985). Another research study describes a group of cancer patients of which only 10% discussed sexual and marital concerns with the health care providers, although 67% would have liked such a discussion (Bullard).
Caregivers often do not address the needs and concerns of these patients even though a patient's sexual relationship may well be affected by this chronic illness. When patients express or hint at sexual concerns, the caregiver often ignores or brushes over these because of a feeling of discomfort or vulnerability, or a lack of information. "The absence of sound sexual adjustment has wide-ranging social and psychological implications for patients. In jeopardy are their feelings of self-worth, their sexual identity, and their self-image, as well as the whole scope of their interpersonal relationship and their sexual relationship with their partner" (McKevitt, 1976, p. 134). "All patients deserve an honest appraisal . . . of the effects of illness on sexual functioning" (Sheridan, 1984, p.74). Considering the nature of CF, it would seem prudent to integrate discussion of sexual concerns into the ongoing counselling of these patients. Often, bringing sexual concerns into the open can be a significant step towards their resolution.

In 1984, a study was conducted in which 100 general hospitalized patients were interviewed about their satisfaction with the sex education and counseling they received during their present illness and hospitalization (Young, 1984). Findings revealed that only 30% had sex-related topics mentioned to them by health professionals. Less than half were satisfied with these discussions. The study revealed that patients seem to be ready and willing to discuss their sexual concerns. In fact, 92% of the sample stated that they thought sexuality was an appropriate topic to be discussed by health professionals. However, the study provided several examples of the fear expressed by some physicians that discussion about sexuality would not be appropriate because of marital status, age, sex, or diagnosis. In an attempt to help educate health professionals on how to discuss sexual matters with
patients, Glasgow and Krane (1986) have developed a 20 minute video entitled, 
**Taking a Sexual History.**

Time is a barrier to dealing with sexual issues. It takes time to deal with sex and feelings, and it seems that time is always in short supply. If health professionals do not value this aspect of a patient's health, then they will consider talking about it a waste of time. However, research has shown that these issues are important to many patients and so logically they should be important to health care professionals as well (Zilbergeld, 1979).

It is important for health professionals to bring up touching and sex in order to point out that the two can exist separately. One of the myths surrounding sex in our society is that once one begins intimate touching, it leads to intercourse. This has the potential to cause serious difficulties between couples. People may avoid touching because of fear that they will be committed to proceed to intercourse. If this subject is discussed, it can be pointed out that there are many creative alternatives and that couples can choose what is appropriate for them. The bottom line is that a patient can feel free to enjoy physical affection without feeling compelled to go on to sexual intercourse.

Research has been done with cancer patients (Bullard, Causey, Newman, Orloff, Schanche, & Wallace, 1980) to determine: (1) Do persons with cancer want to discuss their sexual concerns with health care providers? (2) Who should initiate such a discussion? (3) How should such a discussion be initiated? Their results and recommendations which would seem also relevant to the CF group, are:

(1) many cancer patients and their partners have sexual concerns that they wish to discuss with their physicians or other members of their health care team
(2) patients expect the physician or other staff to bring up the question of sexuality first before they will become comfortable

(3) because of their extensive contact with medical personnel in the treatment of their cancer, such persons are less likely to seek help at a sex counselling clinic even when they are having sexual concerns; only so much energy can be expended by persons in establishing new therapeutic contacts

(4) staff tend to be very protective of their patients, so any sexual health services that are offered must be thoroughly explained to staff who are in the position to make referrals. (p. 58)

Research Questions

It appears that there is a gap between what is suggested in the literature and what is happening in clinical practice. Areas of sexuality are not addressed by health professionals with any consistency even though there are known ways of dealing with problems that may be present. It is the aim of this research study to provide information about the sexuality of adults with CF, and also to narrow the gap between what is suggested in the literature and what is actually the experience of CF patients attending the clinic.

The specific research questions of this study are:

1. What is the sexual profile of adults with cystic fibrosis, described in terms of the following five aspects of sexuality:
   a) sexual self-view and identity
   b) relationship issues
   c) sexual desire
   d) sexual behaviour
   e) fertility and reproduction
2. Which aspects of sexuality are correlated with patients' biodemographic and clinical characteristics (i.e., gender, age, and the severity of cystic fibrosis)?

3. What are the major sexual concerns of this group of CF adults?

4. What do CF adults suggest that the CF Clinic might do to help patients deal with sexual concerns?
CHAPTER III

METHODOLOGY

Research Design

The research was designed as a survey using a mailed questionnaire. Although such a questionnaire is limited as compared to collecting data through interviews, using one made it possible to include subjects who live across the province of British Columbia. Of patients living in the lower mainland, several are seen in the clinic only once a year. Therefore, the survey method chosen permitted the inclusion of patients who would not be attending the clinic during the time that the research was in progress.

The study consisted of administering the questionnaire to a group of CF adults in order to collect data to make a sexual profile of this group and find out about their sexual concerns. There was no control group of non-CF people since the purpose of the study was not to demonstrate differences between CF and non-CF adults, but rather to describe the CF group.
Description of the Sample

The sample for the study consisted of 50 patients (28 men and 22 women) who receive health care services in the Adult Cystic Fibrosis Clinic at Shaughnessy Hospital in Vancouver. This particular clinic was opened in 1981 as the first adult CF Clinic in Canada. Since that time, six other adult clinics have opened in other parts of the country. Patients are seen regularly in the clinic by the physician, nurse, physiotherapist, dietitian, and social worker. Patients also frequently have pulmonary function tests, chest x-rays, and blood tests done when they attend the clinic. The frequency of their clinic visits depends upon the severity of their disease.

In addition to being an adult clinic patient, study criteria also demanded that the patient must have reached the age of majority (19 years). At the age of 18, patients are transferred from the pediatric clinic to the adult clinic. However, the health professionals in the clinic felt that given the sensitive nature of this research, only patients who had reached the age of majority should be included in the study.

Approximately 60% of the patients live in the lower mainland of British Columbia (area surrounding Vancouver extending as far east as Hope and as far north as Squamish) and the remaining 40% are spread across the province.

Instrumentation

Existing questionnaires were reviewed for their suitability in providing data that would answer the research questions. The only studies done in the area of
sexual function for CF patients were conducted in Cleveland, Ohio. Those questionnaires were judged to be too lengthy for use in this study; also, they did not integrate aspects of cystic fibrosis with sexual function. For the purpose of this study then, it was necessary to develop a questionnaire which would specifically address the research questions.

The questionnaires were anonymous, with no identifying marks. One was sent to each subject, along with a covering letter from the physician in the Adult CF Clinic (Appendix A). The questionnaire was introduced in an explanatory letter from the investigator (Appendix B). An addressed, stamped envelope was included and the completed questionnaires were returned to the investigator.

Different questionnaires were designed for males and females (Appendix D). In large part the two were identical, but the sections addressing specific sexual problems, fertility, and reproduction were necessarily different. The questionnaire for women was 15 pages in length and that for men was 14 pages long.

The physician in the clinic ranked each subject in the sample on a five-point scale according to the severity of his/her Cystic Fibrosis. Such factors as number of hospitalizations per year, amount of lung damage, and ability to function on a day-to-day basis were considered. The questionnaires were colour-coded according to the severity of the person's illness.

The questionnaire was constructed to meet the following criteria: (1) to provide data for answering the research questions, (2) to incorporate the framework which was adapted from the Szasz framework for this study, (3) to flow in a logical sequence beginning with less threatening questions, and (4) to provide a straightforward format that subjects could respond to easily.

The resulting questionnaire has seven sections:
Section I: A series of nine background questions. The three most important independent variables were: gender (two different questionnaires), severity (colour coded forms), and age (year of birth was the first question on the form). In order to control for potential contaminating variables, subjects were also asked about: medications, current illnesses other than CF, religion, level of education, whom they were living with, and age at which CF was diagnosed. To give further indication of the severity of their disease, subjects were also asked about the number of hospital admissions over each of the past three years, and about how many hours per week they worked.

Section II: A series of seven questions with responses to be given on a four-point scale. The questions addressed: (1) how much CF interferes with life, (2) self-esteem, (3) self-view based on physical appearance, personality, and intelligence, (4) perceived marketability as a partner for a date and as a sexual partner, (5) importance of intimate physical contact for the person, (6) sexual desire, and (7) level of satisfaction with sex life.

Section III: Questions to find out: (1) what things stimulate sexual interest, (2) how CF interferes with sex, (3) what other factors interfere with sex, (4) frequency of and response to masturbation, and (5) description of sexual activity in relationship context.

Section IV: Questions about gender of partners, and characteristics of relationship with partner (parameters of love, security, affection, sharing, and communication). This section was only for subjects who had partners.
Section V: Questions to find out about: (1) frequency of and satisfaction with frequency of intercourse, (2) desire discrepancies between partners, and (3) possible sexual dysfunctions (For men: early ejaculation, delayed ejaculation, erection difficulties. For women: orgasm difficulties, pain on intercourse).

Section VI: Questions about reproduction to find out about: (1) children, (2) contraception and pregnancy issues for women, (3) fertility and other reproductive concerns for women, (4) for men, how and when they found out they were infertile, (5) for men, how and when they think it would be best for men to find out about infertility.

Section VII: Questions about: (1) sexual concerns, (2) with whom do they discuss sexual issues, (3) discussion of sexual issues in the CF clinic, and (4) suggestions CF patients may have for dealing with sexual concerns in the CF clinic.

Questions were formulated based on this framework and then the resulting questionnaire was reviewed by experts in the field of sexual functioning and cystic fibrosis. The final format was piloted on 15 people of various backgrounds to ensure that the questions would be correctly interpreted and that they would provide the desired information.

