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DELINFEATION OF ELEMENTS OF A SEXUALITY PROGRAM FOR INDIVIDUALS WITH MULTIPLE SCLEROSIS THROUGH A NEEDS ASSESSMENT

The Ohio State University

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DELINEATION OF ELEMENTS OF A SEXUALITY PROGRAM
FOR INDIVIDUALS WITH MULTIPLE SCLEROSIS
THROUGH A NEEDS ASSESSMENT

DISSERTATION

Presented in Partial Fulfillment of the Requirements for
the Degree Doctor of Philosophy in the Graduate
School of The Ohio State University

by

Ann Engelhardt Teske, R.N., B.S., M.A.

The Ohio State University
1980

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Educational Foundations and Research
To my dear friend, Susan McClaskey, to the individuals who so readily agreed to participate in this study, and to the half million Americans who face their future encumbered with multiple sclerosis. It is hoped that studies such as this one will assist these people to understand themselves and their disease, and to encourage health professionals to provide necessary services.
ACKNOWLEDGMENTS

The author wishes to express her appreciation to the individuals whose contributions were instrumental in the development and completion of this dissertation. I particularly want to thank my adviser, Dr. James K. Duncan, and committee members, Dr. D. Alexander Severino and Dr. Gary G. deVoss who gave so generously of their time, expertise, and warm encouragement. The support and interest from the faculty of Educational Foundations and Research has also been appreciated.

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Finally, I thank God who has given me strength when I needed it most.
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CHAPTER I
INTRODUCTION

Health professionals are being urged to accept sexuality as an integral dimension of man as a bio-psycho-social being and thus, will have a responsibility to promote sexual health in their total health practice. Masters and Johnson (Masters, 1977) have estimated that 50 percent of married couples in the United States are experiencing some degree of sexual dysfunction resulting in emotional and/or physical stress. It is unrealistic, then, to believe that an individual with a physical illness or disability does not experience some disruption in his/her sexual functioning. Trieschmann has pointed out that:

...most disabilities do not necessarily affect the sex drive any more than they would affect hunger or thirst. The disability may influence the type of sex acts which would be feasible or advisable, but few disabilities preclude all sex acts. (Meyer, 1976:212)

Sexual expression is a potential for all individuals and not a privilege for the young, attractive, and healthy.

No matter how incapacitated or deformed a patient may be...he or she never ceases to be a sexual being--with the same longings, expectations, and needs as the rest of us. (Golden, 1976:83)

Because disabled persons are not neutered, it is important for
their self-esteem to be able to express themselves sexually. There are numerous modes for sexual expression which can be satisfying and fulfilling when vaginal or anal intercourse is no longer a possibility.

With these concepts in mind, it is imperative that patients understand how their disease process(es), surgery(ies), treatment(s), and medication(s) may affect their sexual functioning. Patients should be discouraged from assuming that their reduced sexual functioning is due to personal deficiencies which results in lowered self-esteem. Rather, they should be encouraged to explore with health professionals alternative procedures and medications which are less damaging to their sexual functioning. In addition, they should be told that the most important factor in the development or continuance of sexual activities is a willing and able sexual partner (Jacobson, 197*51).

Sexual functioning, however, is only one facet of the holistic concept of sexuality. Sexuality has been defined by Miller as:

...maleness or femaleness to which each of us is born. It is the essence of each of us, the unique creative drive that makes each of us an individual of worth; it is the central force that controls our actions—both consciously and subconsciously. (Miller, 1976:21-22)

Sexuality, thus, encompasses body image, self-concept/self-esteem, sexual identity, and social/sexual roles. Alterations in body functioning can result in alterations in other facets of sexuality.
Since sexuality permeates and influences all segments of an individual's life, sexual health becomes a major part of an individual's total health. The integration of sexual health into total health care is relatively recent; thus, the concept of sexual health is in its early stages of development. Five factors are proposed as being necessary for bringing about sexual health. These are:

1. The individual must have a positive self-image or self-concept which includes a positive sexual identity.
   a. There must be congruence between sexual identity and sexual assignment.
   b. Sexual orientation must be satisfying and acceptable to the individual.
   c. Social/sexual roles must be fulfilling and congruent with sexual identity.

2. The individual requires some knowledge about his/her body to gain some degree of control over body functioning.
   a. This requires knowledge of basic human anatomy and physiology of oneself and of the opposite sex.
   b. This would also include knowledge of how alterations in one's body can result in alterations in body functioning and in one's self-image.
   c. Knowledge of the body will assist the individual in gaining some degree of control over body functioning: i.e. fertility/sterility, sexual functioning, elimination.

3. A clarification of values must take place, which enable logical and ethical choices to be made in lifestyle, behavior, and social roles.

4. The ability to clearly and effectively communicate sexual wants and needs is necessary.
5. The individual should have a feeling of freedom to choose intimate partner(s) of either sex; to have a relationship which is not coercive or harmful mentally or physically, to either partner, but which is positive, creative, and satisfying. (Teske, 1979)

These factors reflect contemporary Western thoughts and include a mixture of white, middle-class, Protestant concepts, since this is the author's orientation. It should be noted, that each of these five factors for attaining sexual health can be affected by alterations in body functioning such as those brought about by illness and/or disability.

Curriculum Development Model for Sexuality Education for Individuals Experiencing Illness or Disability

Since human sexuality is an emotional and value-laden subject, it is unrealistic to expect educators to be able to design a "standardized" curriculum which would be relevant and interesting to persons who are ill or disabled. As each individual is unique, so are his/her educational needs. Therefore, a curriculum development model which focuses on the potential learner would appear to be of merit. Such a model has been proposed by the author to be used as a framework for designing, implementing and evaluating patient education programs in sexuality. It was designed to be used with patients who experience medical, surgical, and/or chemical alterations which result in alterations in self-identity, body image changes, and/or sexual dysfunction. Not included are patients who experience psychosomatic and/or psychiatric disturbances. This proposed model may be applicable to these latter patient groups,
but the author is not knowledgeable enough in these disorders to make a determination.

The curriculum development model involves eight inter-related steps as portrayed in Figure 1.1. Each step should receive a formative evaluation as it is developed in consultation with the patient. Formative evaluations are prospective, in that they provide timely feedback to assist in the development of the educational program. Such feedback assures that the program will remain "open" and fluid to meet the evolving needs of the patient. It also assists the health professional in evaluating each stage's effectiveness and efficiency for the individual who is ill or disabled.

The summative evaluation, on the other hand, is retrospective. It is an evaluation of the completed program with fewer time constraints than the formative evaluations. It should include all of the empirical and subjective data collected in the formative evaluations and the value judgments based on this data as the program is implemented.

It is proposed that a program developer begin with the philosophy of sexual health and sexuality education/counseling and proceed clockwise around the model. The summative evaluation, then, may be regarded as the final step or as the first step in continuing through the cycle again.

The philosophy of sexual health and sexuality education/counseling will be delineated by the institution which is sponsoring the program, while the sexual assessment of educational needs
Figure 1.1. A Curriculum Development Model for Patient Education in Sexuality
reflects value judgments by the patient and the health staff within
the context of this philosophy. Value judgments by the staff are
reflected by the type of questions asked the patient and by the
physical assessment, since value-free patient education/counseling
is not an objective of this program.

The aims and objectives are a narrowing of goals from the
grandiose philosophy. The specific learning objectives are, in turn,
more specific than the aims. They are the immediate outcomes which
are planned for the learner. The learning objectives designate
the functional application of the philosophy of sexual health and
sexuality education/counseling. These relationships can be
described as resembling an hourglass. Refer to Figure 1.2.
The hourglass shape suggests that there is more latitude for choice
in some parts of the curriculum development process than in others.

The learning objectives and the content selection occupy
similar space. They are equivalent due to the fact that, in this
model, content selection is directly related and contingent upon
learning objectives.

The learning experiences occupy more space since there
can be a multitude of experiences possible for any one learning
objective and content. Implementation is broader still as each
teacher/counselor will adapt the instructional process to meet
the individual needs of the learner(s) and with regard to his/her
own abilities and creativity. Evaluation continues to widen since
evaluation procedures are numerous and vary with the purpose(s)
Figure 1.2. Relationships of Curriculum Development Steps
of the evaluation.

When all of these steps have been completed, it is time for the cycle to begin again. Curriculum development is a continuous process based on new inputs of knowledge, technology, and philosophies; and is based on the unique needs and wants of individuals.

**Importance of Needs Assessment in Sexuality Education/Counseling**

The needs assessment segment of this and other similar models of curriculum development is essential but often overlooked. Even the multidisciplinary approaches to designing patient education programs usually refer to a group of health professionals who plan educational programs based on their expertise (combination of objective and subjective), the sexuality literature, and opinions from other health professionals. Rarely are the patients themselves consulted.

Patients can provide vital information by responding to the following kinds of questions.

1. **What** knowledges are most important to individuals who must cope with chronic illness and/or disability to assist them in their adaptation?
2. **How** would they want the educational material provided for them?
3. **When** would they feel the most benefit from this knowledge: soon after diagnosis, later in hospital
stay, or after they return home?

Until these questions are answered, it is unlikely that any sexuality education/counseling program will adequately meet the educational needs of these persons.

The assessment must include the needs as perceived by patients as well as needs prescribed by health professionals (Kunstel, 1978:222). Until now, the focus has been on prescriptive needs. It is time to focus on perceived needs of patients. These perceived needs of individuals and groups of patients can then be integrated with prescriptive needs to form comprehensive educational programs.

**Statement of the Problem**

The traditional approach to curriculum development by health professionals has involved one or more such professionals developing and implementing programs which were subjectively felt to address patients' needs. Rarely are patients asked what they perceived their educational needs to be and what would constitute a relevant educational program response for them.

Only fifteen articles have been found in health journals published during the past ten years* which have described patient education programs in sexuality. All of these articles concluded that their programs were beneficial to patients and family members.

The two populations which have been concentrated upon are the spinal cord injured, and, to a lesser extent, individuals with cardiovascular disease. The literature is only peripherally concerned with other groups such as disabled women, persons with strokes, or persons with congenital disorders (Bardach, 1978:510). Little is written about sexual problems of people who must cope with arthritis, emphysema, cancer, kidney disorders, multiple sclerosis, and chronic pain.

Mary Calderone, founder of Sex Information and Education Council of the United States (SIECUS), has stated that the emphasis on the educational program for any group of persons, no matter what their age or health, must meet needs that exist, rather than relying on "telling people what needs they may not have while meeting needs that are often arbitrarily decided they ought to have" (Rosenzweig and Pearsall, 1978:18).

The educational needs of individuals can be obtained from one or all of five sources. These have been outlined by Knowles:

1. from individuals themselves. Most individuals are aware of some of their needs for further development, whether or not they have yet risen to the point of becoming interests (in the sense that he wants to do something about them now).
2. from people in "helping roles" with individuals.
3. from the mass media.
4. from professional literature.
5. from organizational and community surveys.
(Knowles, 1970:91-95)

If time and money prohibit the use of all five sources, it would seem logical and most productive to approach the individuals themselves.
The problem, then, is the lack of active participation by individuals who have illness/disability in the planning, implementation, and evaluation of educational programs for them.

Purpose of the Study

The purpose of this study is to ascertain what knowledges individuals, who are experiencing illness and/or disability, deem most important to their attainment of sexual health, and in what learning environments they would want this information presented. The purpose of this study, also, is to ascertain if these individuals have ever received any sexuality education/counseling; and, if so, to describe it. If they have ever perceived a sexuality problem, whether or not they have received any sexuality education or counseling; and, if so, how effective this assistance was, will also be explored by this study. Any trends in educational needs which are related to demographic data will also be noted. Finally, from the data gathered during this study, elements of an educational program in sexuality for persons who are ill/handicapped will be proposed.

Objectives of the Study

1. To construct, and have professionally screened, a listing of knowledges and attitudes about sexuality and illness/disability which relate to the attainment of sexual health.

2. To ascertain those knowledges and attitudes which a sample of individuals with multiple sclerosis deem most essential to their attainment of sexual health.
3. To ascertain which types of learning experiences a sample of individuals with multiple sclerosis deem most beneficial.

4. To ascertain if the individual has received sexuality education/counseling with regard to his/her illness(es) and/or disability(ies); and, if so, the extent and nature of such intervention and its effectiveness.

5. To ascertain if the individual has perceived a sexuality problem or concern; and, if so, to whom did they turn for help, what type of help was received, and how effective and satisfactory was this assistance in meeting their defined needs.

6. To relate the findings in objective #2 with personal data of the individual including: age, sex, length of time since diagnosis, severity of disability, formal education, occupational status, religion, cultural background, and whether single or in a partner relationship.

7. To propose elements of an educational/counseling program in human sexuality for individuals with multiple sclerosis.

**Significance of the Study**

With few exceptions, curriculum development models have provided for an educational needs assessment as one of the first steps in designing curriculum programs. Examples of such models include those by: Tyler (Tyler, 1950:7-11), Taba (Molnar and Zahorik, Ed., 1977:3), Severino (Severino, 1976: unpublished), Clegg (Orlosky and Smith, 1978:108) and Saylor and Alexander (Saylor and Alexander, 1966:254-256).
The needs assessment should be holistic in that it provides guidance in planning for all subsequent steps of curriculum development. Molnar and Zahorik indicate that sources for obtaining learning objectives are the individual learner, contemporary life outside the school, and subject specialists (Orlosky and Smith, 1978:2). With regard to the learner, they specify three areas of examination of educational needs.

1. Identify the difference between the present condition of the learner and the acceptable norm.

2. Identify the students' interests. If the material interests the learner, he will actively participate and learn.

3. Identify needs that are appropriately met by education, and those which can be properly met through other social agencies.

If these three areas are explored, data collected, and utilized appropriately in designing curriculum, then the resulting learning objectives should be relevant to the learner.

Molnar and Zahorik also focus on the learner when selecting learning experiences. They define a learning experience as an interaction between the learner and the external conditions in the environment to which he can react. "Learning takes place through the active behavior of the student; it is what he does that he learns, not what the teacher does" (Orlosky and Smith, 1978:267).

General principles which Tyler prescribes in selecting learning experiences are:

1. A student must have experiences that give him an opportunity to practice the kind of behavior implied by the objective.
2. Learning experiences must be such that the student obtains satisfactions from carrying on the kind of behavior implied by the objectives.

3. The reactions desired in the experience should be within the range of possibility for the students involved.

4. There are many particular experiences that can be used to attain the same educational objectives.

5. The same learning experience will usually bring about several outcomes. (Tyler, 1950:42-44)

Thus, not only are a learner's interests and deficiencies in knowledge to be ascertained, but also his preferences in learning experiences.

In examining learning patterns, Tyler has set forth a list of conditions of learning. Among these are that the learner must be able to carry on the behavior that he is to learn, and that he must find the learning rewarding. This cannot be brought about unless the learner is motivated to learn and is involved in the process. The learner must then be provided with educational materials which are appropriate to his age, intellectual capacities, and cognitive style (Orlosky and Smith, 1978:45-46). The learner is seen as a complete person; with feelings about what he learns, his intuitive reactions to it, and ways in which learning fits into his purposes in life. Bridges also contends that for humanistic education, the learner must have freedom to learn what he needs to know, and to do it in his own way (Orlosky and Smith, 1978:71-72). Thus, the learner's needs and learning processes are allowed to help define the subject matter and learning environment.

To achieve education which focuses on the learner, an educational needs assessment is fundamental. In preparing for
educational programs in sexuality for individuals who experience illness and/or disability, thorough needs assessments are required. The review of the literature in the next chapter will point out the absence of these assessments for the ill/handicapped person.

Procedures

A random sample of thirty participants was obtained from the Multiple Sclerosis Society Mid-Ohio Chapter. Each participant was not hospitalized at the time of the study, resided within Franklin County, and had agreed to be included in this study on a voluntary basis. Prior to the formal study, a pilot study of three individuals was obtained.

Each potential participant, whose name was drawn from the Multiple Sclerosis (MS) Society records of approximately 400 individuals, by use of a table of random numbers, was mailed a letter on MS Society stationery which described the study, who the researcher was, and what the potential participant would gain by assisting with this project.

Within a week after receiving the letter, each potential participant received a telephone call. During this call, the individual was introduced to the author, the purpose and conduct of the study was briefly reviewed, the willingness to participate was noted, and an interview was scheduled if appropriate.

All interviews were conducted by the author. Each interview lasted approximately one to three hours at the place and time agreed upon during the telephone call. Following the introductions,
the interviewer reviewed the purpose of the study, how the data could be used to design patient-centered educational programs, and expressed appreciation for participation.

The interview was conducted in the following manner. No participant was forced to provide information that he/she did not want to provide or felt uncomfortable about discussing. All information gained through the interview was kept confidential. The interviewer read each question and recorded the participant's answer to all four instruments used. This eliminated problems with eyesight and hand coordination of participants. At any time during the interview, the participant was free to ask any questions.

Participation or nonparticipation in the study did not affect services provided by the MS Society as no one at the MS Society knew who was included in the list of random names. When all of the above information was explained to the participant, a consent form was signed. (Refer to Appendix C.)

At the closing of the interview, the participant was asked if he/she had any questions and was thanked for his/her contribution to the study. Upon completion of the study, each participant received a short summary of the study by mail.

The four instruments included a Q Sort of possible questions to be answered by an educational program about sexuality and multiple sclerosis. Each participant was asked to identify which of these questions were (1) very important, (2) moderately important, (3) less important, or (4) not important in meeting his/her own wants and needs.
The second instrument consisted of questions about preferred learning experiences. The components of learning experiences which were explored were resource persons, educational materials, organization of the program, general atmosphere, and which topics are better handled individually or in small groups. The respondent was also asked who would most benefit from such a program.

The third instrument explored whether the individual had ever received sexuality education/counseling; and, if so, to describe it. The respondent was then asked to rate how effective and satisfactory this assistance was to him/her, and what recommendations he/she could make to make such assistance more beneficial to others. The participant was also asked if he/she had perceived a sexuality problem or concern; and, if so, to describe it (them), and to indicate any relationship to their illness or disability.

The last instrument asked for demographic data which was used to note any relationships between perceived educational needs from the Q Sort and personal characteristics.

In conclusion, the conduct of the study was by interview which included both open and structured questions for the participant to answer regarding his/her sexuality as affected by multiple sclerosis. The individual was able to present his/her perceived educational needs for obtaining sexual health, to describe any assistance received and its effectiveness, and to describe what type of learning experience would be most helpful.
Definition of Terms

The following words and phrases are defined as they were used in this study.

Curriculum—The sum total of experiences, methods, procedures, people, and things which are used in changing learner behaviors. It includes a series of educational decisions which determine the goals, objectives, content, methodology, and scope of all educational activities relating to achieving validated learner growth and achievement, including skills, knowledge, and attitudes (English and Kaufman, 1975:64).

Disability—Signifies loss of function whether cognitive, emotional, or physical (Teske).

Educational need—The discrepancy between what an individual wants himself to be and what he is; the distance between an aspiration and a reality (Knowles, 1970:86).

Illness—Lack of health in body or mind; sickness; disease (Teske).

Interview—A specialized pattern of verbal interaction initiated for a specific purpose, and focused on some specific content area, with consequent elimination of extraneous material. Moreover, it is a pattern of interaction in which the role relationship of interviewer and respondent is highly specialized, its specific characteristics depending somewhat on the purpose and character of the interview (Kahn and Cannell, 1958:16).
Needs assessment—The formal process for identifying outcome gaps between current results and desired results, placing those "gaps" in priority order, and selecting the gaps of highest priority for closure. It is, then, an outcome gap analysis plus the placing of priorities among the needs (English and Kaufman, 1975:64).

Normal sexual behavior—Whatever is pleasurable and gratifying for a single person without a partner or for both participants in a couple relationship as long as there is communication and mutual participation without coercion (Teske).

Normalization—Utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are culturally normative as possible (Flynn and Sha'Ked, 1977:34).

Self-esteem—Belief in oneself; self-respect (Teske).

Sexual dysfunction—Sexual functioning that is less than satisfactory for one or both members of a couple or for a single person without a partner (Teske).

Sexual health—Part of the total health, and applies to more than the sexual functioning of individuals, but also to their self-concept and self-identity as males and females. The capacity to love oneself and others, where there is mutual giving, respect, and trust, with or without sexual intercourse. It is the attainment of personal integrity (Gendel, 1974:358-359).

Sexual identity—The image of the self as a male or a female, and the convictions about what membership in that group
implies...includes beliefs about how one ought to think, act, and feel by virtue of having been born male or female. It includes learned ideals of masculine and feminine behavior and the proper authority relationships between the sexes (Yorburg, 1975:1).

Sexuality--maleness or femaleness to which each of us is born. It is the essence of each of us, the unique creative drive that makes each of us an individual of worth; it is the central force that controls our actions--both consciously and subconsciously (Miller, 1976:21-22).

Sexuality education--The teaching and learning about human sexuality in oneself and in others in order to use it toward the greatest creativity and fulfillment (Teske).
CHAPTER II
REVIEW OF RELATED LITERATURE

This chapter is divided into four sections. The theoretical framework for sexual health and sexuality education/counseling will precede a review of the literature. In the review of the literature, individual perceived educational needs assessments will be examined from literature on patient education programs in general, from literature on sexuality educational programs, and from specific sexuality needs assessments.

Theoretical Framework

There are seven basic human needs defined by Byrne and Thompson. These are conceptualized in the following illustration (Byrne and Thompson, 1972:11). Of these seven, sex is included. "Survival of the species is dependent upon reproduction; therefore, the sex need is universal" (Byrne and Thompson, 1972:11).

All of the above needs are culturally modified; and, therefore, the nature of intensity of these needs varies from culture to culture and from individual to individual. The individual decides for himself/herself the hierarchy of his/her needs. For instance, the need for affiliation and for sex may be given priority over rest, food, and fluid. In any event,
the sex drive is one of the primary forces in the human personality, whether or not the individual is handicapped.

Health sexuality stems from the integration of the somatic, emotional, intellectual, social, and ethical aspects of sexual being. Sexuality which is healthy should enhance the development of personality, interpersonal relationships, and love (Lief, 1976:35).

For most persons, there is a clear relationship between sexuality and self-esteem. Therefore,
...a physical disability which encroaches upon self-esteem could be expected to have an impact upon the individual's sexuality and vice versa. As disabilities limit the individual's performance, they may also limit his comfort to deal with himself or with others. To the extent that comfort is lacking, anxiety may emerge which may create new sexual dysfunctions. (Cole and Cole, 1977:526)

Self-esteem may be affected not only by physical disabilities, but also by altered body image due to surgery or chemical alterations which result in sexual dysfunction. Lowered self-esteem may compound existing problems of sexual functioning by decreasing comfort levels and increasing anxiety, which may in turn lead to new sexual dysfunctions. These relationships can be conceptualized in a downward spiral which may ultimately lead to total sexual nonfunction and very poor self-esteem.

![Diagram of relationships between sexuality and self-esteem](image)

Figure 2.2. Relationship Between Sexuality and Self-Esteem when Medical, Surgical, and Chemical Alterations are Present.
Cole and Cole point out that many patients invest a great deal of energy in protecting their ego from the risks of feeling inadequate and rejected.

To the extent that a patient and the sexual partner can come to a better understanding of the nature of their own sexualities, as influenced by the disability, less energy has to be invested in maintaining a layer of insulation between feelings and outward behaviors of the patient and his sexual partner. (Cole and Cole, 1977: 526)

This energy can then be directed toward a positive relationship with self and with others.

A contributing factor in the decrease in self-esteem is ignorance. Cole (1972) developed a schematic cycle of ignorance to explain how ignorance is passed from generation to generation. Part of his cycle is applicable to this discussion. Myths and taboos which are not corrected result in misinformation and distortion of facts. This, in turn, can lead to ignorance, anxiety, dysfunction, and partner conflict (Glass and Padrone, 1978:44).

![Schematic Cycle of Ignorance](image)

Figure 2.3. Schematic Cycle of Ignorance
Individuals with illness and/or disability and their families are often so overwhelmed by the alterations in body and in self-image, that they are not able to even formulate questions to assist in a healthy adaptation. It is the responsibility of health professionals to raise the questions to assist the disabled or ill person and his/her family in finding suitable answers and coping mechanisms.

Questions and concerns raised by patients and their families are indicative of educational needs. Educational needs are, in part, defined by the individual for himself/herself. Knowles' definition of educational need (Knowles, 1970:86) can be represented in this way, for persons who are ill or disabled who are striving to attain

\[ \text{Desired Level of Sexual Health} \]
\[ \uparrow \]
\[ \text{Perceived Educational Need} \]
\[ \downarrow \]
\[ \text{Present Level of Sexual Health} \]

Figure 2.4. Schematic Definition of Educational Need

sexual health. The more concretely an individual can identify his/her aspirations and assess his/her present level of competencies in relation to these aspirations, the more distinctly he/she can define his/her educational needs.

In order to provide relevant information for the individual experiencing illness and/or disability and for his/her family members, a thorough assessment of educational needs and wants is essential. A thorough assessment includes not only those needs
felt to be present by the health professional (prescribed needs),
but also those perceived by the individual for whom an educational
program is planned. Instruction which is responsive to these
perceived needs has been termed "IRI" or individually responsive
instruction.

It differs from other similar sounding notions
such as IPI (Individually Prescribed Instruction)
in that the learner is a partner in determining
not only how learning should take place but is
also a partner in determining what should be
learned as well. This differs from the
providing of a relatively "authoritarian"
prescription...to learners by the teacher/educator. Individually Responsive Instruction (IRI) can best be derived from an individually
responsive procedure of harvesting individual
characteristics, desires, values, requirements,
and learning, and developmental, emotional, and
survival needs; that is, from a needs assess­
ment which formally dignifies each individual
learner as a unique individual human being,
and documents and formally lists these charac­
teristics and requirements. (English and
Kaufman, 1975:52)

According to Kaufman, a needs assessment must have at least
three characteristics:

1. The data must represent the actual world of
learners and related people both as it exists
now, and as it will, could, and should exist
in the future.

2. No needs determination is final and complete.
We must realize that any statement of needs is
in fact tentative, and we should constantly
question the validity of our needs assessments.

3. The discrepancies should be identified in terms
of products or actual behavior ends, not in
terms of processes or means. (Kaufman, 1972:29)
This type of assessment which focuses on the learner and his/her perceived needs can lead to the development of individually responsive instruction.

Finally, the concept of "need" should be examined in greater depth. Smith and Ennis provide a thorough discussion of different types of prescriptive and motivational "needs" (Smith and Ennis, 1961:24-42). Some of the needs discussed are applicable to individuals who are coping with illness and/or disability. Such an individual may have different types of needs. "Need" may refer to that which is considered necessity: such as positive self-image in order to achieve mental health. "Need" may also refer to that which is considered a deficiency: such as lacking information in order to perform in a certain manner. Also "need" may refer to motives or wants: such as for companionship.

In order to provide individually responsive instruction to aid the individual with illness/disability in achieving sexual health, an assessment of educational needs as perceived by the individual should take place. These needs may be necessities, deficiencies, and/or motives. The assessment should be as objective and comprehensive as possible. A needs assessment must also be considered temporary since needs will change over time.

With this theoretical framework in mind, the literature was searched for patient education programs which had included needs assessments.
General Patient Education Programs

A med-line search of literature in February, 1980 revealed 443 articles on patient education programs appearing in the last ten years. The majority of these articles were descriptions of how patient education programs should be developed for a particular population, or for all individuals with chronic illness or disfiguring surgery or trauma. Forty-six articles were examined for their apparent relevance to this study, since they described specific educational programs which were or are presently used with patient populations. Of these forty-six educational programs, only four (Mullen, 1973; Hecht, 1974; Hartings, Pavlou, and Davis, 1976; and Rand, 1978) indicated that patients' needs as perceived by the patients themselves were incorporated into the design and implementation of the program. Eight additional educational programs included patient diagnostic needs assessments through professional opinions and/or by objective pre-tests, but they did not include an assessment of what patients felt they would want to learn about their health.

Of the four educational programs which included individual perceived needs, three programs focused on the individual learner in a one-to-one interaction with a health professional, while the remaining program involved small group interactions. In the latter program, small groups of individuals, who had multiple sclerosis with varying degrees of disability, selected their meeting times and their topics for discussions. The group leaders, from various
health-related disciplines, did not espouse any particular theoretical models or techniques for the group process, but rather provided reading material, audio-visuals, and brief introductory talks.

Hartings, Pavlou, and Davis concluded, after the program had provided for ten multiple sclerosis groups, each meeting from eight to eighteen times, that six common issues appeared particularly amenable to small group intervention. These were:

1. The ambiguity of health status which is often the result of difficulty in early diagnosis.

2. The marginality or borderline phenomenon that persons with minimal degrees of disability who conduct their activities on the border of illness and health.

3. Since MS is usually a progressive disease, the issue of uncertainty of future status is a concern.

The remaining three issues had to do with personal, emotional adjustment to chronic disease with physical disability.

4. Dependency due to disability often requires changes in social roles and often affects family structure. "Sometimes the behavioral capacity can change without accompanying shifts in expectations and self-concept."

5. Shifts in patterns of aggression occur slowly over time. The sick role can provide an acceptable vehicle to avoid guilt and responsibility. Anger is seldom felt to be justified toward someone who is chronically ill. Illness can prevent the normal expression of feelings toward the ill person and from the ill person who may fear abandonment or loss of affection.

6. Sexuality can be altered by disability. The sense of sexual worth can decrease or be lost
when the individual can no longer perform adequately in many aspects of sexual functioning. (Hartings, Pavlou, and Davis, 1976:68-73)

This last topic was often "treated symbolically" in groups by steering clear of overt sexual issues. Where there had been a loss of sexual function, some of the participants sought out staff members individually for assistance.

The three programs which focused on a one-to-one interaction of the patient with one or more health professionals employed interviews which obtained demographic data, current knowledge about health/disease, attitudes and values, and educational needs. One of these studies, by Mullen, entailed a series of observations and interviews with patients suffering myocardial infarctions (MI) and with their families. The study was designed to generate clues to patient needs that could be the basis for developing both the process and content of education-information programs for such patients in the future. Mullen sought themes which suggested the nature of the processes by which and the contexts in which the person who experiences an MI must make the transition from perceiving himself/herself as a well person to having a chronic illness. This chronic illness may require a reordering of life's priorities for the patient and for his/her family.

Among the themes Mullen identified were that patients and their families need help in dealing with the cause of heart attacks and in accepting themselves as heart patients. She also found that there was a general need for educational approaches which respect
the patient's sense of timing and readiness to deal with the reality of MI, and the changes he/she is forced to make in lifestyle. Another theme was that patients should have an organized opportunity to receive support and guidance from former patients (Mullen, 1973:670-675). Her conclusion from this study was that an educational program would help to increase the effectiveness of both patients and their families in the total health recovery and risk reduction.

This study was followed a year later in 1974 by Hecht who studied four educational approaches to teaching medication compliance among forty-seven adult tuberculosis patients. Each patient was interviewed by a nurse for demographic data. The control group (n = 17) received no special educational attention. All patients in the remaining three groups received longer interviews which included helping them to understand as much as possible about his/her drugs, reinforcing what he/she already knew, answering questions, and correcting any misinformation. Each of these interviews followed no structured format, nor standardized teaching procedure, but was geared toward the individual patient.

Following the interviews, each patient was visited twice by another nurse at home to measure errors by patient reports, urine tests, and pill counts. Group 2 (n = 12) received no additional instruction during these home visits. Group 3 (n = 12) received instruction during the first home visit. Group 4 (n = 6) was added while the study was in progress. This group of patients received
in-hospital teaching prior to the initial interview as an outpatient and home visits. Thus, group 4 received the most instruction.

Hecht concluded that those patients receiving planned, individual drug instruction committed fewer medication errors at home than patients who did not receive such instruction. Results of the study show that a large improvement in the accuracy with which patients take their medications occurs with increased amounts of instruction.

In 1978, Rand, a physical therapist, also conducted a study using patient's perceived needs to develop and implement a program for patients with rheumatoid arthritis. She noted that the first stage of development of an educational program was to assess the needs of both the facility and the patient. The facility needs were factors such as patient population most commonly seen, space, personnel, equipment, and financial resources. The needs of the patient were taken from Green's classification: predisposing, enabling, and reinforcing (Rand, 1978:852).

--predisposing factors relate to the patient: his present knowledge about his disease and treatment, his attitudes and values toward health and illness, and other socioculture factors which influence his ability and motivation to learn.

--enabling factors include the availability and accessibility of specific resources that will allow a patient to change his health behavior (e.g. specific equipment to carry out a set of exercises).

--reinforcing factors refer to those influences the health professional, family, or friends may have in shaping the patient's health behavior.
Rand termed performing a needs assessment as "making an educational diagnosis." This initial step was then followed by specifying goals, selecting criteria for success, planning the program, implementation, improving the program based on intended and unintended outcomes. The evaluation of this educational program was based on both an objective measure (criterion-referenced test) and subjective measures (self-reports). Rand reported that results of this evaluation supported the worth of the program.

Each of the three educational programs which focused on a one-to-one interaction between the patient and health professional revolved around an unstructured discussion of health status, goals, and behavioral changes to achieve goals. None of these programs included a formal educational needs assessment, with a structured interview or questionnaire, which would allow replication with a similar or different patient population.

This has been a review of general patient education programs which are holistic in meeting patients' needs. The focus of the next section will be on sexuality education programs for patients and their families.

**Sexuality Education Programs for the Ill/Disabled**

Studies in human sexuality among the ill or disabled have attracted little concerted effort in the past; and, at present, they are increasing in number. There is still no sizeable amount of empirical data upon which to base psycho-social rehabilitation (Cole and Glass, 1977:585). Much of the literature concerning sexuality
education programs for patients has focused on the preparation of health professionals to provide these programs, such as attending Sex Attitude Reassessment workshops. Reports of five sexuality educational programs, which are presently being implemented, were found.

The first of these is reported by Evans, Halar, DeFreece, and Larsen. Their program involves a multidisciplinary approach to sex education for spinal cord-injured patients. The educational program employs a structured approach to ensure that all members of the staff would be actively involved in the patient's rehabilitation. A total assessment of the patient's physical, psychological, and social functioning is made before individualizing his/her educational program. The physical examination is performed by a physician while the psycho-social aspects are reviewed by a social worker and a psychologist. Evans et al. note that an important method of assessing information needs and helping patients to gain a better understanding of their sexual self-esteem is the Sex Knowledge Inventory (SKI). An advantage of using SKI is its presumption of psychological normality as opposed to psychopathology.

The authors remark that ideally nurses, physicians, physical therapists, occupational therapists, social workers, and psychologists should all have an active part in patient teaching. If available, a speech pathologist can emphasize the importance of words and affect in communication. "A person confined to a
wheelchair must alter seductive approaches to the opposite sex by relying on verbal communication more than on the more mobile ambulatory behavioral cues" (Evans, Halar, DeFreece, and Larsen, 1976:543).

In this multidisciplinary program, the staff member who develops the closest working relationship with the patient and family assumes the primary responsibility as counselor. The primary counselor provides continuity in care and a chance for free association about problematic areas.

Not having the staff for a multidisciplinary approach, Rose Cook is a single staff person involved in sexuality education. She is assistant to the director and social services coordinator for United Cerebral Palsy of Denver. Cook began sex education program services through requests of enrollees and parents of children with cerebral palsy. The program involves small group discussions for adult women, for adult men, for adolescent boys, and for adolescent girls in addition to parent groups. Individual counseling is available upon request. This program developed with Cook as the primary educator, but staff members have engaged in inservice training programs to be able to provide value-free and accurate information (Cook, 1974:264-267).

A third educational program was developed by Rosenbaum while working as a psychiatrist on a physical rehabilitation service of a large hospital. Staff members became interested in his education/counseling sessions with patients and requested sexual education seminars. The basic premise of this program, by hospital
personnel, is to assist the patients in maximally utilizing all remaining strengths and assists, in order to form a new self and self-image based on positive factors, and on areas of worth instead of on deficiencies (Rosenbaum, 1978:502). Sexuality is only one aspect of the total patient's rehabilitation, but he has found that it is a very important concern to these patients once the acute medical crisis is over.

The sexuality part of the program provides for exploration with the patient and spouse of their past sexual life, their hopes, fears, and plans for the future.

We discuss all the aspects of their sexual relations that have been important to them: holding and being held, giving and receiving pleasure, kissing and orogenital contact. We deal with the patient's specific organic impairment in detail, and address very practical problems, such as what to do with a catheter. We point out the reality that the same reflex that triggers erection may trigger urination and defecation. We discuss the partner's need to be more active than previously and some of the initial reluctance usually encountered in this context. If the patient is a man, his feelings about his probable sterility are discussed. We attempt to help the patients mourn their previous sexual ability. We also deal with the somewhat realistic fear of the partner's leaving...use explicit sexual films depicting disabled as well as able-bodied persons to desensitize the subject matter as a stimulus for discussion and as an educational aid. (Rosenbaum, 1978:506)

Rosenbaum reports that he has been most impressed by the need of these individuals for touching, for sensuality, for pleasurable and reassuring body contact, to be held and to hold, and to express
love and caring through caressing, fondling, and kissing (Ibid.).