The questionnaires were mailed in May, 1986. A repeat mailing followed four weeks later to increase the number of returns (covering letter for the second mailing appears as Appendix C).
The information gathered by this research was principally descriptive. Consequently, results were analyzed using measures of distribution and association. Results are described in Chapter IV.

The measures of association used are Kendall's rank correlation coefficient (Swinscow, 1983). This method of rank correlation is particularly useful when observations are difficult to quantify exactly and when they do not conform to a "normal" distribution. For these reasons rank correlation is the most suitable measure of association for this study. Kendall's rank correlation coefficient is represented by the Greek letter "tau". Its value varies from +1 for complete positive correlation through 0 for no correlation to -1 for complete negative correlation.

To compute Kendall's Tau, two variables are ordered according to rank and cross-tabulated; the relationship between the two is then computed. When there are an equal number of categories for each variable, Kendall's "Tau B" is the correlation coefficient used; when the number of categories differs for the two variables, Kendall's "Tau C" is used. In addition to the correlation coefficient for a given cross-tabulation of variables, the probability level (i.e. the likelihood that the relationship could occur by chance) is also calculated.

Cross-tabulation of variables in the study was done to find out if there are associations among the variables. As the research questions indicate, there are some variable relationships that are of particular interest. The variables of gender, severity, and age are cross-tabulated with the variables of sexual self-view, desire, and behaviour.
CHAPTER IV

RESULTS

Description of the Respondents

Of the 50 questionnaires mailed out, a total of 31 completed questionnaires were returned, resulting in a 62% response rate. This rate includes returns from both the initial and the follow-up mailings. Considering the sensitive subject matter and the typical response to mailed questionnaires, 62% was judged to be satisfactory.

The respondents were 16 men and 15 women. A larger proportion of the females in the research population (68%) responded than did males in the population (57%) (Figure 3). The implications of this are, first, that the females are better represented in this sample because of the higher response rate and, second, that the sample of respondents differs from the research population in that it consists of a higher proportion of women. Comparison of respondents and non-respondents based on gender is described in Table 1. On the basis of gender, the respondents seem fairly representative of the population.
Figure 3. Population and Sample Size Divided According to Gender
Table 1

Comparison of Respondents with Non-Respondents on the Basis of Gender and Severity

<table>
<thead>
<tr>
<th></th>
<th>Respondents</th>
<th>Non-Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender Ratio</td>
<td>52% male</td>
<td>63% male</td>
</tr>
<tr>
<td>Severity (mean)</td>
<td>2.45</td>
<td>2.28</td>
</tr>
</tbody>
</table>

The distribution according to severity shows the greatest number of people in the "moderate" category (Figure 4). There were at least three people in each category of severity. Gender and severity were not significantly correlated, although Figure 4 shows that the "extremely severe" category was all men (a detailed breakdown appears in Table 16 in Appendix E). Comparing the severity of the respondents with that of the non-respondents (Table 1), shows that the mean severity of the two groups was very similar. A t-test was performed to find out whether the two means differed significantly. The obtained result (t = 0.213, df = 47) was not significant; the severity distributions of respondents and non-respondents did not differ, so on this basis respondents are representative of the CF population. In order to validate the severity ratings assigned to subjects by the clinic physician, severity was cross-tabulated with three other variables which acted as indicators of severity. The first, the number of hours the subject worked per week (Tau C = -.475, p = .0008) indicated that the more severe the CF was, the less the person worked. When CF severity was cross-tabulated with the age at which CF was diagnosed, there was no significant relationship. The third variable
Figure 4. Distribution of Respondents by Severity of CF

**Degree of Severity of CF**

- **Mild**
- **Moderate**
- **Severe**
- **Very Severe**
- **Extremely Severe**

**Number of Respondents**

- **Females (n=15)**
- **Males (n=16)**
correlated with severity was the number of hospitalizations over the previous three years. This was the strongest relationship (\( \text{Tau C} = .613, p < .00001 \)): the more severe the CF, the more frequent the hospitalizations.

Most of the respondents (82%) were young adults under the age of 35 years. The distribution of the respondents according to age is depicted in Figure 5. When age was grouped and cross-tabulated with the dependent variables in the study no significant differences were observed.

Almost half of the respondents (45%) were married or living with a partner at the time of the questionnaire. Just under one third were living with their parents and a few were living alone or with friends (Figure 6).

Out of the 31 patients, 27 took medications of some sort (Table 2, p. 44). The only drug appearing in the table which has known potential effect on sexual desire and behaviour is Tagamet. This drug can cause a decline in sexual desire (for both men and women) and can also cause erection difficulties for men. Three of the questionnaire respondents were taking Tagamet, but none of them reported problems with sexual desire or erections.

Each subject was asked to list any illnesses he/she had, other than CF (Table 3, p. 44). The only one of these illnesses that has particular implications for sexual function is diabetes, which is known to cause erection difficulties in some men (Kowarinski & Ayres, 1981). Of the three subjects in the sample who reported having diabetes, two were men. Both of them reported that they were able to have erections.

With the exception of one person (who reported having grade 9–11 education), all of the respondents reported having grade 12 education or higher.
Figure 5. Distribution of Respondents by Age
Figure 6. Subjects' Living Arrangements
Table 2
Medications Being Taken By CF Patients

<table>
<thead>
<tr>
<th>Type of Medication</th>
<th>Distribution of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>11</td>
</tr>
<tr>
<td>Bronchodilators</td>
<td>18</td>
</tr>
<tr>
<td>Enzymes</td>
<td>20</td>
</tr>
<tr>
<td>Vitamins and Minerals</td>
<td>11</td>
</tr>
<tr>
<td>Drugs with a G. I. Focus</td>
<td>8</td>
</tr>
<tr>
<td>Circulatory System Drugs</td>
<td>2</td>
</tr>
<tr>
<td>Steroids</td>
<td>1</td>
</tr>
<tr>
<td>Sedative / Anxiolytics</td>
<td>1</td>
</tr>
<tr>
<td>Drugs for Pain Relief</td>
<td>2</td>
</tr>
<tr>
<td>Anticonvulsants</td>
<td>1</td>
</tr>
<tr>
<td>Insulin</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 3
Other Illnesses of CF Patients

<table>
<thead>
<tr>
<th>Illness</th>
<th>Distribution of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
</tr>
<tr>
<td>Respiratory-Related Illness</td>
<td>4</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>1</td>
</tr>
<tr>
<td>Gallstones</td>
<td>1</td>
</tr>
<tr>
<td>Diabetes</td>
<td>3</td>
</tr>
<tr>
<td>Bone and Joint Problems</td>
<td>4</td>
</tr>
</tbody>
</table>
The different religious denominations represented in the sample that replied were: Roman Catholic, United, Anglican, Protestant, and Pentecostal. The question had asked, "In what religion were you raised?" and several respondents commented that they were not particularly religious at this time or never had been. There were no correlations between religion and sexual behaviour.

One question was aimed at finding out the age at which the person was diagnosed as having cystic fibrosis. The results showed that 70% of the group was diagnosed with CF before the age of ten; 15% were diagnosed between 10 and 19 years; and 15% were diagnosed at age 20 or older.

Subjects were asked about how much CF interfered with life in general (Table 4). When this variable was correlated with severity, there was a significant correlation between severity and CF interfering with life (Tau C = .341, p = .01); the milder the CF, the less it interfered with life.

Table 4

<table>
<thead>
<tr>
<th>Amount CF Interferes with Life in General</th>
</tr>
</thead>
<tbody>
<tr>
<td>Descriptor</td>
</tr>
<tr>
<td>&quot;not at all&quot;</td>
</tr>
<tr>
<td>&quot;a little bit&quot;</td>
</tr>
<tr>
<td>&quot;a moderate amount&quot;</td>
</tr>
<tr>
<td>&quot;a great deal&quot;</td>
</tr>
</tbody>
</table>
Data Analysis According to the Theoretical Model

The data collected on the questionnaires is analyzed according to the five aspects of sexuality defined in the research questions.

To provide a point of comparison for the sexual profile, comparisons to the general population are made where feasible, in particular in the "sexual behaviour" section. The CF data is compared with survey data collected from the general population and documented in: Sexual Behavior in the Human Male (Kinsey, Pomeroy, & Martin, 1948); Sexual Behavior in the Human Female (Kinsey, Pomeroy, Martin, & Gebhard, 1953); The Hite Report: A Nationwide Study of Female Sexuality (Hite, 1981); The Hite Report on Male Sexuality (Hite, 1981); Sexual Behavior in the 1970's (Hunt, 1974). There are limitations in making comparisons between this data and data from the CF sample: (1) the populations were not matched for biodemographic characteristics, (2) in many cases the general surveys report data from different questions than those asked on the CF questionnaire, making comparisons less relevant. Comparisons are presented in this chapter together with the CF data to enhance clarity.

Sexual Self-View and Identity

When asked to report about feelings of self-esteem, 55% of the group said that they felt worthy and valuable. Of the remaining 45% half felt somewhat positively about themselves and half somewhat negatively.

Correlation between severity and self-esteem was not significant. Self-view was examined in more detail in the areas of physical appearance, intelligence, and personality. None were "very dissatisfied" with themselves on any of these
parameters (Table 5). Intelligence was the aspect of self that subjects most commonly reported that they felt satisfied with; physical appearance was the aspect associated with the most dissatisfaction. When satisfaction with physical appearance was cross-tabulated with gender, it was found that all six of the people who reported being "very satisfied" with their physical appearance were women.

Table 5

Subjective Reports on Three Aspects of Self-View

<table>
<thead>
<tr>
<th></th>
<th>Physical Appearance (n = 30)</th>
<th>Intelligence (n = 31)</th>
<th>Personality (n = 31)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somewhat Dissatisfied</td>
<td>8</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Somewhat Satisfied</td>
<td>16</td>
<td>13</td>
<td>19</td>
</tr>
<tr>
<td>Very Satisfied</td>
<td>6</td>
<td>15</td>
<td>10</td>
</tr>
</tbody>
</table>

The "marketability" of the CF person as a desirable partner was also investigated. Subjects were asked how appealing they thought others would find them as (a) a partner for a date, and (b) a sexual partner. The views tended to be more positive for dating than for sexual partnership (Table 6).

"How satisfied are you with the sexual aspect of your life?", was asked of the group. Responses were spread over the scale of four possible responses. There were 4 people who reported being very dissatisfied; 6 were somewhat dissatisfied; 11 were somewhat satisfied; and 10 were very satisfied.
Table 6

**Self-View of Subject's Own Marketability**

<table>
<thead>
<tr>
<th></th>
<th>As a Partner for a Date (n = 31)</th>
<th>As a Sexual Partner (n = 29)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not Appealing</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Slightly Appealing</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Moderately Appealing</td>
<td>17</td>
<td>15</td>
</tr>
<tr>
<td>Very Appealing</td>
<td>7</td>
<td>4</td>
</tr>
</tbody>
</table>

Subjects were asked, "How much does CF interfere with the sexual aspect of your life?" Nine people reported "not at all"; four people said "very much"; and the remaining 17 were somewhere in between the two extremes (one person did not answer the question). Not surprisingly, there was a significant correlation between CF interfering with life in general and CF interfering with sex life (Tau B = .423, p = .0038). There was also a significant correlation between severity and CF interfering with sex (Tau C = .367, p = .0078).

The strongest relationship between two of the variables associated with sexuality in this study was the inverse correlation between self-esteem and the amount CF interfered with sex life (Tau C = -.483, p = .0014): the less CF interfered with a person's sex life, the higher his/her self-esteem.
One interesting finding of the study was the ways in which cystic fibrosis interferes with the sexual aspect of people's lives. A list was provided on the questionnaire of seven implications of CF for disruption of sexuality; these were derived from the review of the literature. Each item was identified by four or more people (Figure 7; for detailed breakdown see Table 17 in Appendix E). When gender was cross-tabulated with each of the items, a significant difference was noted between men and women on the issue of limited lifespan (Tau B = .36, p = .024). Sixty-three percent of the men listed "potentially limited lifespan" as an interfering factor, as compared to only twenty-seven percent of the women.

In open-ended responses, subjects raised several new issues and variations of the above that were of particular importance to them. Two people mentioned, in addition to the "easily fatigued" item on the list, that they had poor physical tolerance, no stamina, and experienced shortness of breath with sexual activity. One person summed up his feelings by saying, "I want to, but have no physical energy!" Two people mentioned the negative feelings associated with not being able to father children. One person reported that she felt inhibited by having to get up and "do treatments" (inhalations and chest physiotherapy) after an evening's sexual encounter before going to sleep. Another person reported feeling embarrassed about her medications and equipment, and because of this she was not able to stay overnight with her boyfriend. She reported that she felt she did not want to get too close to her partner because of her uncomfortable feelings about her need for treatments. Other difficulties mentioned were fear of hemoptysis, sexual inexperience, psychological hang-ups about how a CF person is perceived by people of the opposite sex, and getting one's partner to accept the fact that the CF person could die at any time in the near future.
Figure 7. CF Related Factors Affecting Sexuality
Several general questions were asked about the subject's past life experiences from a psychosocial and sexual perspective (Table 7). Subjects reported on difficult areas for them as children and adolescents and also indicated whether or not there were still problems in these areas. Due to the global nature of the questions, results are not definitive although they are of interest.

Table 7

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>Problem Before Age 19*</th>
<th>Still A Problem*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being overprotected by parents</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>Being isolated from friends</td>
<td></td>
<td></td>
</tr>
<tr>
<td>because of limitations of CF</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Being sexually violated</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Worried about being sexually inexperienced</td>
<td>12</td>
<td>3</td>
</tr>
<tr>
<td>Worried about odour of genitals</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Worried about size of breasts (for women)</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>genitals (for men)</td>
<td>8</td>
<td>2</td>
</tr>
</tbody>
</table>

* Number of subjects who answered "yes" are reported in these columns.
Relationship Issues

Subjects were asked to categorize their sexual relationships. The results yield a simple profile of sexual relationships for this group (Table 8). When the sexual relationships were cross-tabulated with gender, the researcher noticed that the men fell into two categories: they were either sexually active with a steady partner, or they were not sexually active now but had been in the past. The females were distributed over all five categories.

Table 8

Categorization of Sexual Relationships
(n = 30)

<table>
<thead>
<tr>
<th>Relationship Category</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexually active currently with a steady partner</td>
<td>18</td>
<td>58%</td>
</tr>
<tr>
<td>Sexually active currently with casual or occasional partners</td>
<td>1</td>
<td>3%</td>
</tr>
<tr>
<td>Have no partner currently but have been sexually active in past</td>
<td>9</td>
<td>29%</td>
</tr>
<tr>
<td>Have no partner currently and have never been sexually active</td>
<td>2</td>
<td>7%</td>
</tr>
<tr>
<td>Have a partner currently but am not (never have been) sexually active</td>
<td>1</td>
<td>3%</td>
</tr>
</tbody>
</table>

Respondents were questioned more specifically about the nature of the relationships. With the exception of one woman who reported that the gender of
her partner(s) was female, all the respondents who were sexually active reported that their current relationships were heterosexual. Subjects were asked to rate their relationships on a four-point scale for each of six characteristics. When ratings of three and four were grouped together as positive ratings, it was obvious that an extremely high percentage of these CF adults felt positively about their relationships (Table 9).

Table 9

<table>
<thead>
<tr>
<th>Relationship Characteristics</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feel loved</td>
<td>26</td>
<td>93%</td>
</tr>
<tr>
<td>Affection</td>
<td>25</td>
<td>89%</td>
</tr>
<tr>
<td>Feel loving</td>
<td>25</td>
<td>89%</td>
</tr>
<tr>
<td>Sharing</td>
<td>22</td>
<td>80%</td>
</tr>
<tr>
<td>Communication</td>
<td>22</td>
<td>80%</td>
</tr>
<tr>
<td>Feel secure</td>
<td>22</td>
<td>80%</td>
</tr>
</tbody>
</table>

One question asked whether there were any factors other than CF that had an upsetting effect on the person's sexual relationship. Job stress and finances were the top two stressors on the list (Table 10).
Table 10

**Stressors (other than CF) Which Affect Sexual Relationships**

<table>
<thead>
<tr>
<th>Stressor</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Job Stress</td>
<td>9</td>
<td>29%</td>
</tr>
<tr>
<td>Finances</td>
<td>7</td>
<td>23%</td>
</tr>
<tr>
<td>Fighting &amp; arguing with partner</td>
<td>5</td>
<td>16%</td>
</tr>
<tr>
<td>Conflict over religious matters</td>
<td>3</td>
<td>10%</td>
</tr>
<tr>
<td>Difficulties with relatives</td>
<td>3</td>
<td>10%</td>
</tr>
<tr>
<td>Difficulties with children</td>
<td>1</td>
<td>3%</td>
</tr>
</tbody>
</table>

**Sexual Desire**

Initially, the research focused on "intimate physical contact", which included cuddling, stroking, intercourse, fondling, kissing, etc. The first question addressed the importance of intimate physical contact in the subject's life. Just over half of the group stated, "very important" (Figure 8). This result is one of the indicators demonstrating that sexuality is in fact important for many of these patients. There was no significant difference between the responses of men and women to this question.

A second question asked how great the desire for intimate physical contact had been over the previous six months. Subjects responded on a four-point scale (Figure 9). A higher percentage of females than of males reported great desire.
FIGURE 8. IMPORTANCE OF INTIMATE PHYSICAL CONTACT TO PATIENTS
FIGURE 9. SEXUAL DESIRE OF ADULTS WHO HAVE CYSTIC FIBROSIS
However, cross-tabulation did not show a significant relationship between gender and desire, nor was there a significant relationship between severity and desire.

Subjects were asked to report on what kinds of things stimulate their sexual interest. Touching an appealing person and seeing an appealing person were the two most frequently reported items. Figure 10 illustrates how many subjects reported that these factors could stimulate sexual interest for them. Significantly more men than women liked erotic pictures (Tau C = .429, p = .0157). There was also a difference in responses with respect to romantic setting (not statistically significant): 10 (67%) of the women compared to 6 (38%) of the men reported liking romantic settings a lot; none of the women said that they disliked romantic settings but 2 men reported disliking them somewhat. There were no other remarkable differences in the responses of men and women to this question. Since this question was stated in general terms, analysis is not documented.

Desire discrepancies between partners are often reported to sex therapists by couples in the general population (Zilbergeld & Ellison, 1980). Of the CF subjects in this study, 58% reported that there was a discrepancy in the desire for sexual activity between themselves and their partners. Eleven subjects reported that their partners desired sexual activity more often than they did, three said that their partner desired sex less often, and ten reported the same frequency of desire for sexual activity.

**Sexual Behaviour**

Of the 31 respondents, only 3 females were not sexually active. When asked about self-stimulation (masturbation), one person did not answer, 9 people (2 men and 7 women) stated that they never masturbate, and 21 subjects answered that
Figure 10. Factors Which Stimulate Sexual Interest
they do engage in self-stimulation. In other words, 88% of the men and 53% of the women masturbate. These percentages are somewhat lower than norms for the general population: 94% of men have masturbated at some time, and 63% of women have masturbated at some time (Hunt, 1974). CF patients were not asked specifically about masturbation experiences when they were younger, and this may be the reason for the lower percentages.