Another study of perceived needs, which has been incorporated into a sexuality education program, is reported by Cole, Chilgren, and Rosenberg. This program is for spinal cord-injured adults at the University of Minnesota. The patient program grew out of a program designed for medical students. In designing the patient program, a group of eight spinal cord-injured adults and their spouses were asked to clarify their needs and wants in organizing the content. The program includes desensitization to explicit sexual materials so that learners can deal with their own sexual feelings. This part of the program is followed by several sessions of small discussion groups which indicate the critical aspect of learning.

The authors recorded the ten most frequently discussed topics ranked by medical students and by the spinal cord-injured individuals. The rankings were as follows:

<table>
<thead>
<tr>
<th>Medical School Group</th>
<th>Spinal Cord Injured Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Evaluation of the programme and discussions of boredom and saturation.</td>
<td>1. Sex for the wheeler, identity, self-image, compensations, and problems of reproduction.</td>
</tr>
<tr>
<td>2. Body touch, massage, body games, turn-ons and turn-offs, sex practices and techniques, body language.</td>
<td>2. Body touch, turn-ons and turn-offs, and body image.</td>
</tr>
<tr>
<td>3. Cultural attitude toward sex and society, moralizing guilt, child rearing, and parental sex roles.</td>
<td>3-4 Evaluations of programme, expectations, communication between wheelers and walkers, relationships, and comparisons of problems.</td>
</tr>
<tr>
<td>Medical School Group</td>
<td>Spinal Cord Injured Group</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>5. Sex related to medical practice.</td>
<td>5-6 Personal injury experiences, present or prior life styles, and masturbation.</td>
</tr>
<tr>
<td>7. Relationships and feelings in sex (love, trust, jealousy, etc.)</td>
<td>7. Homosexuality.</td>
</tr>
<tr>
<td>10. Marriage, extra-marital and premarital sex, and divorce.</td>
<td>10. Fantasy.</td>
</tr>
</tbody>
</table>

(Cole, Chilgren, and Rosenberg, 1973:118)

Obviously, the substance and rankings do not match. The educational needs of medical students (and of possibly physicians and nurses) and of patients with spinal cord injury differ. At the end of each program, the disabled discussed the assets and deficiencies and made very concrete recommendations for future use of the program.

The fifth educational/counseling program is reported by Bardach (1978) and is located at the Institute of Rehabilitative Medicine, New York University Medical Center. Bardach promotes a loosely structured interview with patients to determine: what is still the same, what is different now, and how does the patient think the changes that have occurred can be managed? (Bardach, 1978:512) During the history taking procedure, a sexual history is included. This leads into a discussion about alternative sexual
expressions and the willingness of the patient and partner to explore these in the past and in the future.

When a patient is preparing for a home visit, a counseling session is offered to discuss the upcoming experience and very practical aspects of having sex while paralyzed or in pain are considered. A staff member tries to meet with the patient as soon after the first sexual activity as possible. Questioning determined what it was like for the patient, and what it was like for the partner. The staff works with the patient until some sexual adjustment is achieved, and some of the emotional difficulties are resolving for the patient and partner.

This approach encourages the patient to take an active part in planning his/her educational and counseling goals. Individual meanings and values are explored with the patient; and, thus, the patient's hierarchial wants and needs provide the basis for the individualized program.

Some selected patients also attend a two day Sex Attitude Reassessment workshop which is provided for individuals who are working with the physically disabled. These patients are encouraged to bring someone close to them with whom they can discuss intimate topics.

Each of these five educational programs in sexuality provide the handicapped individual and family members with assistance in setting educational goals. In this manner, the program planners can better be assured of meeting the current and important needs
of the population for whom they provide services.

There are, no doubt, other sexuality educational programs. Apparently, few are reported in professional literature. Most are probably not systematically developed, implemented, and evaluated so that knowledge gained from these experiences can be shared with other professionals who hope to institute sexuality educational programs for the ill or disabled.

**Sexuality Needs Assessments**

Several authors have written about the topic of sexual history taking and how to integrate the resulting information into an educational/counseling program. Griffith and Trieschmann (Meyer, Ed., 1976:Chapter 10) prescribe a review of present physical, psychological, social, and vocational status to define the degree of change that a disability entails, what has been lost, and what assets and liabilities remain. They differentiate the sexual history from medical and physical histories and examinations. The sexual history includes behaviors, attitudes, preferences, and cultural taboos. The authors evaluate social skills and encourage partner participation. Goals that the patient and partner have are explored as to how realistic they are. Careful attention is given to misunderstanding, misconceptions, and fears surrounding the disability, and to sexual functioning.

Wahl has delineated two approaches, the indirect and the direct interview, for sexual history taking (Wahl, Ed., 1967: Chapter 2). The indirect is characteristic of much psychiatric
work, while the direct interview is more comparable to taking a medical history. Wahl suggests that the sexual history be left to last because it requires information that most people find difficult to describe candidly, and, hopefully, rapport has been established by this time.

Wahl also provides general principles for history taking:

1. The history progresses from those topics that are easier to discuss to those that, in our culture, are more difficult to discuss.

2. The patient is asked first about how he acquired sexual information before he is asked about sexual experience.

3. When appropriate, questions are preceded by informational statements on the generality of the experience (ubiquity statements). These reassure the patient as well as supply information; and, usually, they significantly reduce his shame, anxiety, and evasiveness. (Wahl, 1967:15)

He closes the interview by asking two final questions. "Are there any other aspects of your sexual life that I ought to know about in order to understand you better? I have asked you a lot of questions. Are there any you would like to ask me?" The patient is assured that his/her replies are confidential and will be used exclusively for professional purposes.

Croft's approach is somewhat different than that of Wahl. He begins with three "screening" questions to elicit problem areas (Croft, 1976:210).

1. Has there been any change in your (or your partner's) sexual desire or frequency of intercourse?
2. Are you dissatisfied with your (or your partner's) present sexual functioning?

3. Is there anything about your (or your partner's) sexual activity (as individuals or as a couple) that you would like to change?

The author then takes a more in-depth sexual history if a problem has been voiced. His approach is a sexual problem history which is divided into five parts: description of the problem, development and course of the problem, patient's assessment of the cause, past attempts at resolution, and patient's expectations and goals. The latter part of the history would provide what the patient would like to learn in order to specify behavioral goals.

Additional models of sexual histories are provided by Roznoy and by Schwartz. Both authors outline techniques and principles for taking sexual histories which are similar to those already described. In both models, the educational program is developed from information obtained during interviews with the patient by the health professional. Neither model appear to include the health professional specifically asking the patient what he/she wants to learn about his/her sexuality and illness/disability.

A more structured assessment tool is proposed by Baughn in program development. Her structured interview includes demographic data, occupational concerns, past and present medical history, habits, stress factors, coping mechanisms, and nursing observations. From this assessment tool, the nurse then plans the educational program within the nursing care-plan and the subsequent evaluation. This particular assessment procedure does not
facilitate patient goal setting (Baughn, 1977:9).

Another assessment procedure is offered by Gillies and Alyn. Using techniques of health interviewing, the first concern is to discuss the topic that is most important to the patient. They support the concept that the patient's needs and wants are of primary concern (Gillies and Alyn, 1976:3). Their proposed medical history is followed by a psychosocial assessment and intervention. This assessment is based on Maslow's hierarchy of needs which is reproduced in Figure 2.5.

![Hierarchy of Needs](image)

Note that seven of the twenty-one needs are directly related to sexuality.

The only study, which was designed to assess perceived needs of a group of individuals, was by Braham, Houser, Cline and Posner. They studied forty-seven individuals with multiple sclerosis, none
of whom were hospitalized, for an evaluation of their social needs. The ten categories of social needs which were investigated were: social casework, financial, homemaker service, nursing care, vocational rehabilitation, family social situations, household help, transportation, recreation, and friendly visitor.

Their findings indicated that of the forty-seven patients interviewed, twelve couples had stable relationships, thirty-two couples indicated a need for help with their marital relationship; and, in three interviews, that not enough information was gathered to make a determination. The most frequent judgment of need was the absence of mutually satisfying activity. Other judgments in decreasing frequency were poor communication, dissatisfaction between partners characterized by tension and/or bickering, sexual adjustment problems, difficulty accepting debilitated spouse, rejection of a partner, and weak emotional ties (lack of concern for one another) (Braham et al., 1975:409).

Their data under family social problems revealed that ten participants had social problems in their families. Of these ten subjects, five participants were able to manage the situation without outside help.

The authors concluded that of the forty-seven subjects, only one had no need in any of the ten categories of social needs, eight subjects had all their needs met, and thirty-eight subjects had at least one unmet need. The total number of needs identified in all categories was 277, and 48 percent of these were unmet (Braham et al., 1975:407).
This review of the literature suggests the dearth of information about sexuality needs of individuals who are experiencing illness or disability. Although health professionals are increasing their commitment to sexuality education/counseling, the emphasis must turn from staff development and techniques for interviewing to assessing needs and the design, implementation, and evaluation of actual educational/counseling programs. These, in turn, must be reported in the literature so that the results of these experiences can provide valuable information for future planning. And if these future programs are to be relevant and helpful to patients, they must reflect the patient's values and perceived educational/counseling needs. The only way to find out what the patient values, and what he/she wants to learn in order to accomplish his/her behavioral goals, is by doing an educational needs assessment.
CHAPTER III
RESEARCH METHODOLOGY

With consideration of the curriculum development model previously described and the literature review, a survey study was designed based on personal interviews with individuals who are ill and/or disabled. Through the interviews, perceived educational needs and desires in sexuality were recorded and upon these responses, elements for a sexuality program for a particular population were proposed.

Selection of Study Sample

In the early stages of conception of this study, personnel at three social services organizations in Franklin County, Ohio were interviewed concerning what types of educational/counseling programs were provided for clients in sexuality and to whom they referred clients for assistance in this area. In all three instances, the educational materials dealing with sexuality were scarce, the referrals were non-systematic, and the staff felt these referrals were of questionable benefit. Sexuality programs had been presented in the past or were proposed for the future in each agency. All three agency personnel agreed that sexuality is an important but long neglected part of ill and/or handicapped persons' lives.
The Multiple Sclerosis Society was most enthusiastic about a study of the perceived needs of their clients and the expansion of their sexuality program. The author was invited to a one day workshop for nurses offered by the MS Society and Medical Personnel Pool. As part of the workshop, "Sexuality in the Handicapped" was presented by Watson Parker, MD. A panel of five women who have MS related their feelings about their disease, and how they have coped with its limitations.

During the question and answer period that followed the panel presentation, this author asked these women this question, "If you would perceive a sexuality problem or concern, to whom would you turn to for help." The responses varied from minister, doctor, or the MS Society, to two women who did not know to whom to turn to for help. These responses supported the author's previous experience with individuals who face a chronic illness/disability.

It was decided to randomly sample thirty individuals with MS who met the following requirements: they live in Franklin County, are affiliated with the MS Society, are not presently hospitalized, and would agree to be in the study. This was a small sample of the approximately four hundred individuals with multiple sclerosis who reside in Franklin County, Ohio; but, due to random selection of participants, it was hoped the sample would be representative of the population.
Development of Instrumentation for Assessing Needs

The literature reviewed in developing the instruments for this study focused on two areas: educational needs assessments, and interviewing techniques.

Needs Assessment Method

The development and utilization of a needs appraisal system is the first step in establishing an accountability model (Smith and Wilson, 1976:2). It provides an objective system of identifying educational/counseling needs of a particular population of individuals.

Rowntree has described five dimensions of an assessment. These are:

--Why assess? This first step involves deciding why assessment is to be carried out, and what effects it is expected to produce.

--What to assess? During this process, the decision of what one is looking for in the people one is assessing must be made.

--How to assess? Selecting, from among all the means that we have at our disposal for learning about people, those which we regard as being most truthful and fair for various sorts of valued knowledge.

--How to interpret? It is necessary to make sense of the outcomes of whatever observations or measurements or impressions we gather through whatever means employed. This involves explaining, appreciating, and attaching meaning to the raw 'events' of assessment.

--Who to respond? The final step is to find appropriate ways of expressing the response to
whatever has been assessed and of communicating it to the persons concerned. (Rowntree, 1977:11)

The "Why assess?" has been discussed in Chapter I in defining the problem. Traditionally, decisions as to educational program planning has been made by one or more health professionals for a particular population of individuals with certain illnesses and/or disabilities. This method of curriculum development has too often allowed real needs of these individuals, for whom the programs were designed, to go unrecognized and unmet.

The "What to assess?" involved reviewing articles on the effects on sexuality of MS as well as other chronic illnesses and disabilities. (Refer to Appendix A.) The decisions as to what to include in the assessment was also based on discussions with physicians, nurses, and psychologists who are directly involved with sexuality education/counseling in Franklin County, Ohio, and with whom the author has met through the American Association of Sex Educators, Counselors, and Therapists. Face validity of the topics chosen was obtained by a panel consisting of Watson Parker, MD, Gary DeVoss, PhD, and James Duncan, PhD.

The "How to assess?" proved to be more difficult. The major reason for use of an interview format was the nature of the information to be gathered. Sexuality information is personal, emotionally laden, and complex. Mailed questionnaires usually must be broad spectrumed and concise to facilitate response, rather than contain detailed and in-depth focus on certain topics. A personal interview
was believed to probably generate the best participation of individuals and the most valid and reliable data.

The conduct of the study was developed in the following manner.

1. Each potential participant was mailed a letter on MS Society stationery which described the study, who the researcher was, and what the potential participant would gain by assisting with this project. The letter was signed by Ann Teske, RN, and by Watson Parker, MD, chairman of the patient services committee of the MS Society.

2. Within a week after receiving the letter, each potential participant received a telephone call. During this call, the researcher introduced herself, and the purpose and conduct of the study was briefly reviewed, the willingness to participate or not was noted, and an interview was scheduled if appropriate. The interviewee was asked whether he/she would prefer meeting at the MS Society or being interviewed at home. The interviewee was encouraged to invite a friend or spouse to be present if it would assist him/her to be more comfortable.

3. The interviewer met the participant at the designated time and place. All interviews were held in the subjects' homes.

4. Each interview was to last approximately one hour although a few ran as long as two to three hours, depending on how many additional questions and how much information was sought by the interviewee.

5. Following the introduction, the interviewer reviewed the purpose of the study, how the data would be used to design patient-centered educational programs, and expressed appreciation for participation.

6. The interviewer then described how the interview would be conducted.
a. The participant was told that he/she would not be forced in any way to provide information about himself/herself that he/she did not want to provide or felt uncomfortable about discussing.

b. The interviewee was assured that all information gained would be kept confidential. He/she was told that his/her name would not appear on any of the instruments and was shown how a number code has been substituted.

c. The interviewer explained that she would read each question and record the participant's answer to all four of the instruments. (This eliminated problems with eyesight and hand coordination.)

d. At any time during the interview, the respondent was encouraged to feel free to ask any questions that he/she might have.

e. The interviewee was assured that participation or nonparticipation in the study would not affect any services provided by the MS Society, as no one on the staff at the MS Society knew who was included in the list of random names.

f. The researcher explained that she was conducting all of the interviews.

g. After the data was compiled, all participants would receive a letter summarizing the findings of the study. At this time, the author would destroy her list of names.

h. After the above topics were explained to the subject, a consent form, provided by the Human Subjects Committee at The Ohio State University, was asked to be signed. (All but one subject signed the consent form. The exception had very limited eyesight and did not want to sign a paper that she could not read. She gave her verbal consent.)

i. At the closing of the interview, the author asked the participant if he/she had any questions. The participant was thanked for his/her contribution to the study.
The four instruments, Q Sort, Learning Experiences Inventory, Sexuality Education/Counseling, and Personal Information schedules, contained open-ended and structured questions. (Refer to Procedures, Chapter I, p. 16.) Structured questions were included in the Q-Sort and as part of the Learning Experiences Inventory and Personal Information Schedule. These questions required the respondent to select his answer from among a list of possible answers. (Refer to Appendix C.)

Open-ended questions, in which the respondent was asked to provide his/her own answers, were located in all four instruments of the interview. These questions were written following the guidelines outlined by Babbie for open-ended questions.

1. The items should be clear and unambiguous.
2. Only a single question should be asked at one time. Care must be taken to avoid double-barreled questions which ask two questions but only allow one answer.
3. The respondent must be competent to answer the questions with some reliability.
4. The questions should be relevant.
5. Short items are best.
6. Avoid negative items which often pave the way for easy misinterpretation.
7. Avoid 'biased' items and terms. It is necessary to be continually sensitive to the effect of the wording on the results. (Babbie, 1973:140-148)

The instruments for this study, in summary, included a Q-Sort of structured questions which were potential topics for a sexuality program. The participant was asked to rate each of the forty-six topics as to whether they were (1) very important, (2) moderately important, (3) less important, and (4) not important with regard to their own wants and needs concerning attainment of
sexual health. They were then asked through an open-ended question, if they could provide any additional topics for such a program.

The Learning Experiences Schedule, the second instrument, contained both open and structured questions about the implementation of the educational/counseling program. Structured questions centered around their choices for resource persons and types of educational materials, who would most benefit from such a program, and whether the topics which they had previously rated very and moderately important would be better presented in an individual or small group setting. Open-ended questions were used to ask the respondents how they would feel if asked to be a resource person, what information would be valuable to another person coping with MS based on their own experience, and what suggestions they would have for implementation of the program.

Only open-ended questions were included in the third instrument, Sexuality Education/Counseling Schedule. These requested information about any past sexuality education and counseling, how well it met their needs, and what recommendations for increasing the helpfulness of this type of assistance for others could they make. The respondents were also asked if they had perceived a sexuality problem(s) or concern(s); and, if so, to describe the nature of it (them), and how it (they) were related to their illness.

Most of the Personal Information Schedule, the fourth instrument, consisted of open-ended questions, although there were several structured ones.
Interviewing Techniques

The major role of the interviewer is to maximize the communication exchange while reducing or eliminating barriers to communication, and to direct and control the communication process in order to meet the specific objectives.

The interview is one of a sequence of steps for gaining information. Each step is dependent upon the preceding one, starting with the general purpose.

Figure 3.1. The Context of the Interview (Kahn and Cannell, 1958:103)

The interview is actually the implementation of much planning for obtaining the desired information from a specific population. The coding and analysis of this information is performed with respect to the general purpose of the study itself.

In addition to the mechanics of the interview, these ethical considerations were followed:
1. The interviewer did not impose her set of values or an idealistic set of values on the study participants.