The mean frequency of this activity for those who do engage in self-stimulation was 1.77 times per week. Of those who masturbate three times or more per week, four were men, and one was a woman. All of the men who masturbated reported that they were able to have erections and ejaculations in this way. The women were asked equivalent questions about whether they were able to develop vaginal wetness with self-stimulation and whether they were able to have orgasms in this way (Table 11).

Table 11

**Female Responses to Self-Stimulation**
(n = 8)

<table>
<thead>
<tr>
<th>Descriptors</th>
<th>Women reporting Vaginal Wetness</th>
<th>Women reporting Orgasms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Occasionally</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Frequently</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Always</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>
The Hite Report (1981) stated that 95% of the women who masturbated could reach orgasm easily and when they wanted to. The data on the CF women are not as positive, since one woman reports never reaching orgasm and one only occasionally.

The question about frequency of intercourse was not answered by seven people (the three who were not sexually active and four others who did not have partners at the time). For the 24 patients (ranging in age from 19 to 43 years of age) who answered this question, there was no difference between the men and women for frequency of intercourse. The mean frequency of intercourse for CF adults was 2.31 times per week. For norm groups of the same age, Kinsey (1953) reported a mean frequency of intercourse of 2.53 times per week, and Hunt (1974) reported a mean of 2.77 times per week. When intercourse frequencies of the patients over the age of 35 years are isolated, CF patients were again similar. The mean frequency of intercourse for CF adults in this age range was 1.78 per week, as compared to means of 1.85 (Kinsey) and 2.10 (Hunt) for the general population.

Subjects were also asked about their level of satisfaction with the frequency of intercourse. Over half the group stated they would prefer to engage in intercourse more often (Figure 11). There was no one who said he/she would prefer intercourse less often. Desire for more frequent intercourse has also been reported in the general population where 40% of men at most ages said that they would like the frequency of intercourse to be higher; 30% of women also said this (Hunt, 1974).

When gender was cross-tabulated with satisfaction with frequency of intercourse, the difference was more marked than that reported in the general population. Almost twice as many men as women stated that they would prefer
Figure 11. Preference for Frequency of Intercourse
intercourse more often. The CF results also show that twice as many women as men were satisfied with the frequency of intercourse.

Women were asked about three other aspects of sexual behaviour: need to use additional lubricants during intercourse, ability to reach orgasm by various means, and pain on intercourse. Eleven women answered these questions (three women were not sexually active and one woman omitted the questions).

With respect to the use of additional lubricant, seven reported they never use it, four sometimes do, and no one uses it all the time.

Women were asked to indicate all the different ways in which they were able to reach orgasm (Table 12).

Table 12

How Female Subjects Report Reaching Orgasm

(n = 11)

<table>
<thead>
<tr>
<th>Description</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never had an orgasm</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Had orgasms in the past, but not now</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Have orgasms by masturbation</td>
<td>6</td>
<td>55%</td>
</tr>
<tr>
<td>Have orgasms by partner's stimulation other than intercourse</td>
<td>9</td>
<td>82%</td>
</tr>
<tr>
<td>Have orgasms during intercourse</td>
<td>7</td>
<td>64%</td>
</tr>
</tbody>
</table>
The Hite Report (1981) states that 12% of women surveyed have never had an orgasm. This is certainly different from the CF women, none of whom reported never having an orgasm. However, there was one sexually active woman who did not answer the question, and this may be distorting the results.

The Hite Report (1981) states that "not to have orgasm from intercourse is the experience of the majority of women" (p. 232). However, seven out of the twelve sexually active CF women reported having orgasms on intercourse. Table 12 shows that 82% of CF women have orgasms from partner stimulation other than intercourse. Hite reported that, in the general population, 44% of women have orgasms with clitoral stimulation by hand and 42% of women have orgasms with oral stimulation. Since it is not known how many women were counted in both groups, comparison with the present CF data is difficult. However, it appears that the proportion of CF women, who have orgasms with intercourse or other forms of stimulation from their partners, is at least as high and likely higher than that in the general population.

When asked about experiencing pain on intercourse, five women said that this has never been a problem; four reported that it happens occasionally and doesn't bother them; and two reported a minor problem with pain on intercourse.

Men were asked about three different areas of sexual functioning: ability to have erections under various conditions, early ejaculation, and delayed ejaculation.

The intent of the question about morning erections was to determine whether erection problems might have a physiological basis. However, 15 out of the 16 men reported that they do have morning erections. The man who replied that he did not have any morning erections over the past month did not report any erection
problems. It would appear, then, that the erection problems that were reported are likely of a psychogenic nature.

Thirteen men reported never having a problem getting erections with their partner(s), but there were three men who reported that this happened (Table 13).

Table 13

Summary of Male Sexual Difficulties
(n = 16)

<table>
<thead>
<tr>
<th>Self-Report</th>
<th>Erection Difficulties</th>
<th>Early Ejaculation</th>
<th>Delayed Ejaculation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was a problem in the past, but no longer is</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Happens occasionally (doesn't bother me)</td>
<td>1</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Minor Problem</td>
<td>1</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Major Problem</td>
<td>1</td>
<td>3</td>
<td>0</td>
</tr>
</tbody>
</table>

In addition men were asked about difficulty losing their erections when attempting to have intercourse. One man reported losing his erection each time intercourse was attempted (this was a man who reported never having a problem getting an erection). Another man reported losing erections frequently when attempting intercourse; and three men said that this happens to them occasionally.

There were three men (19%) in total who reported erection difficulties (one
major problem, one minor problem, and one problem with losing erection each time intercourse attempted). Kinsey's data (Gebhard & Johnson, 1979) indicates that 12.25% of adults (college and non-college included) report having a problem with impotence. The CF adults appear to have a higher incidence of erection difficulties than the general population.

Early ejaculation was the most frequently reported problem for CF patients: nine men (56%) reported that this happens (although only three perceived the early ejaculation as a major problem, and three as a minor problem). In The Hite Report on Male Sexuality (1981) figures from the general population show that 70% of men answered "yes" to the question, "Do you ever orgasm 'too soon' after penetration — in other words do you find you are not able to continue intercourse as long as you think you should or would like to?" (p. 1098). Since the questions were different in Hite's survey and on the CF questionnaire, clear comparisons are not possible. However, in both populations early ejaculation was the most common sexual difficulty.

Delayed ejaculation was only reported as a minor problem by two people and as an occasional occurrence by two others. In the general population, delayed ejaculation is also less common than early ejaculation or erectile dysfunction (Kaplan, 1974).

Most of the men who reported the sexual difficulties described above also reported that CF interfered to a moderate or great extent with the sexual aspect of their lives. Their disease ranged in severity from very mild to very severe.
Fertility and Reproduction

Subjects were asked about how and when they had found out that most CF males are infertile. The CF clinic physician had confirmed that, at the time of mailing the questionnaire, all of the men in the clinic knew about the infertility issue. A few had been tested to confirm their sterility. When asked how they felt when they found out, 25% of the respondents reported that they were not bothered. The majority of the men described their feelings with such adjectives as discouraged, disappointed, and frustrated. Two men were relieved because they did not want to pass on the CF gene. Three men were angry at not being told sooner about their infertility. One man in particular stated that his wife had been subjected to years of unnecessary birth control because he did not know that he was infertile.

One of the most striking results of the study had to do with how males found out about their infertility versus how they thought it would be best to find out (Figures 12 & 13).

Eleven out of the 16 men found out about their infertility from a pamphlet, 2 found out from their parents, and no one found out from the physicians in the CF pediatric or adult clinics. Of the three who checked "other", one found out from another patient, one from a medical book, and one recounted the startling way in which he found out about being infertile. It is not known where this incident occurred, and it likely happened many years ago. However, it is a valuable illustration of the importance of patient awareness of the fertility issue. This CF male who had been unaware that most CF men are infertile, reported that he had decided that he did not want to have children and so arranged to have a vasectomy done. Apparently it was not until the surgeon was holding the scalpel ready to proceed with the vasectomy, that the subject of CF came up and the surgeon told
Figure 12. How Men Found Out About Infertility

Figure 13. How Men Think They Should Find Out About Infertility
the patient that he was likely already sterile. The vasectomy was cancelled. Due to lack of patient education, this man almost had an unnecessary surgical procedure performed.

In contrast to the way in which these men found out about their infertility are their suggestions for the ideal way for CF men to find out about the infertility issue (Figure 13). Almost all the male respondents said that they thought it would be best for men to find out from the physicians in the pediatric or adult CF clinics. Of the respondents who checked "other", one said a fertility test should be used, and the other said, "Any way — just tell them!"

Out of the 16 males, 2 were diagnosed with CF after the age of 19. Of the remaining 14, only 4 of them found out before the age of 19 that they were likely infertile (Figure 14). However, when asked at what age they would like to have the fertility issue discussed, 100% of them said before the age of 19 (Figure 15).