2. Every human being has a right to sexuality education and counseling no matter what race, creed, color, sex, sexual orientation, or disability.

3. The interviewer embraced the concept of primum non nocere -- above all do no harm.

4. By using current and accurate information when answering questions, the interviewer fostered understanding.

5. There was a responsibility to treat all information received as confidential, even if some portions of the information appeared trivial, irrelevant, or not to require confidentiality.

6. All considerations, relating to confidentiality in the interview relationship and the publication of results, were to be continued after termination of the project and publication.

7. All participation in this research project was voluntary.
   a. Informed consent required that the individual understood his/her role in the study, what information would be asked, and how the information would be used.
   b. The participant was encouraged to feel free to withdraw from the project at any time.

None of these ethical guidelines were knowingly violated during the course of this study.

Arrangement for Conduct of the Study

After initial contact with the MS Society, the study proposal was presented to Watson Parker, MD, chairman of the Patient Services Committee for the Society. His suggestions were requested and noted. Dr. Parker, in turn, arranged for the author to present the study
proposal to the March meeting of the Patient Services Committee. At this meeting, additional suggestions for wording and procedures to be included in the conduct of the study were made. At this time, an agreement was made between the author and one of the directors of the Society, Kelvin Carlisle, to provide a one-day workshop for MS Society clients based on the findings of this study.

Dr. Lyle Schmidt, a member of the Patient Services Committee, presented the proposal to the March meeting of the Board of Trustees of the MS Society. At this meeting, the proposal received board approval.

On April 8, four copies of the study proposal and the summary sheet of answered questions, were presented to the Human Subjects Review Committee for Behavioral and Social Sciences at The Ohio State University. The processing took two weeks, and approval was obtained on April 21.

Following notification of these study approvals, the author went to the MS Society where she was permitted access to their client files. The potential participant sample was drawn with the use of a table of random numbers.

A pilot study was undertaken at the end of April and first part of May. The sample consisted of two women and one man, who were randomly selected from the potential participant list. The purpose of the pilot study was to note any mechanical difficulties in setting up and conducting the interviews as well as comprehension difficulties of vocabulary used and questions asked. The modifications which were made for the formal study were in interview
format. For some individuals, it was found advantageous to ask the respondent to sort those topics which were categorized as very and moderately important into individual and group topics immediately following the Q Sort. This change in format shortened the interview time. The other modification was in instrument 3. After reading the initial introduction, the author found it beneficial to review the various facets of sexuality in which the respondent might have a problem or concern in order to assist him/her in organizing his/her thoughts.

Data Collection

Data were collected between May 5 and May 27. Thirty individuals who were included on the randomly selected list were interviewed. This number is from a total of sixty-five introductory letters that were sent. Among the thirty-five people who did not participate, sixteen had moved, died, or were not located. Six were in exacerbations and feeling so poorly that they could not participate, and three were bedridden and not coherent. One was hospitalized, and one was spending most of his time with his hospitalized father. In addition, one reported that she had been misdiagnosed with MS, and seven stated that they were not interested in participating.

Approximately twelve letters were mailed at a time. Within a week after receiving the letter, the telephone call was made. Appointments were scheduled during the day and evening depending on the participants' daily activities. Between one and four
interviews were scheduled per day. All interviews were conducted at the participants' homes and lasted from one hour and fifteen minutes to three hours, depending on how many questions and topics the participant or family member wanted to discuss. Several spouses and children were present during the interviews.

Method of Data Analysis

The data resulting from this study were analyzed in terms of frequencies, measures of central tendency, and variability. These measures of analysis are appropriate when compiling descriptive data with the purpose of program planning. Following the statistical analysis, decisions regarding the educational aims for a sexuality educational/counseling program for individuals with multiple sclerosis were made.

The information obtained from the Q Sort and from twelve descriptive factors from the personal information was coded numerically and placed on computer cards. The Statistical Package for the Social Sciences (SPSS) was used to compute descriptive statistics for personal information which provided a sample profile, for the forty-six possible topics which provided data for the total sample, and breakdown frequencies which provided data concerning each of the twelve individual characteristics in terms of the forty-six topics from the Q Sort.

Data from the Learning Experiences Schedule, Sexuality Education/Counseling Schedule, and selected data from Personal Information were hand tabulated. This was necessary since most
of the questions in these sections of the interview were open-ended.

Data Interpretation in Terms of the Curriculum Development Model

The data were analyzed and interpreted with reference to identifying elements for a sexuality program for individuals with multiple sclerosis. This is the "how to interpret" step of the needs assessment method mentioned on p. 49.

The information gathered from this study was used in the steps which follow the assessment of the curriculum development model described in Chapter I. The steps are defining educational aims, learning objectives, content selection, and learning experiences.

Questions, upon which a formative evaluation would be based, are presented. These questions are not answered in the text of this study since actual speakers, resource persons, and participants have not been established.

The most important and moderately important topics upon which the sample agreed are noted. Tentative relationships are also noted for personal characteristics which have at least five respondents rating in a similar manner. These relationships are not included in the proposed educational programming since the specific population for which such a program is designed has not been established. Therefore, a generalized program based on the total sample response was proposed.
Validity and Reliability of Data

The interview schedule received face validity from a panel of experts in curriculum development, qualitative research, and human sexuality. The interview process was appropriate for obtaining personal data on a highly emotional and value laden subject. This information was retrospective, current, and prospective in nature.

A possible threat to the internal validity of the study was that the researcher was a woman. The sex of a researcher may influence the participants' responses; but, the extent of which, the author was not able to determine. All respondents appeared to offer information freely during the interviews. In addressing this concern, Kolodny, Masters and Johnson have stated in their Textbook of Sexual Medicine that in working with handicapped patients, "knowledge and professional competence of the health-care professional are usually far more important than his or her gender" (Kolodny, Masters, Johnson, 1979:358).

External validity may have been decreased by the small sample size, and the fact that the data may be biased since it is based on interviews with individuals who are comfortable enough with their sexuality to discuss it with a stranger.

Certain measures in the interview process were included to increase the reliability of the data. These included: face-to-face contact with researcher and respondent, assurances of confidentiality, option of nonresponse by participant, fourth grade level vocabulary, and a date, time, and place that was most convenient to the participant. These measures, to increase
reliability of the data, were taken rather than incorporating repetitive questions or having the individual reinterviewed by another individual.

**Limitations**

The following limitations of this study have decreased its external validity when generalizing to other populations of individuals with multiple sclerosis.

1. The sample size of thirty individuals was small.

2. The data may be biased since it was based on interviews with individuals who were comfortable enough with their sexuality to discuss it with a stranger.

The following limitation may have decreased the internal validity.

1. The researcher was a woman which may have influenced participants' responses.
CHAPTER IV
RESULTS OF THE STUDY

The purpose of this study was to delineate elements of a sexuality program for individuals with multiple sclerosis through a needs assessment. Therefore, the analysis and interpretation of the data were performed with respect to program development.

The Participants: A Profile

Thirty men and women with multiple sclerosis were interviewed as to their educational needs and wants with regard to MS and their sexuality. These thirty people were among a list of randomly selected individuals from the files of the Multiple Sclerosis Society of Mid-Ohio, who had agreed to be interviewed. (Refer to Table 4.1.)

The ages of the participants ranged from age 25 to age 60 with a mean of 40.9 years. Of the twenty-two females and eight males in the study, only one woman and one man were black, and the remainder were white. All but one woman had family who could trace several generations living in America, and so identified with American culture. The exception was a woman who was born and raised in Germany until the time of her marriage.
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Their formal education varied from a sixth grade education to graduate degrees. The majority of the respondents had graduated from high school and many had had some college work or additional special training. Of these thirty individuals, only seven were presently employed. Of those who were not working, sixteen stated that their loss of job or early retirement was due to the limitations placed upon them by multiple sclerosis.

Only three persons said that they would not be able to attend a sexuality program if it was held on a weekday. This is compared with ten who stated they would not attend if a program was held on a weekend, and eight who could not attend if it was held in the evening. Reasons for not attending on weekends and evenings included childcare, the desire to spend time with the family, and to recover strength. Only eight individuals would not be able to provide their own transportation to such a program.

Concerning religious preference, seventeen persons were Protestant, ten were Catholic, and three stated that they had no religious affiliation. The majority were presently in a partner relationship while nine were single. The partner relationships varied from one year to thirty-seven years with a mean of 17.6 years. Of those who were single, one was widowed, and six were divorced. Four of the six who were divorced claimed that multiple sclerosis and its limitations were a major factor in the break-up of their marriages.
The participants' health status is detailed in Table 4.2. All but two of the respondents had been diagnosed with MS for less than fifteen years. The mean time since diagnosis was 7.6 years with the range from less than one year to twenty-two years. Only five participants stated that they had other illnesses or disabilities besides multiple sclerosis.

The majority described their former health status before diagnosis of MS as good. Four persons described their former health status as fair and one as poor.

The severity of disability was rated on a mobility scale ranging from no assistance to bedridden. Sixteen respondents had no need of assistance when walking. Canes or walker were used by eight individuals and four persons used wheelchairs for more than 50 percent of the time. Two individuals who were interviewed spent more than 50 percent of their time in bed.

Other limitations imposed by MS were noted during the interview. These are reported in Table 4.3. Symptoms of multiple sclerosis are quite varied among individuals, and no two people follow the same patterns with the disease. Common limitations imposed by MS appear to be that it causes an individual to tire quickly, to have pain, to be weak on one side of the body, to be subject to emotional swings, and to have impaired eyesight, in addition to experiencing limitations in mobility. All of these limitations have sexual implications.
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<td></td>
</tr>
<tr>
<td><strong>Illnesses and Disabilities</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Severity of disability</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No assistance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cane/walker</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wheelchair</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bedridden</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
TABLE 4.3

LIMITATIONS, OTHER THAN MOBILITY, DUE TO MS

<table>
<thead>
<tr>
<th>Limitation</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitive to heat and cold</td>
<td>1</td>
</tr>
<tr>
<td>No heavy work</td>
<td>6</td>
</tr>
<tr>
<td>Cooking and house cleaning restrictions</td>
<td>6</td>
</tr>
<tr>
<td>Tires easily</td>
<td>21</td>
</tr>
<tr>
<td>Balance and coordination affected</td>
<td>7</td>
</tr>
<tr>
<td>Not able to stand for long periods</td>
<td>1</td>
</tr>
<tr>
<td>Muscle spasms</td>
<td>9</td>
</tr>
<tr>
<td>Pain-constant or transient</td>
<td>17</td>
</tr>
<tr>
<td>Weakness on one side of body</td>
<td>16</td>
</tr>
<tr>
<td>Urinary incontinence</td>
<td>2</td>
</tr>
<tr>
<td>Concentration</td>
<td>2</td>
</tr>
<tr>
<td>Eyesight affected</td>
<td>12</td>
</tr>
<tr>
<td>Speech impediment</td>
<td>4</td>
</tr>
<tr>
<td>Emotional swings</td>
<td>21</td>
</tr>
</tbody>
</table>

Rating of Sexuality Topics

Although the sexuality topics were conceptually divided into five categories, the participants received the 5x8 cards with the topic questions on them, in a random order. When coding the answers, a numerical value was given:

- very important: 3 points
- moderately important: 2 points
- less important: 1 point
- not important: 0 points
Decisions concerning importance of the topic were based on frequencies and measures of central tendency. For a topic to be considered very important by the sample, a mean of 2.2 or greater was required. Topics considered moderately important had to have a mean between 1.9 and 2.1. Topics that were considered less important fell within the range of 1.2 and 1.8 and those receiving means of 1.1 or less were considered not important. (Refer to Appendix D.) There were no topics that were rated 1.1 or less by the total sample.

The topics are organized for reporting here under the conceptual categories of sexual health described in Chapter I, pp. 3-4. Those topics which were considered less important were then examined through the SPSS breakdown process to note any discernible relations to the following twelve characteristics: age, sex, race, length of time since diagnosis, former health status, number of illnesses and disabilities, severity of disability, years of formal education, employment status, religious affiliation, cultural background, and relationship status. Only those characteristics which were rated very, moderately, or not important are reported in noting relationships.

**Self-Image/Self-Concept**

**Very Important**

(mean of 2.2 or greater)

HOW TO USE NEW WAYS TO DEAL WITH YOUR ILLNESS/DISABILITY?

HOW ILLNESS OR DISABILITY CAN AFFECT BEING A FAMILY MEMBER?

HOW TO CONTEND WITH LOSS OF EASINESS OF MOVEMENT?
Moderately Important
(mean of 1.9-2.1)

HOW TO DEAL WITH WORRY AND FEAR ABOUT FUTURE LOSS OF BODY OR MIND FUNCTIONS?

HOW TO DEAL WITH VARYING FEELINGS AND EMOTIONS...HAPPINESS TO DEPRESSION, JOY TO ANGER?

HOW TO MANAGE WITH LOWER ENERGY LEVELS WHICH INTERFERE WITH DAILY ACTIVITIES?

Less Important with wide variability in ratings
(mean of 1.2-1.8)

WHY YOUR ILLNESS OR DISABILITY CAN CHANGE THE WAY THAT YOU FEEL ABOUT YOUR BODY?

Relationships Between Demographic Characteristics and Topic Area:*

Characteristics of persons who rated it very important
no religious affiliation . n = 3**

Characteristics of persons who rated it moderately important
high school education n = 9
no assistance for mobility n = 16
2-3 illnesses/disabilities n = 5

Characteristics of persons who rated it not important
50 years of age or older n = 6
Black n = 2
required a cane/walker, wheelchair, or were bedridden n = 14
college degree n = 4

*Relationships are noted only for characteristics rated by two or more individuals.

**n = Refers to the number of individuals in the sample who responded in this manner.
WHY YOUR ILLNESS OR DISABILITY CAN CHANGE THE WAY YOU FEEL ABOUT BEING MASCULINE OR FEMININE?

Relationships Between Demographic Characteristics and Topic Area:

Characteristics of persons who rated it **moderately important**

<table>
<thead>
<tr>
<th></th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-34 years of age</td>
<td>10</td>
</tr>
<tr>
<td>diagnosed less than 5 years</td>
<td>7</td>
</tr>
<tr>
<td>no assistance for mobility</td>
<td>16</td>
</tr>
<tr>
<td>no religious affiliation</td>
<td>3</td>
</tr>
</tbody>
</table>

Characteristics of persons who rated it **not important**

<table>
<thead>
<tr>
<th></th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>50 years of age or older</td>
<td>6</td>
</tr>
<tr>
<td>diagnosed 10-14 years</td>
<td>8</td>
</tr>
<tr>
<td>required a wheelchair or were bedridden</td>
<td>6</td>
</tr>
<tr>
<td>college degree or graduate degree</td>
<td>6</td>
</tr>
</tbody>
</table>

HOW YOUR FEELINGS ABOUT YOUR SEXUAL ATTRACTION TO THE SAME OR TO THE OTHER SEX MAY CHANGE?

Relationships Between Demographic Characteristics and Topic Area:

Characteristics of persons who rated it **very important**

<table>
<thead>
<tr>
<th></th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>graduate degree</td>
<td>2</td>
</tr>
<tr>
<td>no religious affiliation</td>
<td>3</td>
</tr>
</tbody>
</table>

Characteristics of persons who rated it **moderately important**

<table>
<thead>
<tr>
<th></th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>fair former health status</td>
<td>4</td>
</tr>
<tr>
<td>no assistance for mobility</td>
<td>16</td>
</tr>
</tbody>
</table>

Characteristics of persons who rated it **not important**

<table>
<thead>
<tr>
<th></th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black</td>
<td>2</td>
</tr>
<tr>
<td>required a wheelchair or were bedridden</td>
<td>6</td>
</tr>
<tr>
<td>9 years or less of schooling or college degree</td>
<td>6</td>
</tr>
</tbody>
</table>
HOW ILLNESS OR DISABILITY CAN AFFECT BEING A SEXUAL PARTNER?

Relationships Between Demographic Characteristics and Topic Area:

Characteristics of persons who rated it **very important**

- 20-34 years of age  
  - n = 10
- male  
  - n = 8
- 3 illnesses/disabilities  
  - n = 2
- no assistance for mobility  
  - n = 16
- high school diploma or graduate degree  
  - n = 11
- no religious preference  
  - n = 3

Characteristics of persons who rated it **moderately important**

- diagnosed 1-9 years  
  - n = 20
- required cane or walker  
  - n = 8
- not employed  
  - n = 23
- single  
  - n = 9

Characteristics of persons who rated it **not important**

- diagnosed 10-14 years  
  - n = 8
- fair former health  
  - n = 4
- 2 illnesses/disabilities  
  - n = 3
- required a wheelchair or were bedridden  
  - n = 6

HOW ILLNESS OR DISABILITY CAN AFFECT BEING A PAYCHECK EARNER?

Relationships Between Demographic Characteristics and Topic Area:

Characteristics of persons who rated it **very important**

- 20-34 years of age  
  - n = 10

Characteristics of persons who rated it **moderately important**

- male  
  - n = 8
- diagnosed less than 5 years  
  - n = 7
3 illness/disabilities n = 2
required a cane or walker n = 8
high school diploma or some college or special training n = 22
no religious affiliation n = 3

Characteristics of persons who rated it not important

50 years of age or older n = 6
bedridden n = 2
college degree or graduate degree n = 6

HOW ILLNESS OR DISABILITY CAN AFFECT BEING AN ACTIVE MEMBER OF YOUR COMMUNITY?

Relationships Between Demographic Characteristics and Topic Area:

Characteristics of persons who rated it very important

Black n = 2
fair former health n = 4
bedridden n = 2
9 years of schooling or less n = 2
no religious affiliation n = 3

Characteristics of persons who rated it moderately important

35-49 years of age n = 14
diagnosed 10-14 years n = 8
high school diploma or college degree n = 13

Characteristics of persons who rated it not important

graduate degree n = 2
HOW TO DEAL WITH USING ARTIFICIAL OR MECHANICAL AIDS?

Relationships Between Demographic Characteristics and Topic Area:

Characteristics of persons who rated it **very important**

- 3 illnesses/disabilities  
- required a cane or walker  
- high school diploma  
- no religious affiliation  
  
  n = 2  
  n = 8  
  n = 9  
  n = 3  

Characteristics of persons who rated it **moderately important**

- 50 years of age or older  
- diagnosed 10-14 years  
- single  
  
  n = 6  
  n = 8  
  n = 9  

Characteristics of persons who rated it **not important**

- Black  
- 2 illnesses/disabilities  
- bedridden  
  
  n = 2  
  n = 3  
  n = 2  

HOW TO CONTEND WITH LOSS OF FUNCTIONING SUCH AS ELIMINATION, FERTILITY, OR SEXUAL FUNCTIONING?

Relationships Between Demographic Characteristics and Topic Area:

Characteristics of persons who rated it **very important**

- 20-34 years of age  
- male  
- Black  
- 3 illnesses/disabilities  
- required no assistance for mobility  
- 9 years of schooling or less or college degree  
- no religious affiliation  
  
  n = 10  
  n = 8  
  n = 2  
  n = 2  
  n = 16  
  n = 6  
  n = 3
Characteristics of persons who rated it **moderately important**

- diagnosed 5-9 years ago \( n = 13 \)
- bedridden \( n = 2 \)
- high school diploma \( n = 9 \)
- not employed \( n = 23 \)
- partner relationship \( n = 21 \)

Characteristics of persons who rated it **not important**

- 2 illnesses/disabilities \( n = 3 \)
- required a wheelchair \( n = 4 \)

**HOW TO DEAL WITH GROOMING DIFFICULTIES?**

Relationships Between Demographic Characteristics and Topic Area:

Characteristics of persons who rated it **moderately important**

- 3 illnesses/disabilities \( n = 2 \)
- college degree \( n = 4 \)

Characteristics of persons who rated it **not important**

- Black \( n = 2 \)
- diagnosed less than 5 years \( n = 7 \)
- 2 illnesses/disabilities \( n = 3 \)
- required a wheelchair or were bedridden \( n = 6 \)
- less than 9 years of school or graduate degree \( n = 4 \)
- employed \( n = 7 \)

**HOW TO CONTEND WITH FEWER CONTACTS WITH FRIENDS AND FAMILY MEMBERS DUE TO LIMITATIONS CAUSED BY ILLNESS OR DISABILITY?**

Relationships Between Demographic Characteristics and Topic Area:

Characteristics of persons who rated it **very important**

- bedridden \( n = 2 \)
- high school diploma \( n = 9 \)
- no religious affiliation \( n = 3 \)
- single \( n = 9 \)
### HOW TO CONTEND WITH PERSISTENT PAIN OR DISCOMFORT?

**Relationships Between Demographic Characteristics and Topic Area:**

#### Characteristics of persons who rated it **very important**
- Black: n = 2
- 3 illnesses/disabilities: n = 2
- Less than 9 years of schooling: n = 2

#### Characteristics of persons who rated it **moderately important**
- 20-34 years of age: n = 10
- Diagnosed 5-9 years: n = 13
- Fair former health: n = 4
- Required a cane or walker: n = 8
- Graduate degree: n = 2
- No religious affiliation: n = 3
- Single: n = 9

#### Characteristics of persons who rated it **not important**
- Diagnosed 10-14 years: n = 8
- Required a wheelchair: n = 4

### HOW TO ACHIEVE ACCEPTANCE OF LOSS?

**Relationships Between Demographic Characteristics and Topic Area:**

#### Characteristics of persons who rated it **very important**
- No assistance for mobility: n = 16
- Employed: n = 7
- No religious affiliation: n = 3
Characteristics of persons who rated it moderately important

- 20-34 years of age and 50 and older n = 16
- diagnosed 9 years or less n = 20
- 3 illnesses/disabilities n = 2
- high school diploma or some college or special training n = 22
- Protestant n = 17
- partner relationship n = 21

Characteristics of persons who rated it not important

- Black n = 2
- required wheelchair or were bedridden n = 6
- 9 years or less schooling n = 2

Knowledge of Body and Some Degree of Control over Body Functioning

Very Important with limited variability in ratings (mean of 2.2 or greater)

WHY UNCERTAIN INCREASES IN SYMPTOMS WILL AFFECT THE OUTCOME OF YOUR ILLNESS OR DISABILITY?

Moderately Important with limited variability in ratings (mean of 1.9-2.1)

HOW CHANGES IN ONE'S BODY DUE TO ILLNESS OR DISABILITY CAN RESULT IN OTHER CHANGES IN BODY FUNCTIONING?

HOW CHANGES IN ONE'S BODY CAN RESULT IN CHANGES IN THE WAY A PERSON THINKS ABOUT HIMSELF/HERSELF?

HOW TO REGAIN SOME CONTROL OVER BODY FUNCTIONING AFTER ILLNESS OR DISABILITY?

WHAT CAUSED YOUR ILLNESS OR DISABILITY?

WHY CHANGES IN BODY FUNCTIONING RESULT IN CERTAIN SYMPTOMS THAT YOU ARE EXPERIENCING?
Less Important with wide variability in ratings  
(mean of 1.2-1.8)

**HOW YOUR BODY FUNCTIONS AND HOW THE BODY OF THE OPPOSITE SEX FUNCTIONS?**

Relationships Between Demographic Characteristics and Topic Area:

<table>
<thead>
<tr>
<th>Characteristics of persons who rated it very important</th>
</tr>
</thead>
<tbody>
<tr>
<td>male n = 8</td>
</tr>
<tr>
<td>high school diploma n = 9</td>
</tr>
<tr>
<td>Catholic or no religious affiliation n = 13</td>
</tr>
</tbody>
</table>

Characteristics of persons who rated it moderately important

| 20-34 years of age n = 10                             |
| 2 or 3 illnesses/disabilities n = 5                   |
| required a cane or walker n = 8                       |
| not employed n = 23                                   |

Characteristics of persons who rated it not important

| bedridden n = 2                                      |
| employed n = 7                                       |

**HOW DRUGS WHICH ARE PRESCRIBED FOR YOU MAY AFFECT YOUR SEXUAL FUNCTIONING?**

Relationships Between Demographic Characteristics and Topic Area:

<table>
<thead>
<tr>
<th>Characteristics of persons who rated it very important</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 illnesses/disabilities n = 2</td>
</tr>
<tr>
<td>high school diploma or graduate degree n = 11</td>
</tr>
<tr>
<td>no religious affiliation n = 3</td>
</tr>
</tbody>
</table>

Characteristics of persons who rated it moderately important

| 20-34 years of age n = 10                             |
| male n = 8                                            |
| diagnosed less than 5 years n = 7                     |
| no assistance for mobility or required a cane or walker n = 24 |
Characteristics of persons who rated it **not important**

- fair former health  \( n = 4 \)
- 2 illnesses/disabilities  \( n = 3 \)
- bedridden  \( n = 6 \)

**HOW TREATMENTS FOR YOUR ILLNESS OR DISABILITY MAY AFFECT YOUR SEXUAL FUNCTIONING?**

Relationships Between Demographic Characteristics and Topic Area:

**Characteristics of persons who rated it **very important**

- 20-34 years of age  \( n = 10 \)
- 3 illnesses/disabilities  \( n = 2 \)
- no assistance for mobility  \( n = 16 \)
- high school diploma or graduate degree  \( n = 11 \)
- no religious affiliation  \( n = 3 \)

**Characteristics of persons who rated it **moderately important**

- male  \( n = 8 \)
- diagnosed 9 years or less  \( n = 20 \)
- not employed  \( n = 23 \)
- single  \( n = 9 \)

**Characteristics of persons who rated it **not important**

- required wheelchairs or were bedridden  \( n = 6 \)

**HOW SEX DRIVE IS AFFECTED BY DISABILITY OR ILLNESS?**

Relationships Between Demographic Characteristics and Topic Area:

**Characteristics of persons who rated it **very important**

- male  \( n = 8 \)
- 3 illnesses/disabilities  \( n = 2 \)
- no assistance for mobility  \( n = 16 \)
- no religious affiliation  \( n = 3 \)

**Characteristics of persons who rated it **moderately important**

- 20-49 years of age  \( n = 24 \)
diagnosed 5-9 years n = 13
good former health n = 25
high school diploma or graduate degree n = 11
not employed n = 23
partner relationship n = 21

Characteristics of persons who rated it not important

2 illnesses/disabilities n = 3
required a wheelchair or were bedridden n = 6

WHY ILLNESS OR DISABILITY MAY RESULT IN THE NEED FOR DIET/SMOKING/DRINKING RESTRICTIONS?

Relationships Between Demographic Characteristics and Topic Area:

Characteristics of persons who rated it very important

2 illnesses/disabilities n = 3
high school diploma n = 9
no religious affiliation n = 3

Characteristics of persons who rated it moderately important

20-34 years of age n = 10
diagnosed for less than 5 years n = 7
3 illnesses/disabilities n = 2
no assistance for mobility n = 16

Characteristics of persons who rated it not important

50 years of age or older n = 6
required cane or walker, wheelchair, or were bedridden n = 14
some college or special training or graduate degree n = 15

Clarification of Values

Very Important with limited variability in ratings (mean of 2.2 or greater)

HOW VALUES AND GOALS FOR BEING A FAMILY MEMBER CAN BE AFFECTED BY ILLNESS OR DISABILITY?
Moderately Important with limited variability in ratings
(mean of 1.9-2.1)

HOW VALUES AND GOALS FOR LIFESTYLE CAN BE AFFECTED BY ILLNESS OR DISABILITY?

HOW TO DEVELOP, ALTER, OR CONFIRM AGAIN PERSONAL BELIEFS, INCLUDING YOUR PURPOSE FOR LIVING?

HOW TO DECIDE HOW MUCH AND WHAT TYPE OF HELP YOU NEED TO ACHIEVE YOUR GOALS IN LIFE?

Less Important with wide variability in ratings
(mean of 1.2-1.8)

HOW VALUES AND GOALS FOR SEXUAL BEHAVIOR CAN BE AFFECTED BY ILLNESS OR DISABILITY?

Relationships Between Demographic Characteristics and Topic Area:

Characteristics of persons who rated it **very important**

- male
- 3 illnesses/disabilities
- no assistance for mobility
- high school diploma
- no religious affiliation

Characteristics of persons who rated it **moderately important**

- 20-49 years of age
- White
- diagnosed 5-9 years
- good former health
- 1 illness/disability
- required a cane or walker
- graduate degree
- not employed
- Catholic
- single or in partner relationship

Characteristics of persons who rated it **not important**

- 2 illnesses/disabilities
- bedridden
HOW PROBLEM SOLVING SKILLS CAN BE USED TO ACHIEVE CHANGING SELF-GOALS?

Relationships Between Demographic Characteristics and Topic Area:

<table>
<thead>
<tr>
<th>Characteristics of persons who rated it very important</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 illnesses/disabilities</td>
</tr>
<tr>
<td>no assistance for mobility</td>
</tr>
<tr>
<td>no religious affiliation</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Characteristics of persons who rated it moderately important</th>
</tr>
</thead>
<tbody>
<tr>
<td>35-49 years of age</td>
</tr>
<tr>
<td>males</td>
</tr>
<tr>
<td>diagnosed for 5-9 years</td>
</tr>
<tr>
<td>2 illnesses/disabilities</td>
</tr>
<tr>
<td>high school diploma or graduate degree</td>
</tr>
<tr>
<td>Catholic</td>
</tr>
<tr>
<td>partner relationship</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Characteristics of persons who rated it not important</th>
</tr>
</thead>
<tbody>
<tr>
<td>required a wheelchair or were bedridden</td>
</tr>
</tbody>
</table>

HOW TO DECIDE WHICH PERSONS WOULD BE MOST HELPFUL TO YOU IN ACHIEVING YOUR GOALS IN LIFE?

Relationships Between Demographic Characteristics and Topic Area:

<table>
<thead>
<tr>
<th>Characteristics of persons who rated it very important</th>
</tr>
</thead>
<tbody>
<tr>
<td>male</td>
</tr>
<tr>
<td>no religious affiliation</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Characteristics of persons who rated it moderately important</th>
</tr>
</thead>
<tbody>
<tr>
<td>35-49 years of age</td>
</tr>
<tr>
<td>diagnosed 5-9 years</td>
</tr>
<tr>
<td>no assistance for mobility</td>
</tr>
<tr>
<td>high school diploma</td>
</tr>
<tr>
<td>not employed</td>
</tr>
<tr>
<td>partner relationship</td>
</tr>
</tbody>
</table>
Characteristics of persons who rated it **not important**

- 50 years of age or older  n = 6
- 2 illnesses/disabilities  n = 3
- bedridden  n = 2
- college degree  n = 4

**Ability to Communicate Clearly and Effectively**

Very Important with limited variability in ratings  
(mean of 2.2 or greater)

*HOW ILLNESS AND DISABILITY CAN AFFECT THE WAY OTHER PEOPLE UNDERSTAND WHAT YOU ARE TRYING TO COMMUNICATE TO THEM?*

Moderately Important with limited variability in ratings  
(mean of 1.2-1.8)

*HOW TO ACCURATELY INTERPRET UNSPOKEN MESSAGES FROM OTHERS?*

Less Important with wide variability in ratings  
(mean of 1.2-1.8)

*HOW TO "KNOW" YOURSELF WITH YOUR SEXUAL WANTS AND NEEDS?*

**Relationships Between Demographic Characteristics and Topic Area:**

Characteristics of persons who rated it **very important**

- 3 illnesses/disabilities  n = 2
- high school diploma  n = 9
- no religious affiliation  n = 3

Characteristics of persons who rated it **moderately important**

- 20-34 years of age  n = 10
- diagnosed 5-9 years  n = 13
- no assistance for mobility or required a cane or walker  n = 24
- not employed  n = 23
- Catholic  n = 10

Characteristics of persons who rated it **not important**

- Black  n = 2
- 2 illnesses/disabilities  n = 3
HOW TO EXPRESS YOUR SEXUAL WANTS AND NEEDS CLEARLY AND EFFECTIVELY?

Relationships Between Demographic Characteristics and Topic Area:

Characteristics of persons who rated it very important

- 3 illnesses/disabilities \( n = 2 \)
- high school diploma \( n = 9 \)
- Catholic or no religious preference \( n = 13 \)

Characteristics of persons who rated it moderately important

- diagnosed 5-9 years \( n = 13 \)
- no assistance for mobility \( n = 16 \)
- graduate degree \( n = 2 \)
- not employed \( n = 23 \)
- partner relationship \( n = 21 \)

Characteristics of persons who rated it not important

- Black \( n = 2 \)
- required a wheelchair or were bedridden \( n = 6 \)
- employed \( n = 7 \)

HOW TO DEVELOP A FEELING OF FREEDOM TO DISCUSS SEXUAL FEARS AND CONCERNS WITH OTHERS?

Relationships Between Demographic Characteristics and Topic Area:

Characteristics of persons who rated it very important

- male \( n = 8 \)
- no religious affiliation \( n = 3 \)

Characteristics of persons who rated it not important

- 2-3 illnesses/disabilities \( n = 5 \)
- required a wheelchair or were bedridden \( n = 6 \)
- college degree \( n = 4 \)
- employed \( n = 7 \)
HOW TO DEAL WITH THE FEELING OF RISK WHEN EXPRESSING INTIMATE WANTS AND DESIRES?

Relationships Between Demographic Characteristics and Topic Area:

Characteristics of persons who rated it very important

- high school diploma n = 9
- no religious affiliation n = 3

Characteristics of persons who rated it moderately important

- 35-49 years of age n = 14
- male n = 8
- 3 illnesses/disabilities n = 2
- no assistance for mobility or required a cane or walker n = 24
- graduate degree n = 2
- Catholic n = 10

Characteristics of persons who rated it not important

- 50 years of age or older n = 6
- Black n = 2
- 2 illnesses/disabilities n = 3
- bedridden n = 2
- 9 years of schooling or less or college degree n = 6

Choosing Sexual Partner(s) for Relationship(s) Which Is(Are) Positive, Creative, and Fulfilling

Less Important with wide variability in ratings (mean of 1.2-1.8)

WHY ILLNESS OR DISABILITY DOES NOT MAKE ANYONE ANY LESS CAPABLE OR LESS RESPONSIBLE FOR HIS/HER SEXUAL RELATIONSHIPS?

Relationships Between Demographic Characteristics and Topic Area:

Characteristics of persons who rated it moderately important

- 20-34 years of age n = 10
- male n = 8
- diagnosed 5-9 years n = 13
- 3 illnesses/disabilities n = 2
- no assistance for mobility n = 16
- graduate degree n = 2
Characteristics of persons who rated it **not important**

2 illnesses/disabilities \( n = 3 \)
required a wheelchair or were bedridden \( n = 6 \)

**HOW ILLNESS OR DISABILITY CAN AFFECT THE WAY YOU FEEL ABOUT OBTAINING A SEXUAL PARTNER OR MAINTAINING A SEXUAL RELATIONSHIP?**

**Relationships Between Demographic Characteristics and Topic Area:**

Characteristics of persons who rated it **very important**

male \( n = 8 \)
no religious affiliation \( n = 3 \)

Characteristics of persons who rated it **moderately important**

20-34 years of age \( n = 10 \)
diagnosed 5-9 years \( n = 13 \)
3 illnesses/disabilities \( n = 2 \)
no assistance for mobility \( n = 16 \)
high school diploma or graduate degree \( n = 13 \)
partner relationship \( n = 21 \)

Characteristics of persons who rated it **not important**

Black \( n = 2 \)
required a wheelchair or were bedridden \( n = 6 \)
9 years of schooling or less or college degree \( n = 6 \)

**HOW ILLNESS OR DISABILITY MAY AFFECT THE WAY YOU FEEL ABOUT PARTNERS OF THE SAME OR OPPOSITE SEX?**

**Relationships Between Demographic Characteristics and Topic Area:**

Characteristics of persons who rated it **very important**

male \( n = 8 \)
graduate degree \( n = 2 \)
no religious affiliation \( n = 3 \)
Characteristics of persons who rated it **moderately important**

- 35-49 years of age \( n = 14 \)
- 3 illnesses/disabilities \( n = 2 \)
- No assistance for mobility \( n = 16 \)
- Required a cane or walker \( n = 8 \)
- High school diploma \( n = 9 \)

Characteristics of persons who rated it **not important**

- Black \( n = 2 \)
- 2 illnesses/disabilities \( n = 3 \)
- Required a wheelchair or were bedridden \( n = 6 \)
- College degree \( n = 4 \)

**WHAT NEW MODES OF SEXUAL PLEASURE MAY BE OPEN FOR YOUR DESPITE YOUR ILLNESS OR DISABILITY?**

Relationships Between Demographic Characteristics and Topic Area:

Characteristics of persons who rated it **very important**

- Male \( n = 8 \)
- 3 illnesses/disabilities \( n = 2 \)
- High school diploma \( n = 9 \)

Characteristics of persons who rated it **moderately important**

- 20-49 years of age \( n = 24 \)
- Good former health \( n = 25 \)
- No assistance for mobility or required a cane or walker \( n = 24 \)
- Employed \( n = 23 \)
- Catholic or no religious affiliation \( n = 13 \)

Characteristics of persons who rated it **not important**

- 50 years of age or older \( n = 6 \)
- Black \( n = 2 \)
- Fair former health \( n = 4 \)
- 2 illnesses/disabilities \( n = 3 \)
- Bedridden \( n = 2 \)
- 9 years of schooling or less \( n = 2 \)
These were the ratings of the topics by the sample of respondents, and all were rated very, moderately, or less important. No topic received a rating by the sample of not important.