For women the fertility issue is different since their fertility is merely somewhat reduced. When asked about when women thought the fertility issue should be discussed in the CF clinic, 75% of the group recommended before 19 years of age (Table 14). However, there were three people who responded by checking the "only when they ask" option. Interestingly, two of these people were female teens who were living with their parents and had not been sexually active. The third person happened to be the only person out of the sample who thought sex was an inappropriate topic for discussion in the CF clinic. This person was certainly consistent in portraying her attitude.
Figure 14. Age Men Found Out About Infertility

Figure 15. Age Men Thought They Should Find Out About Infertility
Table 14

When Women Think the Fertility Issue
Should Be Discussed With Women

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before age 16</td>
<td>5</td>
<td>33%</td>
</tr>
<tr>
<td>16 – 18 years</td>
<td>6</td>
<td>40%</td>
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<tr>
<td>19 – 25 years</td>
<td>1</td>
<td>7%</td>
</tr>
<tr>
<td>After age 25</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Only when they ask</td>
<td>3</td>
<td>20%</td>
</tr>
</tbody>
</table>

Subjects were asked whether they would rather talk to a male health professional or to a female about infertility. Of the 31 subjects, 20 reported that it wouldn’t matter; 4 men preferred to talk to a male; 7 women preferred to talk to a female.

Women were asked to report the degree of their concern about several reproduction issues. "Passing on a CF gene to your child" was the issue causing the most concern (seven people reported great concern, four had some concern, and two reported no concern). There were three issues that ranked similarly with respect to the amount of concern expressed by women: effectiveness and safety of birth control (considering CF), ability to carry pregnancy without adverse effects to the mother's health, and ability to bear a healthy child. The responses to questions about concern over these three issues were about the same: five or six women
expressed great concern, four women expressed no concern, and the remainder were in between. The fertility issue raised the least concern. Six women expressed no concern, five said that they had some concern, and two reported great concern.

The results of questions about methods of birth control presently used by these women showed that oral contraceptives and sterilization were the most popular (four women use each method). One woman uses an I.U.D. and a few use no birth control. Other methods, such as a diaphragm and jelly, condom, spermicidal foam, and rhythm, were used in the past by some of these women, but these methods are not used now.

Only two of the fifteen women reported that they had been pregnant; both terminated the pregnancy because of their CF. One woman had two adopted children. Other than these, the only children reported were by two men each of whom had had one child by means of artificial insemination of their partners.

Dealing With Sexual Concerns

Subjects were asked "With whom do you discuss sexual concerns?" Results show that 24 people discuss sexual concerns with their partners (Figure 16). Five people reported that they do not discuss sexual concerns with any one (two of these were people who are not sexually active).

Results of the question about the appropriate age for talking about sex showed that most of the respondents (84%) suggested that it would be desirable to begin discussing sexual issues in the CF clinic between the ages of 13 and 18 years (Table 15).
Figure 16. People With Whom Subjects Discuss Sex
Table 15

Suggested Age for Initiating Discussion of
Sexual Issues in the CF Clinic

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 - 12 years</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>13 - 15 years</td>
<td>12</td>
<td>39%</td>
</tr>
<tr>
<td>16 - 18 years</td>
<td>14</td>
<td>45%</td>
</tr>
<tr>
<td>After 18 years</td>
<td>2</td>
<td>6%</td>
</tr>
<tr>
<td>Not appropriate for</td>
<td>1</td>
<td>3%</td>
</tr>
<tr>
<td>discussion in the CF clinic</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

One question inquired about which factors, if any, inhibit discussion of sexual issues at the CF clinic. Two thirds of the respondents listed "no one brought it up, so I didn't either" as one of the factors (Figure 17). Eight people reported that discussion of sexual issues was inhibited by not feeling comfortable with the clinic staff. Cross-tabulation of gender with this variable demonstrated that the proportion of the female group who reported this as an inhibiting factor was three times greater than the proportion of the male group. Subjects added several other inhibiting factors to the list. The most striking factor was a brief vignette from a subject who reported (slightly altered to maintain anonymity):

When I was younger, I tried to talk to the CF clinic staff about future plans of marriage (night time treatments concerned me) and about having children. The health professional involved made jokes. I gave up the topic.
Figure 17. Factors Which Inhibited Discussion of Sexual Issues in the CF Clinic
Another patient was asked, "Do you have any problems with sex?" by one of the clinic staff. This person replied, "No" and that was the end of the discussion. One subject reported that since he/she was diagnosed at a late age, specific questions did not arise. Another subject reported that feeling uncomfortable discussing sex in a big group of strangers was an inhibiting factor in talking about sexual issues in the CF clinic.

The respondents provided some useful information about what the CF clinic could offer to help them deal with sexual issues by checking off suggestions that they favoured and adding some others. The results demonstrated that the most popular suggestion was "Discussion of sexual issues" (Figure 18), and the physician was the person with whom the largest number of patients wanted to talk. Discussion of sexual issues by psychiatrist, nurse, and social worker were also suggested by some people. Other suggestions for ways in which the CF Clinic could help patients deal with sexual issues are reported in Figure 19. Fourteen people supported the idea of a questionnaire on sexual concerns to be given to the patients when they first start attending the adult clinic. Twelve people suggested recommended reading of commonly available self-help books such as For Each other (by Lonnie Barbach) and Male Sexuality (by Bernie Zilbergeld). Referral to a sexual counsellor when needed was suggested by twelve people. Three suggestions were added to the list by a subject: a CF adult group meeting to share discussion of concerns, genetic counselling, and information about birth control specifically for women with CF.

An open-ended question allowed subjects to describe any sexual concerns they had that were not addressed on the rest of the questionnaire. Four people
Figure 18. Preferred Clinic Staff Members for Discussing Sexual Issues
Other Ways in Which CF Clinic Could Help Patients Deal With Sexual Issues
responded to this question, and some of them listed several concerns. All of the
cconcerns mentioned are listed below:

1. psychological impact of infertility
2. concern about passing on the CF gene
3. the effect of pregnancy on a CF woman's health
4. holding back intimacy because of having CF
5. fear of poor marketability because of CF
6. need to feel comfortable to talk about sex with health
   professionals
7. counselling regarding alternatives to child bearing

Only two of the thirty-one respondents had ever discussed sexual problems
with a sexual counsellor/therapist. However, when asked whether they would use
such a service if it were available and they had sexual problems, 75% of the group
said "yes" (Figure 20).

Seven people provided general comments about the questionnaire. Four gave
some positive comments; two constructively criticized the questionnaire; a few
shared personal preferences for dealing with sexual concerns and gave their views
on sexual activity and marriage. One respondent commented, "even CF patients who
are sick can have satisfying sex lives."
FIGURE 20. WOULD SUBJECTS USE SEXUAL COUNSELLING SERVICES?
CHAPTER V

DISCUSSION AND CONCLUSIONS

Summary of Findings

The results are summarized below following the outline of the research questions.

Question 1. What is the sexual profile of adults with cystic fibrosis, described in terms of the following five aspects of sexuality?

(a) Sexual Self-View and Identity

These chronically ill adults have surprisingly good self-esteem — 75% view themselves positively. The self-view aspect which they rated most positively on a four-point scale was intelligence, whereas physical appearance was the aspect viewed with the most dissatisfaction. This is perhaps due to the effect of CF on physique. Subjects reported a broad range of levels of satisfaction with sex life.

Responses to questions about the impact of CF, revealed that not only does CF affect people's lives to varying degrees, it also affects people's sex lives in a number of different ways. For 70% of the respondents, CF interfered with the sexual aspect of life in either a direct (e.g., excessive coughing during sexual
relations) or indirect (e.g., potentially limited lifespan) way (cf. Figure 7). Two interfering factors that were highlighted by respondents were: (1) lack of energy, and (2) having to take inhalations and do physiotherapy at bedtime. There are some psychosocial factors that affect these people even as adults. Approximately 20% of the respondents reported that they still feel overprotected by their parents and isolated from friends because of the limitations of CF (cf. Table 7).

(b) Relationship Issues

In spite of the limitations of their disease, the majority of CF adults report positive relationships with their partners. They are influenced by some of the same stressors as non–CF couples (cf. Table 10). The two most common stressors for the general public, in addition to sex, are work and money problems (Schwartz & Blumstein, 1983). The subjects in this study similarly reported job stress and finances as the major stressors.

One specific question asked in the study was: "Are CF adults involved in sexual relationships?" The answer provided by the respondents was: "Yes." Ninety percent of the respondents are or have been sexually active. Over half the group are sexually active currently with a steady partner.

(c) Sexual Desire

Intimate physical contact was of some importance to almost all the subjects and very important to over half the group. The desire for this intimate physical expression tended to fall into the "moderate" to "great" range.

Over half the respondents reported a discrepancy between themselves and their partners in amount of desire for sexual activity. In most cases, the partner desired
sexual activity more often than the CF person. This is not surprising, in view of
the additional stresses resulting from cystic fibrosis. The reported desire
discrepancies may or may not be creating sexual difficulties depending on how the
desire discrepancies are being dealt with and what effect they are having on the
couples.

(d) Sexual Behaviour

Self-stimulation (masturbation) is considered by contemporary sexual therapists
to be a healthy form of sexual expression as well as a helpful means of dealing
with certain sexual difficulties (Zilbergeld, 1978). Two-thirds of the CF group
reported that they engage in self-stimulation and many of them are able to become
aroused and have orgasms in this way. A higher percentage of men than women
masturbate, as is also the case in the general population.

Those people who have steady sexual partners reported engaging in intercourse
on an average of two to three times per week. On the basis of frequency of
masturbation and frequency of intercourse, the CF adults are similar to the general
population.

Over half the CF respondents stated that they would prefer to engage in
intercourse more often. Similar reports have arisen from surveys of the general
population.

Females did not report any problems having orgasms; all reported that they
were able to reach orgasm by masturbation, intercourse, or other forms of
stimulation from their partners. With respect to sexual difficulties, two women
reported having a minor problem with pain on intercourse.
The percentages of CF women who are able to have orgasms with intercourse and those able with oral or manual stimulation from partners was higher than in the general population. However, with regard to having orgasms with masturbation, the percentage of CF women was lower than in the general population.