Each respondent was asked if he/she had any additional topics that were important to his/her sexuality that had not been included in the Q Sort. Ten participants responded with one topic each. The topics were:

1. How does one handle being handicapped and working: especially relating to people in the work situation?
2. What medications are being used for MS?
3. What are some alternatives for behavior in various life situations?
4. Does MS affect changes in the life cycle? Can it cause menopause to come earlier?
5. How do you make the decision whether or not to have children when you have MS?
6. How can a mother cope with discipline problems when the child knows that mother is sick and then takes advantage of the situation?
7. How can we get companies to provide make-up and clothing that is more attractive but still easy to get into and out of?
8. How do you cope with feelings of hopelessness, a giving up, before the battle has even started?
9. How can family members learn to cope?
10. How to maintain a happy sexual atmosphere?

**Learning Experiences**

Each respondent answered several questions relating to how they would want an educational/counseling program developed and implemented.
Table 4.4 shows the responses concerning speakers and resource persons. Individuals with similar illness/disability received the highest rating from the respondents. They were

<table>
<thead>
<tr>
<th>Individuals</th>
<th>Yes</th>
<th>Maybe</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>relative(s)</td>
<td>5</td>
<td>4</td>
<td>21</td>
</tr>
<tr>
<td>friend(s)</td>
<td>6</td>
<td>8</td>
<td>16</td>
</tr>
<tr>
<td>doctor(s)</td>
<td>23</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>nurse(s)</td>
<td>22</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>social worker(s)</td>
<td>21</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>related social agency personnel</td>
<td>20</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>psychologist(s)</td>
<td>20</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>clergymen(men)</td>
<td>13</td>
<td>13</td>
<td>4</td>
</tr>
<tr>
<td>teacher(s)</td>
<td>5</td>
<td>9</td>
<td>16</td>
</tr>
<tr>
<td>individual(s) with similar illness/disability</td>
<td>25</td>
<td>4</td>
<td>1</td>
</tr>
</tbody>
</table>

followed by doctors, nurses, social workers, related social agency personnel, and psychologists. Relatives, friends, clergymen, and teachers were not considered by the sample to be as beneficial as speakers or resource persons for such a program.

In response to who else they might want to include as speakers or resource persons, two respondents wanted health professionals who have MS themselves, and one respondent mentioned...
each an occupational therapist, physical therapist, dietitian, and for a specific volunteer at the MS Society.

Sixteen of the thirty respondents stated they would agree to be a speaker or resource person if they were asked. Ten persons replied no, and four said that they might consider it.

When asked what information each felt would be valuable to another person trying to cope with MS based on their experience, the replies focused on seven major areas.

1. One should have faith in God and receive help through prayer.

2. One-to-one contact with other individuals with MS is supportive, but one should not dwell on symptoms and limitations since each person is unique; besides, negative attitudes are boring and depressing.

3. One should see the best professionals possible and keep informed. It will be up to you to treat yourself. It will be your attitude that determines the outcome of your illness.

4. Don't give up. Do whatever you can for as long as you can. Your philosophy and willpower can keep you independent.

5. Get help with fears right away and don't let them grow.

6. One should keep an open mind to alternative treatments. Don't listen to people who say it is hopeless. One should be moderate and find resource people who are competent but imaginative.

7. This disease is not contagious nor hereditary. During remissions, you can function fairly normally which is about 90%. Basic problems are not caused by MS but accentuated by this disease. MS tends to magnify situations and emotions. Sometimes, you can lose your ability to make rational decisions.
The responses to rating various types of educational materials indicated that small group discussions, lectures, and "hot line" telephone networks were favored. These were followed by books, pamphlets, movies, and simulations. Ten individuals felt that tapes or records would be beneficial to those who have altered vision. (Refer to Table 4.5.)

TABLE 4.5

RATING OF EDUCATIONAL MATERIALS BY MS RESPONDENTS

<table>
<thead>
<tr>
<th>Type of Educational Material</th>
<th>Very Beneficial</th>
<th>Somewhat Beneficial</th>
<th>Not Beneficial</th>
</tr>
</thead>
<tbody>
<tr>
<td>books</td>
<td>15</td>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td>pamphlets</td>
<td>16</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>movies</td>
<td>17</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>simulations</td>
<td>16</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>educational games</td>
<td>9</td>
<td>15</td>
<td>6</td>
</tr>
<tr>
<td>lectures</td>
<td>19</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>discussions</td>
<td>26</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>&quot;hot line&quot; telephone network</td>
<td>19</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>others</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>tapes, records</td>
<td>10</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>panels</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Following questions concerning resource persons, speakers, and educational materials, there was a series of open-ended questions about implementation of the program. Some participants felt that they could only comment on some aspects of implementation due to their limited knowledge of educational programming. Suggestions
for use of resource persons or speakers included: treat participants as equals, deal with practical aspects of the disease, provide up-to-date information, keep speeches short, and to really "listen" to what the participants are saying. Several respondents felt it would be very beneficial if a doctor or nurse who is personally coping with MS would be a speaker.

The respondents emphasized the need for active participation in the program by individuals with MS as well as by family members. Twelve respondents wanted active discussions between MS individuals and between the participants and speakers. Some concern was voiced that some level of confidentiality of information be upheld during these discussions.

There were fewer comments about the use of educational materials, but several people suggested that pamphlets or hand-outs be given in conjunction with lectures to facilitate understanding. Other suggestions included interspersing movies throughout the program.

Concerning program organization, suggestions were made to have movies followed by small group discussions with guidelines. Other suggestions included to have the program flow interestingly, and that there should be one coordinating chairman.

Twenty-two respondents felt an informal atmosphere would be most advantageous, and the remaining respondents did not comment on this question.

When asked who would most benefit from such a program, the respondents were fairly homogeneous in their answers. Table 4.6
TABLE 4.6

TYPES OF INDIVIDUALS WHO WOULD BENEFIT FROM PROPOSED PROGRAM
AND NUMBER OF MS RESPONDENTS SO INDICATING

<table>
<thead>
<tr>
<th>Types of Individuals</th>
<th>Number of MS Respondents*</th>
</tr>
</thead>
<tbody>
<tr>
<td>An individual who has just been diagnosed</td>
<td>5</td>
</tr>
<tr>
<td>An individual who has been coping with MS for a matter of months</td>
<td>6</td>
</tr>
<tr>
<td>An individual who has been coping with MS for a matter of years</td>
<td>5</td>
</tr>
<tr>
<td>Spouses</td>
<td>7</td>
</tr>
<tr>
<td>Children (the participants qualified this category to be children 10 years or older)</td>
<td>4</td>
</tr>
<tr>
<td>Relatives</td>
<td>3</td>
</tr>
<tr>
<td>Others</td>
<td></td>
</tr>
<tr>
<td>Fellow workers and employers</td>
<td>2</td>
</tr>
<tr>
<td>All of the above</td>
<td>21</td>
</tr>
</tbody>
</table>

*The respondents could rate more than one category.

records their responses. The majority (n = 21) felt that all of the persons listed would benefit from such an educational/counseling program.

The last question in this segment of the interview asked the respondent to sort Q cards with topics which had been previously rated as very and moderately important into two new piles. The piles would be those topics which the individual felt would best be presented on a one-to-one basis between a professional and themselves, and those topics which would best be presented for discussion to a small group. Each of the forty-six topics were included in this
<table>
<thead>
<tr>
<th>Topic</th>
<th>One-to-One</th>
<th>Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>--How to use new ways to deal with your illness/disability?</td>
<td>3</td>
<td>21</td>
</tr>
<tr>
<td>--How illness or disability can affect being a family member?</td>
<td>3</td>
<td>21</td>
</tr>
<tr>
<td>--How to contend with loss of easiness of movement?</td>
<td>5</td>
<td>18</td>
</tr>
<tr>
<td>--How to deal with worry and fear about future loss of body and mind functions?</td>
<td>6</td>
<td>16</td>
</tr>
<tr>
<td>--How to deal with varying feelings and emotions...happiness to depression, joy to anger?</td>
<td>6</td>
<td>16</td>
</tr>
<tr>
<td>--How to manage with lower energy levels which interfere with daily activities?</td>
<td>5</td>
<td>16</td>
</tr>
<tr>
<td>--How changes in one's body due to illness or disability can result in other changes in body functioning?</td>
<td>6</td>
<td>16</td>
</tr>
<tr>
<td>--Why uncertain increases in symptoms will affect the outcome of your illness or disability?</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td>--How changes in one's body can result in changes in the way a person thinks about himself/herself?</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td>--How to regain some control over body functioning after illness or disability?</td>
<td>4</td>
<td>15</td>
</tr>
<tr>
<td>--What caused your illness or disability?</td>
<td>5</td>
<td>13</td>
</tr>
<tr>
<td>--Why changes in body functioning result in certain symptoms that you are experiencing?</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>--How values and goals for being a family member can be affected by illness or disability?</td>
<td>4</td>
<td>20</td>
</tr>
<tr>
<td>--How values and goals for lifestyle can be affected by illness or disability?</td>
<td>2</td>
<td>20</td>
</tr>
<tr>
<td>--How to develop, alter, or confirm again personal beliefs, including your purpose for living?</td>
<td>4</td>
<td>16</td>
</tr>
</tbody>
</table>
TABLE 4.7--CONTINUED

<table>
<thead>
<tr>
<th>Topic</th>
<th>One-to-One</th>
<th>Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>--How to decide how much and what type of help you need to achieve your goals in life?</td>
<td>7</td>
<td>13</td>
</tr>
<tr>
<td>--How illness and disability can affect the way other people understand what you are trying to communicate to them?</td>
<td>2</td>
<td>23</td>
</tr>
<tr>
<td>--How to accurately interpret unspoken messages from others?</td>
<td>4</td>
<td>16</td>
</tr>
</tbody>
</table>

rating by the sample. Therefore, only those topics which were felt to be very and moderately important by the total sample will be reported. All of the topics rated higher for small group discussion than for one-to-one interaction between the individual with MS and a health professional. It should be noted, though, that six topics were rated by 20-30 percent of the sample as preferring a one-to-one interaction with health professional.

Sexuality Education/Counseling

The third segment of the interview contained open-ended questions concerning any education or counseling that the respondent had received with regard to sexuality and their illness, and what sexuality problems or concerns they presently had identified.

Twelve respondents said that they had received some sexuality education/counseling while the other seventeen had not. Of those who had, nine stated that it was provided by either a doctor and/or
nurse who did not offer information but answered questions frankly. Three respondents attended therapy or courses at Dodd Hall, Rehabilitation Center, University Hospital-Ohio State University. One such course at Dodd Hall was a "Creative Child Care" for preparing for arrival of baby when mother-to-be is handicapped. One individual had attended a ten-week course offered by the MS Society. Two individuals had sought additional assistance with private psychologists.

Those who had received education/counseling rated the assistance as fair (5), as not really helpful (2), and as very limited (5). One respondent who had rated her assistance with a psychologist as not that helpful stated that he did not understand multiple sclerosis and treated her like an "average" depressed person.

In responding to the question of what recommendations would each have to increase the helpfulness of this type of assistance for yourself and for others, these were the replies:

1. Tell me what MS really is...even if don't know all the answers, I need to have some kind of an answer.

2. The individual doing the counseling needs to be caring and to build up a rapport first before delving into sexuality counseling. It should be done in private. The day I was discharged from Dodd Hall, one of the nurses walked up to me and told me that if I wanted to have sex, I should tape my catheter up on my stomach. We were in the hallway at the nurses' station. That's all I got.

3. I would have preferred to have some counseling on a one-to-one basis and told what to expect even if it was just to expect the unexpected. I need more specific information. Would like to meet Watson Parker.
4. The free offer of information would be better instead of me having to ask all the questions first.

5. A specialist in MS who is comfortable with their own sexuality would be helpful.

6. Experience is the best teacher.

The respondents were then asked if they presently perceived a sexuality problem or concern. Five stated no, the balance of the thirty people admitted to one or more problems and concerns. These problems and concerns with a frequency number is included here.

4 - independence: the need to do more for self
17 - exhaustion: mind is more active than body
3 - depression
15 - body image alterations: ashamed, angry, and frustrated with body
1 - loss of fine motor control
5 - many fewer new friends made: loss of some old ones too
7 - decreased feminine feelings
6 - decreased masculine feelings
21 - psychological ups and downs
5 - altered role as parent due to limitations
10 - altered role as spouse due to limitations
8 - altered role as worker due to limitations
2 - altered role as daughter due to chronic illness
1 - personality changes which are uncontrollable
15 - sexual functioning: actually dysfunctioning
5 - active role in community is restricted
4 - recreational activities restricted
1 - tranquilized mental state due to being loaded down with drugs
3 - self-consciousness about self when out in public

These problems and concerns were felt to be strongly related to the limitations which the illness/disability had placed on their daily activities.

Several of the participants in this study expressed a profound need to receive sexuality education/counseling and voiced
an interest in future programming. All participants were told at the end of the interview that they would be notified of an autumn workshop on sexuality based on the findings of this study. Three respondents have called the author at home to discuss problems, concerns, and to offer additional information.
Summary

The purpose of this study was to delineate elements for a sexuality program for individuals with multiple sclerosis through a needs assessment. This was accomplished by ascertaining what knowledges and attitudes were considered important to the attainment of sexual health. In conjunction with this information, demographic data were compiled in order to note any relationships between educational/counseling needs by age, sex, severity of disability, formal education, race, length of time since diagnosis, former health status, number of illnesses and disabilities, employment status, religious affiliation, cultural background, and relationship status. The participants were also questioned about their preferences in learning experiences. The respondents were asked if they had ever received any sexuality education/counseling; and, if so, to describe it. They were also asked to describe any sexuality problems or concerns that they have had in the past or are currently having.

Thirty individuals who have multiple sclerosis participated in this study. Their names were randomly drawn from the Mid-Ohio
Chapter of the Multiple Sclerosis Society, and they had all agreed to an interview. Each individual resided in Franklin County and was not hospitalized at the time of the study.

All interviews were conducted in the participants' homes by their preference and lasted from one hour fifteen minutes to three hours. The same interviewer conducted all interviews and recorded the participant's answers to avoid problems with eyesight and hand coordination. All but one participant signed a consent form after an explanation of what the interview would consist of and before the actual interview took place. The individual who did not, refused since her eyesight was so diminished that she could not read the form. She gave her verbal consent.

The first instrument used in this study was a Q Sort of forty-six questions for possible topics to be included in a sexuality educational/counseling program which each participant rated as to importance for their attainment of sexual health. The second instrument of the interview included open-ended and structured questions regarding learning experiences. This was followed by open-ended questions about any previous sexuality education/counseling and any perceived sexuality problems and concerns. The last instrument included open-ended and structured questions about personal information.

The results of this needs assessment indicated that the thirty men and women with multiple sclerosis who were included in this study rated the following topics as very important to their
attainment of sexual health:

--How to use new ways to deal with your illness/disability?

--How illness or disability can affect being a family member?

--How to contend with loss of easiness of movement?

--Why uncertain increases in symptoms will affect the outcome of your illness or disability?

--How values and goals for being a family member can be affected by illness or disability?

--How illness and disability can affect the way other people understand what you are trying to communicate to them?

The subjects rated as moderately important to them the following topics:

--How to deal with worry and fear about future loss of body or mind functions?

--How to deal with varying feelings and emotions... happiness to depression, joy to anger?

--How to manage with lower energy levels which interfere with daily activities?

--How changes in one's body due to illness or disability can result in other changes in body functioning?

--How changes in one's body can result in changes in the way a person thinks about himself/herself?

--How to regain some control over body functioning after illness or disability?

--What caused your illness or disability?

--Why changes in body functioning result in certain symptoms that you are experiencing?

--How values and goals for lifestyle can be affected by illness or disability?
— How to develop, alter, or confirm again personal beliefs, including your purpose for living?

— How to decide how much and what type of help you need to achieve your goals in life?

— How to accurately interpret unspoken messages from others?

There were no topics that the sample agreed were not important. Many topics, though, were rated less important and had a wide variability of ratings.

In this latter case, each personal characteristic was analyzed for general relationships which could be helpful in future program development. General relationships were noted only for characteristics which had five or more subjects responding in a similar manner, or for sub-groups which could be combined due to their similarity in rating topics. The following are the relationships by characteristic.

**Age**

— Those persons who were 20-34 years of age rated topics pertaining to self-concept and to knowledge about the body as very and moderately important. Topics relating to obtaining or maintaining a sexual partner were moderately important.

— Those who were 35-49 years of age were more concerned with topics relating to value clarification and obtaining or maintaining a sexual partner. These topics were rated moderately important.

— Those persons who were 50 years old or older were divided in their response to self-concept questions and rated some moderately important and others not important.

**Sex**

— Females only rated one topic moderately important which was dealing with fewer contacts with friends and family members due to limitations caused by MS.
Males, on the other hand, rated as very important or moderately important, several topics from each factor of sexual health. Especially strong relationships for very important were topics concerning knowledge of the body, clarification of values, and obtaining or maintaining a sexual relationship.

**Relationship Status**

--Single people rated as very important coping with fewer contacts with friends and family members. They rated as moderately important several topics concerning self-concept. Also rated as moderately important were how treatments affect sexual functioning, and values and goals for sexual behavior.

--Persons in partner relationships also rated values and goals for sexual behavior as moderately important in addition to two other value clarification topics. Self-concept topics were also rated moderately important.

**Education**

--Those persons with nine years or less of school, and those with a college degree rated topics similarly. Both of these groups rated as very important how to cope with loss of physical functioning. Not important were several topics relating to self-concept, how to deal with the feeling of risk when expressing intimate wants and desires, and two of the four topics relating to sexual partner(s).

--Those persons with a high school diploma and those with graduate degrees were more similar in their ratings than other groups. They rated as very or moderately important numerous topics relating to self-concept, knowledge of the body, value clarification, communication, and sexual partner(s). However, there were differences. The high school education individuals, as a group, did not rate any topic as not important. Those with graduate degrees rated five topics relating to self-concept, one concerning diet/smoking/drinking restrictions, and how to "know" yourself as not important.

**Employment**

--Persons who were employed rated how to achieve acceptance of loss as very important. Moderately
important was the rating for new modes of sexual pleasure. Two topics each dealing with self-concept and communication were rated as not important.

Persons who were not employed rated two to three topics pertaining to self-concept, knowledge of the body, value clarification, and communication as moderately important. This group did not rate topics very or not important.

Religion

An interesting relationship was noted in this subcategory. Seven topics were rated as very important or moderately important by both those who were Catholic, and those who had no religious affiliation. Both groups felt it important to know how the body functions, and what new modes of sexual pleasure were possible. Each of these groups rated several topics concerning value clarification and communication as very or moderately important.

Length of Time Since Diagnosis

Those who were in the less than five years, five to nine years, and ten to fourteen years categories rated several topics relating to self-concept as moderately important. Those who were in the less than five and five to nine years categories also rated several topics dealing with knowledge of the body as moderately important.

Those diagnosed from five to nine years rated topics of value clarification, communication, and sexual partner(s) as moderately important.

Those diagnosed less than five years rated how to deal with grooming difficulties as not important while those who were diagnosed five to nine years rated feeling masculine or feminine with regard to changes of MS as not important. Those diagnosed ten to fourteen years rated being a sexual partner, and how to contend with persistent pain or discomfort as not important.

Former Health Status

Those who reported good and fair health status rated new modes of sexual pleasure as not important. Those who reported good health status prior to MS rated values and goals for sexual behavior as moderately important.
Severity of Disability

Persons who required no assistance and those who required a cane or walker were more similar in their ratings. These two groups rated most or all of the topics in each factor of sexual health as moderately or very important.

Persons who required a wheelchair or who were bedridden were more similar in their scoring. Three or four topics in each of the following categories: self-concept, knowledge of the body, communication, and sexual partner(s) were rated not important.

Ten additional topics were proposed by participants. (Refer to page 88.) Each topic can be related to one of the five factors of sexual health which is proposed in Chapter I.

When asked about learning experiences, the participants preferred doctors, nurses, social workers, social agency staff, and psychologists as speakers and resource persons. Individuals with multiple sclerosis received the highest rating for being speakers or resource persons; since, as it was explained by the respondents, they really understand what it is like to cope with MS, while health professionals can really only be sympathetic and empathetic when providing education and counseling. The value of having clergymen as speakers was split between yes and maybe. Those persons who were not wanted as speakers were relatives, friends, and teachers.

Of the respondents, sixteen stated they would consider being speakers or resource persons for an educational/counseling program, four were undecided, and ten said they would not.
Information, which they felt would be helpful to another person trying to cope with MS based on their experience, focused on faith in God, optimistic outlook on life, receiving support from other persons with MS and from health professionals, and understanding that the disease will magnify situations and emotions out of proportion to reality.

Pamphlets, movies, simulations, lectures, discussions, and a "hot line" telephone network were the preferred educational materials. Books were rated between very and somewhat beneficial since some respondents felt that they would not want to take time to read books while attending an educational/counseling program. Educational games rated somewhat helpful, but every respondent admitted that they had no experience with such educational materials. Several participants also suggested the use of tapes and records for those persons with diminished eyesight, and one participant thought a panel discussion might be interesting.

In response to questions about implementation of the program, the emphasis was on active participation by those attending the program, with active dialogue between them, the speakers, and resource people. The content should be concise, practical, and up-to-date. Several respondents stated their desire to hear from a health professional who is coping with MS.

Several individuals suggested that written materials be handed out in conjunction with lectures so that note taking is not necessary, and that movies might be followed by discussion groups. Twenty-two of the respondents felt that an informal
atmosphere for the program would be most advantageous.

When asked who would most benefit from such a program, the majority felt that any individual with MS, spouses, children (qualified to be children 10 years or older), and relatives. Two respondents also felt that fellow workers and employers would also benefit.

The respondents were then asked to separate those topics which they had felt to be very and moderately important to their attainment of sexual health into topics to be dealt with most effectively on a one-to-one basis with a health professional or in a small group discussion. All topics received higher scores for small group discussions, although it should be noted that some topics received 20-30 percent of the respondents preferring presentation on a one-to-one basis.

Of the thirty respondents, twelve had received some type of sexuality education/counseling in the past, whereas seventeen had not. Of the twelve, nine had received answers to their questions from doctors or nurses. Three participants had sought help from private counselors or rehabilitation courses. Of those who had received some education/counseling, five rated the assistance as fair, five rated it very limited, and two stated that the assistance was not really helpful.

Their recommendations for improving such assistance was to have free offer of information by a health professional who is not only comfortable with his/her own sexuality, but who is supportive
and caring. He/she should offer accurate and current information about the facts and the questions still to be answered. It would be helpful to know what to expect, even if it is just to expect the unexpected.

Twenty-five respondents admitted to one or more sexuality problems or concerns. Those with the highest frequency of occurrence were: exhaustion, problems with body image, psychological ups and downs, role of spouse, and sexual functioning.

Several participants voluntarily expressed an interest and need for educational/counseling programs in sexuality.

Implications for Program Planning

This educational needs assessment was comprehensive in that it supplies data on not only what the participants want and need to know about sexuality and their disease, but also how they would like this information presented.

The assessment procedures must undergo a formative evaluation. (Refer to model of curriculum development, p. 6.) These questions were addressed.

--Does the sexuality assessment reinforce the philosophy of sexual health and sexuality education/counseling?

This assessment did reinforce the philosophy of sexual health and sexuality education/counseling which was promoted by the author, and which agreed with the Multiple Sclerosis Society Mid-Ohio Chapter, and with the Human Subjects Committee at The Ohio State University. The assessment was conducted under the ethical
considerations outlined on p. 56. It included assessing all five factors for obtaining sexual health which were discussed on pages 3-4. In designing educational programs which center upon sexuality and how it is affected by MS, and which meet the needs of the individuals for whom they are designed, it is first necessary to ask what their needs are, and how best can they be served.

---Was the information gathered during the assessment valid?

The assessment instruments received face validity from a panel of experts in curriculum development, qualitative research, and human sexuality from The Ohio State University. Information concerning all five factors of sexual health was gathered in an interview format. The interview approach permitted the opportunity for questions and answers as well as an opportunity to build up a rapport between the researcher and the respondent. Thus, the information received was in-depth focusing on problematic areas of his/her life. The information was sufficiently meaningful in designing an educational/counseling program proposal.

---Was the information gathered during the assessment reliable?

The vocabulary of the interview schedule was reviewed by the panel of experts from The Ohio State University and by the patient services committee of the MS Society to ensure that it was at the fourth grade level, in order to facilitate understanding by respondents with minimal education. The respondents were encouraged to ask questions as to the meaning of words and phrases during the interview.
All those who participated in the study appeared to provide information freely, and no one omitted answering questions. This can probably be explained by the fact that those who consented to be interviewed probably felt more comfortable with their sexuality than those who chose not to participate in the study.

All participants were told that they were not expected to reveal information which they did not want to reveal, or which they might feel uncomfortable discussing with the researcher. This approach was made to foster honest and consistent response, so that fabrication was not necessary.

---Were measures taken to provide privacy and lack of interruptions during the assessment(s)?

All interviews were conducted in the participants' homes at their request. The participants were encouraged to have a spouse, family member, or close friend present during the interview, if it would increase their comfort level. In some cases, this is what took place; and in others, the author and the participant were alone. Few interruptions took place since most of the respondents chose times and dates which were most convenient for them.

---Were measures taken to ensure confidentiality of the information received?

First of all, only the author knew whose names had been drawn from the MS Society files. The author was also the only one who knew who was or was not in the study. Secondly, all interview forms were identified in code numbers rather than names. Lastly, the list of names and addresses of participants was destroyed after
sending summary letters to the participants.

Following the educational needs assessment, educational aims should be formulated. (Refer to curriculum development model, p. 6.) Educational aims are concepts that describe expected life outcomes based on the philosophy and assessment. They are the intentions of the program: the sought after "ends." "Ends" refers not to terminal points of learning; but, rather, as Dewey proposed, as "terminals of deliberation, and so turning points in activity" (Zais, 1976:298). Means and ends are not considered to be distinct entities, but rather compose a continuum with ends becoming means for newly determined ends. Thus, educational aims should be in a "fluid" state of development.

The educational aims, proposed from the data of this study, are the following:

1. To promote learning about sexuality in self and in others in order to use it toward the greatest creativity and fulfillment.

2. To promote the attainment of sexual health in the manner(s) prescribed by the individual(s) involved, unless these are unrealistic or involve unethical behavior on the part of the health professional.

3. To increase self-esteem: the belief in oneself, self-respect. With increased self-esteem, there is a greater potential for attaining sexual health; since, sexual health is a result of the integration of physical, emotional, intellectual, social, and ethical aspects of being a sexual being.

4. To foster obtaining the opportunity for a more "normal" life. This involves utilizing means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible.
These educational aims then must receive a formative evaluation before proceeding to the next step of curriculum development, which is the formulation of learning objectives. The formative evaluation should include these questions:

---Do the selected educational aims represent the individual's educational goals?

---Are they worthwhile? Are the selected educational aims worth the time, effort, and money which will be expended upon their achievement?

---Do the educational aims provide a rationale for the determination of educational objectives?

---Can the health professional(s) involved in the education/counseling program accept these aims?

---Were steps taken to ensure confidentiality of educational aims for individual patients?

It is the judgment of the author that all of these questions can be answered in a positive manner, and it is acceptable to proceed to the next step.

Learning objectives are the most immediate specific outcomes which are planned for the learner. They are directly related to the educational aims and can be categorized into process, content, and behavioral objectives.

1. To promote learning about sexuality:

   A. To augment understanding of how medical, surgical, or chemical alterations have affected or may affect body functioning and self-image.

   B. To review and to increase understanding of the body's anatomy and physiology in health and in illness.

   (These are content objectives.)
2. To promote the attainment of sexual health:
   A. Sexuality is a component of self-actualization.
   B. Sexuality is a part of relationships at all ages.

   (These are process objectives.)

3. To increase self-esteem which is the belief in oneself:
   A. To enhance feelings of self-worth and begin to develop control over sexual thoughts, emotions, and behaviors.
   B. To identify personal sexual values and attitudes, and to learn how they affect interpersonal relationships.

   (These are process objectives.)

4. To foster obtaining the opportunity for a more "normal" life:
   A. To engage in sexual expressions which are satisfying singly or with a partner.
   B. To seek out further assistance and/or information if needed, and to know where to find this assistance.

   (These are behavioral objectives.)

These learning objectives must be evaluated with consideration for a formative evaluation which answers these questions:

--Has each educational aim been contained in the learning objectives?

--Have the participants been self-directing in formulating these learning objectives?

--Are they clearly stated?

--Are they definitive enough to permit selection of content?
--Have the learning objectives included process, content, and behavioral objectives? If not, was this the participants' choice?

--Can the learning objectives be realistically achieved?

--Are the learning objectives within the value system of sponsoring organization?

--Are the values which are being reaffirmed by the priority given to these objectives consistent with the philosophy?

--Have steps been taken to ensure confidentiality of the information?

If all of these questions can be answered in a positive manner, the development of content for the program can begin. As mentioned in Chapter I, p. 8, the learning objectives and the content are directly related since the content is contingent upon the learning objectives.

The content for this proposed educational counseling program is based on the learning objectives and the specific topics given priority in the Q Sort and upon those problems and concerns in sexuality which were most prevalent. The substance for the proposed program with the relationships between educational aims, learning objectives, and content selection is represented in Table 5.1.

As in the preceding steps, the content selection must also receive a formative evaluation. This includes:

--Is each learning objective provided with content?

--Does the selected content meet the wants and needs of the individuals for whom the program is planned?

--Are the health professional(s) competent in dealing with this content?

--Have steps been taken to ensure confidentiality of the information?
<table>
<thead>
<tr>
<th>Educational Aims</th>
<th>Learning Objectives</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. To promote learning about sexuality in self and in others in order to use it toward the greatest creativity and fulfillment.</td>
<td>A. To augment understanding of how medical, surgical, or chemical alterations have affected or may affect his body functioning and self-image.</td>
<td>(1) Uncertain increases in symptoms can affect the outcome of your illness and disability.</td>
</tr>
<tr>
<td></td>
<td>B. To review and increase understanding of the body's anatomy and physiology in health and in illness.</td>
<td>(2) Changes in one's body due to MS can result in other changes in body functioning.</td>
</tr>
<tr>
<td></td>
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<td>(3) Changes in one's body can result in changes in the way a person thinks about himself/herself.</td>
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<td>(4) Some control over body functioning can be regained after an exacerbation.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(5) Changes in body functioning result in certain symptoms that you are experiencing.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(1) The most current theories for the cause of MS as well as the most current treatments for the disease would be discussed.</td>
</tr>
<tr>
<td>Educational Aims</td>
<td>Learning Objectives</td>
<td>Content</td>
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</tr>
<tr>
<td>2. To promote the attainment of sexual health in the manner(s) prescribed by the individuals involved.</td>
<td>A. Sexuality is a component of self-actualization.</td>
<td>(1) New ways to deal with your illness and disability would be explored.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(2) How to contend with loss of easiness of movement.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(3) How to deal with worry and fear about future loss of body or mind functions.</td>
</tr>
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<td></td>
<td>(4) How to deal with varying feelings and emotions: happiness to depression, joy to anger.</td>
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<tr>
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<td>(5) How to manage with lower energy levels which interfere with daily activities.</td>
</tr>
<tr>
<td></td>
<td>B. Sexuality is a part of relationships at all ages.</td>
<td>(1) Multiple sclerosis can affect being a family member.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(2) There are various factors to consider in making the decision whether or not to have children.</td>
</tr>
<tr>
<td>Educational Aims</td>
<td>Learning Objectives</td>
<td>Content</td>
</tr>
<tr>
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<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>3. To increase self-esteem: the belief in oneself, self-respect.</td>
<td>A. To enhance feelings of self-worth as begin to develop control over sexual thoughts, emotions, and behaviors.</td>
<td>(3) Problems and &quot;solutions&quot; of being handicapped and employed.</td>
</tr>
<tr>
<td></td>
<td>B. To identify own sexual values and attitudes and to learn how they affect interpersonal relationships.</td>
<td>(1) How to develop, alter, or confirm again personal beliefs, including your purpose for living.</td>
</tr>
<tr>
<td>4. To foster obtaining the opportunity for a more &quot;normal&quot; life.</td>
<td>A. To engage in sexual expressions which are satisfying singly or with a partner.</td>
<td>(1) Values and goals for being a family member can be affected by multiple sclerosis.</td>
</tr>
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<td></td>
<td></td>
<td>(2) Values and goals for one's lifestyle can be affected by multiple sclerosis.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(1) Illness and disability can affect the way other people understand what you are trying to communicate to them.</td>
</tr>
<tr>
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<td>(2) How to accurately interpret unspoken messages from others.</td>
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</tbody>
</table>
### TABLE 5.1—CONTINUED

<table>
<thead>
<tr>
<th>Educational Aims</th>
<th>Learning Objectives</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>(3) Alternative expressions of sexual feelings when faced with sexual dysfunction.</td>
</tr>
<tr>
<td>B. To seek out further assistance and/or knowledge if needed, and to know where to find this assistance.</td>
<td></td>
<td>(4) Options to promote optimum sexual functioning.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(1) To achieve one's goals in life, and how much, and what type of assistance is required.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(2) Resources in your community may be beneficial.</td>
</tr>
</tbody>
</table>
If these questions can also be answered in a positive manner, then the focus of attention can be on learning experiences.

When considering learning experiences, ethical issues of program implementation must be considered. The ethical issues which were raised during the assessment continue to be relevant during the program implementation of learning experiences. (Refer to p. 56.)

There are two additional ethical issues which are specific to learning experiences. The first of these deals with confidentiality of information received. A case history is not anonymous. Therefore, it is necessary to use hypothetical individuals with common difficulties or concerns as examples. The second ethical issue is maintaining confidentiality of information in group discussions. Information received in the group must stay within the group and not be permitted to be discussed with others. Certain restraints may also prove to be useful, such as stating that anyone who violates confidentiality would no longer be permitted back in the group.

Speakers and resource persons would be drawn from doctors, nurses, social workers, MS Society staff, psychologists, and individuals with MS. First priority would be given to professionals who are knowledgeable about the proposed content, and who have direct experience either with MS or another chronic illness. Direct experience would mean having MS or another chronic illness, having a family member who is so coping, or working directly with individuals who do have MS or another chronic illness.
The second priority would be to include individuals, who are not professionals but who have MS, to be resource persons such as small group discussion leaders. Sixteen of the thirty respondents said they would be willing to fill these roles if asked.

Educational materials would be selected from pamphlets, movies, simulations, short lectures, discussions, and possibly educational games. The latter might be tried to impart information about facts and myths about MS. A "hot line" telephone network could be made available for an hour or two, one or two days a week for several weeks following the program. The "hot line" would permit individuals to call in anonymously with questions about MS.

The atmosphere would be informal with frequent periods of time allotted to small group discussion, with or without structured questions, and for question and answer periods following presentations. The educational experience which received the highest rating was group discussions; and, since individuals with MS also received the highest rating for resource persons, these could easily be combined to foster the sharing of ideas and coping mechanisms of peers.

Although small group discussions were the most preferred for all the topics rated, there was a substantial number of people, 20-30 percent, who preferred a one-to-one interaction. This proposed program could include small group discussions initially which could be followed by one-to-one interactions with a health professional as the participants deemed helpful. It should always be remembered
that sexuality is a value-laden issue and even anxiety provoking to some individuals who may not feel comfortable sharing intimate concerns and problems in a group setting.

Before implementing the learning experiences, they too must receive a formative evaluation of the following questions.

--Do the selected learning experiences incorporate the learning objectives, the content, and the preferred learning style of the recipients.

--Do the learning experiences reinforce the individual's learning, self-concept, and critical thinking?

--Are the approaches for instruction/learning varied? Is a multisensory-stimulation approach feasible?

--Do the learning experiences meet the individuals' learning needs without over-powering them with information?

--Were steps taken to ensure confidentiality of participation in this sexuality education/counseling program?

--If a small group format is planned, were opportunities for individual counseling provided?

If positive responses can be made to these questions, then the implementation of the program can take place.

These, then, are the elements of a proposed sexuality program for individuals with multiple sclerosis based on an educational needs assessment.

Recommendations

It is proposed that educational needs assessments using similar or improved formats, such as used in this study, be implemented with additional groups of individuals with multiple sclerosis
and with other chronic illnesses and disabilities. The interview schedule is valuable in providing an in-depth focus on sensitive and emotionally laden information. Fifty-five percent of those persons contacted agreed to be in the study. In comparison with the thirty-three individuals who participated in the pilot project and the study, twelve persons said they did not wish to be in the study, eleven were in exacerbation or were too physically and mentally debilitated to participate, one woman was hospitalized, and one woman reported that she had been misdiagnosed. Fifty-five percent compares favorably to 40-60 percent return rate which is common among mailed questionnaires.