The most common male sexual complaint was early ejaculation: three men reported that early ejaculation was a major problem for them, and three reported it as a minor problem. Delayed ejaculation was less common: minor problems with this were reported by two men. Three men reported some form of erection problem: either the man had difficulty getting an erection when together with his partner, or he lost the erection when intercourse was attempted. CF males are similar to males in the general population where the "two major sexual problems are premature ejaculation and impotency" (Herold, 1984). However, the incidence of erectile difficulties in the CF group was higher than in the general population.

(e) Fertility and Reproduction

One of the most remarkable findings of the study was in relation to fertility and how this subject is dealt with in the CF clinic. Most of the men found out about their infertility from a pamphlet; however, they suggest that the best way to find out would be from either the physician in the pediatric CF clinic or the physician in the adult CF clinic. The majority of the men were 19 years or older when they found out; however, 100% of the men suggest that they be told about their likely infertility before the age of 19 years. Three-quarters of the women suggested that the fertility issue be discussed in the CF clinic before the age of 19 years. Two-thirds of the total group of men and women said that it would not
matter whether the health professional discussing the fertility issue was a man or a woman.

None of the female respondents reported having given birth to a child. They did express concerns, in particular about passing on the CF gene, and also about the special implications of birth control, pregnancy, and childbirth for them because of their disease. One woman had adopted children and two men had used artificial insemination so that their partners could become pregnant. It appears then that there are very few CF adults who have children. Several factors affecting couples in their decision to have children are the likelihood of a shorter lifespan, not wanting to pass on the CF gene, and the risks associated with pregnancy.

**Question 2.** Which aspects of sexuality are correlated with patients’ biodemographic and clinical characteristics (i.e., gender, age, and the severity of cystic fibrosis)?

When gender was cross-tabulated with sexual desire and certain sexual behaviours, the following differences between men and women were noticed: (1) there was a higher percentage of women than men who reported that they had great desire for sexual activity, (2) a higher percentage of men than women masturbated, (3) a higher percentage of men than women reported having orgasms with masturbation, (4) a higher percentage of men than women wanted to have a higher frequency of intercourse.

Although age is one of the most common biodemographic characteristics used for grouping survey results, in this study age was not significantly correlated with any of the variables. Significant correlations occurred when severity of cystic
fibrosis was cross-tabulated with other variables. Severity was significantly correlated with how much CF interfered with the person's life and also with how much CF interfered with the sexual aspect of life. There was no correlation between severity and the importance of, or desire for, intimate physical contact. Self-esteem was negatively correlated with the extent to which cystic fibrosis interfered with the sexual aspect of the subjects' lives: the less CF interfered with the sexual aspect of a person's life, the more worthy and valuable he/she felt.

The questionnaires of each of the subjects who reported sexual dysfunctions were reviewed to see if these were correlated with any of the biodemographic characteristics. There were no noticeable characteristics that these people had in common with one another.

**Question 3.** What are the major sexual concerns of this group of CF adults?

Many of the sexual concerns of the CF adults are related to the ways in which CF interferes with the sexual aspect of their lives. One direct effect that was mentioned by a number of people was excessive coughing during sexual activity. Several people also complained of lack of energy for sexual activity, and about being dissatisfied with their physical appearance.

One major concern is the discrepancy between how the male infertility issue is being dealt with and how the men suggest this issue best be dealt with by health professionals.

The sexual difficulties mentioned most often were desire discrepancies between the partners and, for men, early ejaculation. Both of these sexual problems are
based in large part on the perceptions and beliefs of the respondents and their partners.

**Question 4.** What do CF adults suggest that the CF Clinic might do to help patients deal with sexual concerns?

The suggestion that was supported by the greatest number of respondents was discussing sexual issues in the CF clinic. The majority of the subjects were in favour of initiating discussion of sexual issues in the clinic between the ages of 13 and 18. The main inhibiting factor that had prevented these people from talking about sex was the fact that none of the health professionals raised the issues. People are unlikely to share their concerns in this area unless they are invited to do so. The suggestion supported by more respondents than was any other suggestion was talking about sexual issues with the physician. Other suggestions supported by 30% – 40% of the group were: a sexual concerns questionnaire, suggested readings on sexual matters, and referral to a sexual therapist when needed.

**Limitations of the Study**

One minor limitation of this research is that the study relies on subjects' self-report in written form. The inability to check the responses given is one of the problems associated with the use of questionnaires. Beyond preparing the questionnaire carefully and wording questions appropriately, it is not possible to check the accuracy or detailed meaning of the responses. There are numerous
instances where the implications of the information gathered in this study are not clear because it was not possible to probe responses to a question, such as can be done in an interview.

Another limitation of the study is the lack of a control or comparison group, precluding comparisons with the general non–CF population or with other chronically ill people. However, although such comparisons may have been interesting, the emphasis in this study was not to prove such similarities or differences, but rather to describe the given population on the basis of sexual functioning and find out more about their sexual concerns.

The extrapolation of the results of this study are subject to limitations of sampling. The 50 CF adults living in B.C. were selected as the research population because the needs assessment was focused on this group and also because of the feasibility of using one health care service (as opposed to numerous clinics across the country).

Mailed questionnaires often result in low return rates, and therefore it is often not valid to generalize to a larger population. However, in this study there was a 62% response rate, which makes it possible to generalize the findings to the population of CF adults in British Columbia. In order to find out whether or not there were differences between the group of subjects who responded and those who did not, respondents and non–respondents are compared. This comparison was only possible with the characteristics of gender and severity because the questionnaires were anonymous. It is not possible to evaluate how representative the sample is based on other characteristics. Respondents and non–respondents were not significantly different on the basis of mean severity and with respect to the
proportion of males and females. These comparisons provided some indication that the respondents were representative of the research population.

**Recommendations**

The CF patients who responded to the questionnaire indicated that sexuality was important to them. The majority of the subjects were presently sexually active or had at one time been sexually active with partners. Cystic fibrosis can threaten a person's sexuality in numerous ways which have been identified in this needs assessment.

One of the main recommendations of this study is that health professionals' awareness of the sexuality and sexual concerns of CF patients should be increased. If patients with a chronic illness such as cystic fibrosis are perceived as sexual beings, then caregivers are more likely to recognize discussion of sexual issues as having an important place in health care.

However, more than awareness will be needed to integrate attention to sexual concerns into health care. Subjects' responses to the question about what factors inhibited discussion of sexual issues in the CF clinic, indicate that the major reason they did not talk about sexual issues was that the clinic staff did not initiate the discussion. Health professionals should be the ones to initiate discussion of sexual issues. In order to do this, education is needed.

Educating health professionals is an ongoing process, especially since there is often little emphasis on sexuality in faculties of medicine, nursing, and social work. There are health professionals who maintain that:
It is essential to educate health care staff about the sexual needs and problems of patients: sex is important to many patients. They want help in this area, and without such help they are likely to develop problems. (Zilbergeld, 1979, p. 240)

To help teach health professionals how to deal with sexual issues, teaching aids such as video tapes are available (e.g., Taking A Sexual History (Glasgow & Krane, 1986)).

There is information in related research literature about the importance of sexuality for chronically ill patients. However, health professionals were uncertain about what the patients’ sexual concerns might be and whether they should be discussed in the CF clinic. There were many other priorities that seemed more urgent, and there were no guidelines for how to address sexuality. This study provides direction for health professionals who deal with cystic fibrosis patients.

There is now information available to begin setting up clinic protocols which identify what should be done and by whom. Although the population for this study was CF adults living in British Columbia, the results and recommendations may have some application for health professionals in other CF clinics as well.

Health professionals may have concerns about the time necessary to incorporate discussion of sexual issues into clinic visits. Certainly, it is likely that some additional time will be required to address the subject of sexuality. However, once the subject has been raised (which may take only two to ten minutes initially), patients will feel that this topic is acceptable for discussion, and they are more likely to feel free to volunteer any concerns at subsequent clinic visits. There may be clinic visits when there is little or no discussion of sexuality and there may be other times when the discussion will expand to twenty minutes or longer. When
this is the case, and if this results in any scheduling difficulties, discussion may have to be scheduled for a subsequent visit, or referral may be in order.

The recommendations summarized from the research results are:

1. Address sexual issues with patients in the pediatric CF clinic, between 13 and 18 years of age.

   The majority (87%) of CF respondents reported that they would have liked to have had sexual issues discussed at those ages in the CF clinic.

2. Give adults attending the CF clinic the opportunity to discuss sexual concerns.

   Results of this study clearly show that patients want to discuss issues related to sexuality and CF with the clinic physician. Respondents mentioned numerous ways in which CF had an impact on the sexual aspect of their lives. A number of subjects supported specific suggestions for ways in which the Adult CF Clinic could help patients deal with sexual concerns:

   (a) discuss sexual issues
   (b) recommend appropriate reading
   (c) refer patients to sexual counsellor when needed
   (d) incorporate a sexual concerns questionnaire on admission to the Adult CF Clinic

3. Men suggested that males be told about the infertility issue by the pediatric or adult physician.

   One of the main sexual issues which comes up frequently for CF patients is
infertility. This information should be imparted to the males before the age of 19 years; about 16 years of age was deemed appropriate by most.

Further recommendations which evolved from the research results are discussed below with reference to each of the major recommendations made by the CF respondents.

1. Address sexual issues with patients in the pediatric CF clinic, between 13 and 18 years of age.

   Different questions will be appropriate at each developmental stage: pubescence (the two years prior to puberty, which may occur in the teen years since puberty in CF patients may be delayed), puberty (point of sexual maturity), postpubescence, and later adolescence. The course of the discussion of sexual issues will vary greatly from person to person. Also, the same issues may be discussed in more detail and with a different focus as a person grows through the teen years into adulthood.

2. Give adults attending the CF clinic the opportunity to discuss sexual concerns.

   Find out what sexual concerns they have that health professionals in the CF clinic might be able to help with. It is often the case that these sexual problems can be alleviated by open discussion and the provision of information. As an adult, the CF patient may have sexual concerns about how he/she relates sexually to his/her partner. It is wise to include the patient's sexual partner in discussions about sex whenever possible, because the partner's understanding and cooperation are crucial. One format of general questions which elicit information about sexual
dysfunctions is the "The Glasgow Short Form — Assessment of Sexual Health" (Glasgow, 1986). As a result of this study, this form has been recommended to the B.C. Adult CF Clinic staff to provide some guidelines in this area.

3. Men suggested that males be told about the infertility issue by the pediatric or adult physician.

This topic is one that would be most appropriately discussed by caregivers in the CF clinic, since they have the specialized information about the implications of cystic fibrosis. Clinic health professionals should discuss this issue and the results of the study in more detail amongst themselves (cf. Figures 12, 13, 14, and 15), and decide who will take responsibility for dealing consistently with these important issues.

CONCLUSIONS

In conclusion, cystic fibrosis does have an effect on a person's sexuality. People are affected differently, and concerns range from fertility issues to the impact of a potentially limited lifespan. CF adults report sexual behaviour similar to that in the general population, and the percentages of CF adults experiencing sexual difficulties also appear to be similar when compared.

Further research could gain more in-depth information about the aspects of sexuality described in the sexual profile of CF adults, which was based on the questionnaire data. It is suggested that for more detailed research, time and budget permitting, personal interviews with the patients would be a useful form of gathering data.
There is a need for further research with patients having other chronic illnesses to find out about the impact of other diseases on sexuality, and to begin to address sexual issues and concerns for other patient groups as well.

It is important for health professionals to give serious consideration to the sexuality and sexual concerns of each of their patients. For the person with a chronic illness, sexuality is not a luxury to be attended to only after all other needs have been met; rather, it may be a central element in achieving a good level of health.
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APPENDICES

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<tr>
<td>100</td>
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<td>101</td>
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<td>E. Additional Tables</td>
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<tr>
<td>122</td>
<td>Table 17</td>
</tr>
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</table>
Hello!

This is a note to remind you about the "Sexual Concerns Questionnaire for Adults with Cystic Fibrosis" which you recently received in the mail. A number of questionnaires have been returned, but a number remain outstanding. The more questionnaires that are returned, the more accurate will be the information gleaned. Therefore, if you had set aside the questionnaire, please do complete and return it now.

In the event that you have misplaced the questionnaire, I am sending along another copy of it with this reminder note.

If you have already completed the questionnaire, please disregard this reminder and dispense with this packet.

I would like to thank each of you very much for your cooperation.

Yours sincerely,

Bianca M.G. Rucker, RN, BScN, MA(Cand.)
SEXUAL CONCERNS QUESTIONNAIRE
FOR MEN WITH CYSTIC FIBROSIS

SECTION I: Please answer these background questions about yourself.

1. Year of birth: ________

2. Place a check beside the highest level of education that you have completed.
   [ ] Grade 8 or below
   [ ] Grade 9 - 11
   [ ] Grade 12
   [ ] Trade or vocational school
   [ ] University (some, but degree not completed)
   [ ] University (Bachelor's degree or higher)

3. a) Are you employed? Yes [ ] No [ ]
   b) How many hours, on average, do you currently work per week?
      ________ hours

4. In what religion were you raised? ___________________________

5. Check which of the following phrases describe your present situation. Check one or more.
   [ ] Living with parents
   [ ] Married or living with partner
   [ ] Separated or divorced
   [ ] Living alone
   [ ] Living with friend(s)
   [ ] Other (please specify): ____________________________

6. How old were you when Cystic Fibrosis was diagnosed?
   ________ years old
7. Number of hospital admissions due to Cystic Fibrosis

In 1986 ___  In 1985 ___  In 1984 ___

8. Are you currently taking any medications? Yes ☐  No ☐
   If so, please list here.

9. Please list any illnesses that you have, other than CF.

SECTION II: Each of the following questions includes a scale of 1 to 4. Please circle the number which best indicates your answer to the question.

1. How much does having Cystic Fibrosis interfere with living your life as you would like to?

   1  2  3  4
   Not at all  A great deal

2. How do you currently feel about yourself as a person?

   1  2  3  4
   Worthless  Worthy & Valuable

3. Indicate how satisfied you feel about each of the following characteristics of yourself.

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</table>
4. a) If you were available, how appealing do you think others would find you as a partner for a date?

1 2 3 4
Not Appealing Very Appealing

b) If you were available, how appealing do you think others would find you as a sexual partner?

1 2 3 4
Not Appealing Very Appealing

5. How important is intimate physical contact (cuddling, stroking, intercourse, fondling, kissing, etc.) in relation to other aspects of your life (such as work)?

1 2 3 4
Not Important Very Important

6. Over the past six months, how great has been your desire for intimate physical contact?

1 2 3 4
No desire A great deal of desire

7. How satisfied are you with the sexual aspect of your life?

1 2 3 4
Very dissatisfied Very satisfied
SECTION III: This section focuses on the sexual aspect of your life. Most of the questions in this section ask you to check the responses that apply to you.

1. Sexual interest (desire for intimate physical contact) may be stimulated by a variety of things around us that help us get into a sexy mood. How does each of the following affect your mood for sex? Circle the appropriate number in each row.

<table>
<thead>
<tr>
<th></th>
<th>Never Experienced</th>
<th>Dislike a Lot</th>
<th>Dislike Somewhat</th>
<th>No Effect at All</th>
<th>Like Somewhat</th>
<th>Like a Lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Erotic movies</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Erotic pictures</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Erotic stories or books</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Romantic setting</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Seeing an appealing person</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Touching an appealing person</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
2. a) How much does CF interfere with the sexual aspect of your life?

1 2 3 4
Not at all Very Much

b) If the sexual aspect of your life is affected by CF, how so? Check all which apply to you.

☐ No effect on my sex life
☐ Easily fatigued
☐ Excessive coughing during sexual relations
☐ Increased dependence on partner due to my illness
☐ Depression over illness
☐ Poor body image
☐ Potentially limited lifespan
☐ Frequent hospitalizations
☐ Other (please specify):

3. There may be other factors which have(had) an upsetting effect on the sexual aspect of your life. Check all which apply to you.

☐ Conflict over religious matters
☐ Finances
☐ Job stress
☐ Fighting & arguing with your partner
☐ Difficulties with children
☐ Difficulties with relatives
☐ Other (please specify):


4. a) Self-stimulation (masturbation) is a form of sexual pleasuring that one can carry out alone. Estimate how frequently you masturbate. Place a number in one of the following three blanks (whichever one applies best to you).

_____ times per week
_____ times per month
_____ times over the past 6 months
_____ never

b) Do you usually achieve a full erection when masturbating?

Yes □ No □

c) Do you usually ejaculate when masturbating?

Yes □ No □

5. Check which one of the following best describes your sexual relationship(s).

□ Sexually active currently with a steady partner

□ Sexually active currently with casual or occasional partners

□ Have no partner currently but have been sexually active in the past

□ Have no partner currently and have never been sexually active

□ Have a partner currently but am not (nor have I been in the past) sexually active
SECTION IV: Please respond to these questions as they relate to your current partner. If you have no partner, respond as the questions apply to your most recent relationship. If the questions do not apply to you at all, then skip them and continue with the next section.

1. Gender of partner(s): male □ female □

2. On each of the following scales, circle the number which indicates how you feel or behave in your relationship with your partner.

   1  2  3  4
   Unloved    Loved

   1  2  3  4
   Not loving Loving

   1  2  3  4
   Insecure Secure

   1  2  3  4
   No affection Great affection

   1  2  3  4
   Share very Share a great little deal

   1  2  3  4
   Poor Communication Good Communication

SECTION V: This section contains questions about sexual activity with others. This questionnaire is being sent to all adults with CF. However, it is expected that this section will not apply to all people. If you have not had sexual intercourse or other forms of stimulation that could lead to climax, then check here , and proceed to Section VI.

1.a) Estimate how frequently, over the past six months, you have had intercourse. Place a number in one of the following three blanks (whichever one applies best to you).

   ____ times per week

   ____ times per month

   ____ times over the past 6 months
b) Check which one of the following phrases best describes your satisfaction with the frequency of intercourse.

- Satisfied
- Would prefer more often
- Would prefer less often

2. Sometimes there is a discrepancy between partners with respect to how often each wishes to engage in sexual activity together. Which one of the following phrases describes your situation?

- Both desire the same frequency of sexual activity
- Partner desires sexual activity less often than you do
- Partner desires sexual activity more often than you do

3.a) Some men ejaculate (come to climax) sooner than they would like to during sexual activity with a partner. They would like to be able to have more control and last longer. Check the one phrase which best describes you.

- Has never been a problem
- Was a problem in the past, but no longer is
- Happens occasionally & doesn't bother me
- Is a minor problem now
- Is a major problem now

b) Some men experience difficulty ejaculating during sexual activity with a partner. They would like to be able to come to climax easier. Check the one phrase which best describes you.

- Has never been a problem
- Was a problem in the past, but no longer is
- Happens occasionally & doesn't bother me
- Is a minor problem now
- Is a major problem now
4.a) Looking back over the past month have you, under any circumstances (for example, on waking in the morning), had an erection which you would consider firm enough to have intercourse?  
Yes □ No □

b) Some men have difficulty getting erections when with a partner. Check the one phrase which best describes you.

□ Has never been a problem
□ Was a problem in the past, but no longer is
□ Happens occasionally & doesn't bother me
□ Is a minor problem now
□ Is a major problem now

c) Some men have erections when with a partner, but lose their erections when they are about to have intercourse. On a scale of 1 to 4, indicate how frequently this has happened to you (over the past few months).


SECTION VI: Please answer the following questions about reproduction.

1.a) Most CF males, although not impotent (inability to have an erection), are infertile (inability to father children). How old were you when you found out that most CF males are infertile? _____ years

b) How did you find out? Check one.

□ From parents
□ From physician in pediatric CF clinic
□ From physician in adult CF clinic
□ From a CF pamphlet
□ Other (please specify): _____________________
c) How did you feel/respond when you found out about your infertility?

________________________________________________________________________

2. Ideally, at what age do you think the fertility issue should be discussed with CF males? Check one.

☐ Before age 16
☐ 16 - 18 years
☐ 19 - 25 years
☐ After age 25
☐ Only when they ask

3. What do you think would be the best way for CF men to find out about infertility? Check one.

☐ From parents
☐ From physician in pediatric CF clinic
☐ From physician in adult CF clinic
☐ From a CF pamphlet
☐ Other (please specify):

________________________________________________________________________

4. If you had had a choice at the time would you have preferred talking about infertility to a health professional who was:

☐ a male     ☐ a female     ☐ wouldn't matter

5.a) How many children do you have? ____

b) If you do have children, how many of them are:

_____ your own natural children
_____ from artificial insemination
_____ adopted
_____ step-children
### SECTION VII: Please answer the following questions about your sexual concerns.

1. Looking back on your life experiences before age 19, did any of the following things apply to you? Check the appropriate columns.

<table>
<thead>
<tr>
<th>Before Age 19</th>
<th>Is this still a problem?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td><strong>Being overprotected by parents</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Being isolated from friends because of limitations of CF</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Being sexually abused</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Worried about being sexually inexperienced</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Worried about odour of genitals</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Worried about size of genitals</strong></td>
<td></td>
</tr>
</tbody>
</table>

2. With whom do you discuss sexual issues? Check as many as you wish.

- [ ] No one
- [ ] Parents
- [ ] Partner
- [ ] Certain friends
- [ ] Family doctor
- [ ] Counsellor or therapist
- [ ] Minister
- [ ] Other (please specify): ________________________
3.a) At what age would you have liked to have had sexual issues discussed in the CF clinic? Check one.

- [ ] 10 - 12 years
- [ ] 13 - 15 years
- [ ] 16 - 18 years
- [ ] After 18 years
- [ ] Not appropriate for discussion in the CF clinic
- [ ] Did discuss sexual issues in the CF clinic

b) Check factors, if any, which have inhibited your discussion of sexual issues at the CF clinic. Check as many as apply to you.

- [ ] There were no inhibitions
- [ ] Parents present
- [ ] Not comfortable with clinic staff
- [ ] General embarrassment about sex
- [ ] No one brought up sexual issues, so I didn't either
- [ ] Other (please specify): __________________________

_______________________________

_______________________________

_______________________________
4. Is there anything that the CF clinic could offer to help you deal with sexual issues? Check as many as you wish.

☐ Sexual concerns questionnaire given to patients when they first start attending the adult clinic

☐ Discussion of sexual issues by physician

☐ Discussion of sexual issues by nurse

☐ Discussion of sexual issues by social worker

☐ Discussion of sexual issues by clinic psychiatrist

☐ Referral to sexual counsellor when needed

☐ Recommended reading of commonly available self-help books such as For Each Other (by Lonnie Barbach) and Male Sexuality (by Bernie Zilbergeld)

☐ Other (please specify): __________________________

________________________________________

5. Please list here any of your sexual concerns that you feel have not been addressed in the preceding questions.

________________________________________

________________________________________

________________________________________

________________________________________
6.a) Have you ever discussed sexual problems with a sexual counsellor/therapist?
   Yes □   No □

6.b) Would you use such a service if it were available and you were having sexual problems?
   Yes □   No □

Thank-you very much for your cooperation in responding to these questions. Please add any general comments about the questionnaire here.
Questions that were different on the women's questionnaire.

SECTION III:

4. b) During masturbation does vaginal wetness develop?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never</td>
<td></td>
<td></td>
<td>Always</td>
</tr>
</tbody>
</table>

c) Do you have an orgasm when you masturbate?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never</td>
<td></td>
<td></td>
<td>Always</td>
</tr>
</tbody>
</table>

SECTION V:

3. Women's experiences with having orgasms are quite varied. Check all which apply to you.

- [ ] Never had an orgasm
- [ ] Had orgasms in the past, but not now
- [ ] Have orgasms by masturbation
- [ ] Have orgasms by partner's stimulation other than intercourse
- [ ] Have orgasms during intercourse
2.a) Cystic Fibrosis affects the fertility of many CF women. When do you think the fertility issue should be discussed with women in the CF clinic? Check one.

- [ ] Before age 16
- [ ] 16 - 18 years
- [ ] 19 - 25 years
- [ ] After age 25
- [ ] Only when they ask

b) If you had a choice, would you prefer talking about infertility to a health professional who was:

- [ ] a male
- [ ] a female
- [ ] wouldn’t matter

3. Birth control may be an important issue for CF women. Put checks in the appropriate columns below to indicate methods of birth control that you use(d).

<table>
<thead>
<tr>
<th>Method</th>
<th>Used in past</th>
<th>Use now</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pill</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I.U.D.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diaphragm &amp; jelly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Condom</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spermicidal Foam</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rhythm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sterilization</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No birth control</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4.a) Some women experience pain during intercourse. Check the one phrase which best describes you.

- [ ] Has never been a problem
- [ ] Was a problem in the past, but no longer is
- [ ] Happens occasionally & doesn't bother me
- [ ] Is a minor problem now
- [ ] Is a major problem now

b) Do you require additional lubricant (such as saliva or KY Jelly) during intercourse?

- [ ] Always
- [ ] Sometimes
- [ ] Never

SECTION VI: Please answer the following questions about reproduction.

1. Fertility, pregnancy, and childbirth are important issues for CF women. Indicate on the scale provided, the amount of concern you have experienced about each of the following issues.

<table>
<thead>
<tr>
<th>Fertility (the ability to get pregnant)</th>
<th>1 No concern</th>
<th>2</th>
<th>3</th>
<th>4 Great concern</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effectiveness and safety of birth control (considering CF)</td>
<td>1 No concern</td>
<td>2</td>
<td>3</td>
<td>4 Great concern</td>
</tr>
<tr>
<td>Ability to carry pregnancy without adverse effects to your health</td>
<td>1 No concern</td>
<td>2</td>
<td>3</td>
<td>4 Great concern</td>
</tr>
<tr>
<td>Ability to bear a healthy child</td>
<td>1 No concern</td>
<td>2</td>
<td>3</td>
<td>4 Great concern</td>
</tr>
<tr>
<td>Passing on a CF gene to your child</td>
<td>1 No concern</td>
<td>2</td>
<td>3</td>
<td>4 Great concern</td>
</tr>
</tbody>
</table>
4. The experience of pregnancy and childbirth can cause difficulties for women with CF. Please describe your experience by answering the following questions.

a) Have you ever been pregnant?  Yes  ☐  No  ☐

b) Did you continue the pregnancy to childbirth?  
   Yes  ☐  No  ☐

c) If no, did you:  ☐ miscarry
   ☐ end pregnancy because of your CF
   ☐ end pregnancy for other reasons

d) If you continued your pregnancy to childbirth, did you experience any complications for yourself or the baby? If so, please list briefly.

..........................................................
..........................................................
..........................................................

5. a) How many children do you have?  ____

b) If you do have children, how many of them are:
   ____ your own natural children
   ____ from artificial insemination
   ____ adopted
   ____ step-children
Appendix E.

Table 16

Breakdown of Respondents According to Severity with Male/Female Ratio Given for Each Category

<table>
<thead>
<tr>
<th>Degree of Severity</th>
<th>Proportion of Sample</th>
<th>Male/Female Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>22.6%</td>
<td>3 men / 4 women</td>
</tr>
<tr>
<td>Moderate</td>
<td>38.7%</td>
<td>5 men / 7 women</td>
</tr>
<tr>
<td>Severe</td>
<td>19.4%</td>
<td>4 men / 2 women</td>
</tr>
<tr>
<td>Very Severe</td>
<td>9.7%</td>
<td>1 men / 2 women</td>
</tr>
<tr>
<td>Extremely Severe</td>
<td>9.7%</td>
<td>3 men / 0 women</td>
</tr>
</tbody>
</table>
Table 17

Ways in Which CF has an Impact on Sex Life

<table>
<thead>
<tr>
<th>Item</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Potentially limited lifespan</td>
<td>14</td>
<td>45%</td>
</tr>
<tr>
<td>Excessive coughing during sexual relations</td>
<td>12</td>
<td>39%</td>
</tr>
<tr>
<td>Poor body image</td>
<td>9</td>
<td>29%</td>
</tr>
<tr>
<td>Easily fatigued</td>
<td>8</td>
<td>26%</td>
</tr>
<tr>
<td>Depression over illness</td>
<td>8</td>
<td>26%</td>
</tr>
<tr>
<td>Increased dependence on partner due to illness</td>
<td>7</td>
<td>23%</td>
</tr>
<tr>
<td>Frequent hospitalizations</td>
<td>4</td>
<td>13%</td>
</tr>
<tr>
<td>No Effect</td>
<td>7</td>
<td>23%</td>
</tr>
<tr>
<td>Others</td>
<td>9</td>
<td>29%</td>
</tr>
</tbody>
</table>