The resulting information from future educational needs assessments will be valuable for educational/counseling programming in that these data would note what the most important perceived needs are by individuals with various chronic illnesses and disabilities. The relationships between demographic characteristics and topic areas may be expanded, supported, or not supported.

In addition to other needs assessments, other facets of human sexuality should be explored:

--What is the relationship between past sexual health and coping ability in relation to present illness/disability and attainment of sexual health?

--What modes of sexuality education/counseling are the most effective and efficient in meeting needs?

--On what bases do participants evaluate educational programs for content, presentation, location, time, and underlying value systems.
---How does stress affect validity and reliability of needs assessments and for educational programming?

Continued research in the field of human sexuality in health and illness will contribute to the growth and development of relevant and efficient educational/counseling programming for individuals who are faced with chronic illnesses and disabilities.
ALTERATIONS IN BODY FUNCTIONING AND SELF-CONCEPT
DUE TO MULTIPLE SCLEROSIS WHICH MAY
AFFECT SEXUALITY

Individuals who have multiple sclerosis have the potential of incurring sexuality difficulties due to their illness. Multiple sclerosis (MS) literally means "many scars" and is a neurological disorder involving demyelination and affects about half a million people in the United States.* The majority of diagnoses are made between the ages of twenty and forty which is a time when people commonly raise a family and set their life goals.

The disease is characterized by sudden attacks and remissions. The time interval between exacerbations can vary from days to thirty years. With each exacerbation, there is usually some additional permanent damage to the nervous system. Remissions can be partial or seemingly complete.

MS has no known etiology, and no known cure nor treatment. The major theories of causation include a slow virus infection, vitamin deficiency, hormone imbalance, enzyme system dysfunction, change in blood flow, and an allergic reaction (Hess, 1962:14+).

Multiple sclerosis is very difficult to diagnose. Experienced neurologists have estimated a diagnosis revision rate of 20 percent of their primary diagnoses (Field, 1977:3). There is generally a period of four years between initial symptoms and

*Statistic provided by Craig Carrelts, Patient Services Coordinator of the MS Society of Mid-Ohio, November, 1978.
definitive diagnosis. Diagnosis is only assured at autopsy, and then it depends on the thoroughness of the examination. The often-quoted study by Georgi in 1961 of misdiagnosis indicated that only 69.7 percent of MS cases were correctly diagnosed at autopsy. He based his results on 15,644 postmortem examinations (Field, 1977:4).

Heslinga has delineated common physical symptoms experienced by individuals with multiple sclerosis, and how they affect their sexual functioning and self-concept. They are:

1. Ophthalmic symptoms range from blurred vision to blindness.
2. Ataxia is another symptom, involving difficulties in regulating the strength and size of movements, so that holding things is a problem and walking is difficult to impossible.
3. Spastic symptoms are especially prevalent in the legs, resulting in fixed postures and restricted movements.
4. The sensibility of the individual is sometimes disturbed. Decreased sensibility affects excitability and the ability to achieve orgasm.
5. Bladder control is often lost. The urge to urinate is felt, but the spastic condition of the bladder (hyper-reflexia) as well as lack of control over the external sphincter results in incontinence.
6. Libido usually remains intact and is sometimes reinforced. The ability to have an erection may vary from impotence to very strong reflexes under stimulation and intermediate, short, quick erections, which disappear before coitus can be attempted. Ejaculation varies from normal, to premature, to retrograde. If ejaculation does occur and sensibility is intact, orgasm is a possibility. Procreation is also then possible. There are no apparent congenital defects due to multiple sclerosis.
7. Euphoria (overly optimistic and unrealistic view) may actually be true dementia, with symptoms such as lack of insight into the nature of the illness.
8. Pregnancy and contraception must also be considered. a. It is certain that MS frequently begins in connection with pregnancy and lactation. If the individual is well controlled with treatment, she may go ahead and try to have a
family. If MS is active, abortion is indicated for medical reasons.

b. Contraception is indicated if the disease is progressing. There are many indications that birth control pills have a harmful effect on existing MS and can bring latent MS into an active stage. If no family is desired or is already formed, sterilization of patient or partner is desirable. (Heslinga, 1974:86-88)

Chemical alterations due to some of the medications which are commonly prescribed for MS may also have sexual side effects.

Tranquilizing drugs which act as sympathetic nervous system depressants may interfere with emission and ejaculation. Antidepressant drugs, which have an indirect stimulatory effect on the sympathetic system and an inhibitory effect on the parasympathetic system, may interfere with erection. In addition Valium used as an antispasmodic may cause a slight reduction of sexual interest in some people. (Barrett, 1977:7)

Barrett only reported male sexual functioning effects of drugs, but it is probable that there are comparable effects on females. There are few studies which document female sexual functioning alterations due to drugs.

In addition to these physical problems, the following psychological problems related to multiple sclerosis have been described by Heslinga, Pulton, Smith, Burnfield, Schneitzer, and their associates.

1. Due to physical alterations and dysfunctions, self-esteem, aversion of self, self-consciousness, and social alienation are strongly affected.

2. The disease often exists for a long time without being diagnosed. This time may be spent in reproach and estrangement, in reproof about laziness, lack of initiative, unsuccessful attempts at intercourse, and adductor spasms linked with vaginismus.

3. With reduced self-esteem and anxiety over the future in selected social roles and as a sexually competent individual, depression and feelings of
worthlessness often occur. These feelings increase the likelihood of sexual dysfunction, and the cycle repeats itself and spirals downward until the individual sees himself as neutered and useless. (Burnfield and Burnfield, 1978:1194)

These psychological problems may be more traumatic and cause more suffering than the physical problems. Sexual health involves not only biological function, but also physical competence and psychological comfort as well (Cole and Cole, 1977:526).
Dear

Health professionals are being urged to accept sexuality as an integral part of people and thus, are accepting a responsibility to promote sexual health in their total health practice. Patient education programs which center upon sexuality and how it is affected by illness and disability are being developed. To make such programs meet the needs of the individuals for whom they are designed, it is first necessary to ask what these needs are and how best can people who experience illness or disability be served.

The Mid-Ohio Chapter of the MS Society is joining with the College of Education at Ohio State University in a project to find out what the sexuality educational needs are of individuals who have multiple sclerosis. This will be your opportunity to make your needs and wants known, and to provide useful information to be used in developing educational programs for others.

Within a week of receiving this letter, you will receive a telephone call from Ann Teske, R.N. who will be conducting this study. Ann is currently a doctoral candidate in the College of Education at OSU. She has provided a sexuality course and numerous workshops for nurses in sexuality, and has provided sexual education and counseling for various patient groups.

Ann would like to meet with you for an interview which will take approximately one hour. This interview can take place in your home or at the MS Society, whichever is more convenient for you. All information will be kept confidential. If you would like, your spouse or a friend may be present during the interview.

If you would like to discuss this study with Ann further, prior to her calling you, please contact her at her home at 459-0418. Questions and concerns that you might have are welcome--now and during the study.

We hope that you will be able to participate in this study. Thank you for your consideration.

Sincerely yours,

Watson Parker, M.D., Chairman
Patient Services Committee

Ann Teske, R.N., M.A.
I consent to participating in (or my child's participation in) a study entitled **Delineation of Elements of a Sexuality Program for Individuals with Multiple Sclerosis Through a Needs Assessment** has (Investigator/Project Director or his/her authorized representative) explained the purpose of the study and procedures to be followed. Possible benefits of the study have been described as have alternative procedures, if such procedures are applicable and available.

I acknowledge that I have had the opportunity to obtain additional information regarding the study and that any questions I have raised have been answered to my full satisfaction. Further, I understand that I am (my child is) free to withdraw consent at any time and to discontinue participation in the study without prejudice to me (my child). The information obtained from me (my child) will remain confidential and anonymous unless I specifically agree otherwise.

Finally, I acknowledge that I have read and fully understand the consent form. I have signed it freely and voluntarily and understand a copy is available upon request.

Date: ________________________________ Signed: ________________________________

(Participant)

(Investigator/Project Director or Authorized Representative) (Person Authorized to Consent for Participant - If Required)

PA-027 (2/79) -- To be used only in connection with social and behavioral research for which an OSU Human Subject Review Committee has determined that the research poses no risk to participants.
Sexuality is the maleness or femaleness to which each of us is born. It is the essence of each of us, the unique creative drive that makes each of us an individual of worth. Therefore, it is a broad concept which encompasses how masculine or feminine you feel, how you feel about your body, your sexual functioning, and your roles as spouse, parent, family member, worker, and member of your community.

Imagine that within the next week, you will be attending a program on sexuality and the illness or disability that you are experiencing. Thinking about your own wants and needs, how would you arrange the following possible questions to be answered by such a program. Identify those that you think of as (1) very important, (2) moderately important, (3) less important, and (4) not important.

Please do so at this time, making four piles of these 5x8 cards.

Sexual Health Q Sort Cards

(Cards relating to positive self-image or self-concept)

-- Why your illness or disability can change the way that you feel about your body?

-- Why your illness or disability can change the way you feel about being masculine or feminine?

-- How your feelings about your sexual attraction to the same or to the other sex may change?

-- How to use new ways to deal with your illness/disability?

-- How illness or disability can affect being a sexual partner?

-- How illness or disability can affect being a family member?

-- How illness or disability can affect being a paycheck earner?

-- How illness or disability can affect being an active member of your community?

-- How to deal with worry and fear about future loss of body or mind functions?
-- How to deal with varying feelings and emotions... happiness to depression, joy to anger?

-- How to deal with using artificial or mechanical aids?

-- How to contend with loss of functioning such as elimination, fertility, or sexual functioning?

-- How to contend with loss of easiness of movement?

-- How to manage with lower energy levels which interfere with daily activities?

-- How to deal with grooming difficulties?

-- How to contend with fewer contacts with friends and family members due to limitations caused by illness or disability?

-- How to contend with persistent pain or discomfort?

-- How to achieve acceptance of loss?

(Cards relating to knowledge of body and some degree of control over body functioning)

-- How your body functions and how the body of the opposite sex functions?

-- How changes in one's body due to illness or disability can result in other changes in body functioning?

-- How changes in one's body can result in changes in the way a person thinks about himself/herself?

-- How to regain some control over body functioning after illness or disability?

-- How drugs which are prescribed for you may affect your sexual functioning?

-- How treatments for your illness or disability may affect your sexual functioning?

-- What caused your illness or disability?

-- Why changes in body functioning result in certain symptoms that you are experiencing?

-- How sex drive is affected by disability or illness?
Why illness or disability may result in the need for diet/smoking/drinking restrictions?

Why uncertain increases in symptoms will affect the outcome of your illness or disability?

(Cards relating to clarification of values)

How values and goals for lifestyle can be affected by illness or disability?

How values and goals for sexual behavior can be affected by illness or disability?

How values and goals for being a family member can be affected by illness or disability?

How problem solving skills can be used to achieve changing self-goals?

How to develop, alter, or confirm again personal beliefs, including your purpose for living?

How to decide how much and what type of help you need to achieve your goals in life?

How to decide which persons would be most helpful to you in achieving your goals in life?

(Cards relating to ability to communicate clearly and effectively)

How illness and disability can affect the way other people understand what you are trying to communicate to them?

How to "know" yourself with your sexual wants and needs?

How to express your sexual wants and needs clearly and effectively?

How to accurately interpret unspoken messages from others?

How to develop a feeling of freedom to discuss sexual fears and concerns with others?

How to deal with the feeling of risk when expressing intimate wants and desires?
(Cards relating to choosing sexual partner(s) for relationship(s) which is (are) positive, creative, and fulfilling)

--Why illness or disability does not make anyone any less capable or less responsible for his/her sexual relationships?

--How illness or disability can affect the way you feel about obtaining a sexual partner or maintaining a sexual relationship?

--How illness or disability may affect the way you feel about partners of the same or opposite sex?

--What new modes of sexual pleasure may be open for you despite your illness or disability?

Are there any other topics which you feel are important to your sexuality which are missing from these provided for you? If so, what are they?
Learning Experiences

Imagine that an educational/counseling program in sexuality is being planned in your community for individuals who are coping with _______________________. You have been asked, along with several other people, to present your ideas on how this program should be developed and implemented.

1. Who would you want to include in the program as speakers or resource persons?

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<td>individual(s) with</td>
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<td>similar illness or</td>
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2. How would you feel if you were asked to be a resource person?

_________________________________________________________________

_________________________________________________________________

3. What information do you feel would be valuable for another person who is trying to cope with ________________________ based on your experience?

_________________________________________________________________

_________________________________________________________________
4. What type of educational materials would you recommend?

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5. What suggestions would you have for:

(a) use of resource people or speakers ____________________
_______________________________________________________
_______________________________________________________

(b) activities and roles of participants __________________
_______________________________________________________
_______________________________________________________

(c) use of educational materials ________________________
_______________________________________________________
_______________________________________________________

(d) organization of the program _________________________
_______________________________________________________
_______________________________________________________
(e) the atmosphere or general climate of the program ______

6. Who do you feel would most benefit from such a program? Place a circle around those who you feel would most benefit.

an individual who has just experienced this illness or disability

an individual who has been coping with illness or disability for a matter of months

an individual who has been coping with illness or disability for years

spouses

children

relatives

others

7. Some information or counseling is felt to be better provided individually and other information or counseling can better be provided in a group setting. Take the two piles of cards which you have already decided are very important and moderately important, and place the cards into two new piles. The piles should be those topics which you feel would best be presented between a professional and an individual, and those topics which you feel would be best presented to a group of individuals who are experiencing ____________________.

Individual topics: ________________________________________________

___________________________________

___________________________________

___________________________________

___________________________________

Group topics: ________________________________________________

___________________________________

___________________________________

___________________________________

___________________________________
Sexuality Education/Counseling

1. Have you received any sexuality education or counseling?
   Yes _____  No _____

1.a. If yes, what did it consist of?

1.b. How well did it meet your needs?

1.c. What recommendations would you make to increase the helpfulness of this type of assistance for yourself and for others?
2. In addition to your response to question #1, have you perceived a sexuality problem or concern? Remember that sexuality encompasses masculine and feminine feelings, feelings about your body, your roles as parent, spouse, worker, and community member and your sexual functioning.

2.a. If yes, before your illness or disability? What was the nature of the problem or concern?

2.b. If yes, after the illness or disability? What was the nature of the problem or concern?

2.c. If you experienced a sexuality problem or concern prior to becoming ill or disabled, was it aggravated by your illness or disability?
Personal Information

Age ___________ Sex___________ Race___________

Length of time since diagnosis ____________________________

General level of former health_______________________________

Any other illnesses or disabilities at this time__________________

Severity of disability or illness (What limitation(s) do(es) it(they) impose on daily activities?)

_________________________________________________________

_________________________________________________________

_________________________________________________________

_________________________________________________________

Educational background: highest year of former education_______

_________________________________________________________

Any special training________________________________________

Occupational background: present employment, if any ___________

_________________________________________________________

Have there been any changes in occupation due to illness or disability? ___________ If yes, what have they been? _________

_________________________________________________________

Does your financial situation allow you to attend a sexuality educational/counseling program?

If it was held on a weekday? ________________________________

If it was held on a weekend? ________________________________

If it was held during an evening? _____________________________

Would you be able to provide your own transportation to such a program? ___________________________________________
Religious Affiliation ________________________________

Cultural background:

How long has your family been in America? ________________

Do you identify with any culture other than American? ______

If yes, specify __________________________________________

Are you presently single or are you in a partner relationship?

If presently single, have you been in a partner relationship in the past? __________________________

If in a partner relationship at present, what is the duration of the relationship? ____________________
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<th>Topic Question</th>
<th>Code*</th>
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<th>Mode</th>
<th>Standard Deviation</th>
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<td>2. Why your illness or disability can change the way you feel about being masculine or feminine?</td>
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<td>4. How to use new ways to deal with your illness/disability?</td>
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<td>5. How illness or disability can affect being a sexual partner?</td>
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*Code: (0) not important, (1) less important, (2) moderately important, (3) very important.
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<td>8. How illness or disability can affecting being an active member of your community?</td>
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<td>42. How to deal with the feeling of risk when expressing intimate wants and desires?</td>
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<td>8</td>
<td>26.7</td>
<td>1.667</td>
<td>3.000</td>
<td>1.213</td>
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<td>10</td>
<td>33.3</td>
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<tr>
<td>43. Why illness or disability does not make anyone any less capable or less responsible for his/her sexual relationships?</td>
<td>0</td>
<td>8</td>
<td>26.7</td>
<td>1.567</td>
<td>3.000</td>
<td>1.194</td>
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<td>9</td>
<td>30.0</td>
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<tr>
<td>44. How illness or disability can affect the way you feel about obtaining a sexual partner or maintaining a sexual relationship?</td>
<td>0</td>
<td>6</td>
<td>20.0</td>
<td>1.733</td>
<td>3.000</td>
<td>1.172</td>
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<td>3</td>
<td>11</td>
<td>36.7</td>
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<tr>
<td>45. How illness or disability may affect the way you feel about partners of the same or opposite sex?</td>
<td>0</td>
<td>7</td>
<td>23.3</td>
<td>1.733</td>
<td>3.000</td>
<td>1.202</td>
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<td>11</td>
<td>36.7</td>
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<tr>
<td>46. What new modes of sexual pleasure may be open for you despite your illness or disability?</td>
<td>0</td>
<td>6</td>
<td>20.0</td>
<td>1.733</td>
<td>3.000</td>
<td>1.143</td>
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Dear

Thank you for participating in this study about sexuality and multiple sclerosis. The information that you and twenty-nine other people provided has been very valuable in identifying elements for an educational/counseling program.

I promised you a first-hand look at the results during our interview, and here they are. The topics which were rated most important to attaining sexual health were: learning new ways to cope, effects on family member roles, loss of easiness of movement, effect of uncertain increases in symptoms on the outcome of MS, effects on family member values and goals, and effects of illness/disability on communication with others.

The topics which were moderately important were: dealing with worry and fear about future losses, varying feelings and emotions, lower energy levels, changes in body functioning, changes in self-concept, regaining control over body functioning after illness, MS cause, symptoms due to body changes, values and goals for lifestyle, personal beliefs, nonverbal communication, and assistance for achieving goals.

Many topics were rated less important but had a wide range of ratings. Among relationships of personal characteristics and topic areas were: age, sex, relationship status, education, employment, religion, length of time since diagnosis, former health status, and severity of disability.

Individuals who have MS were rated highest as speakers and resource persons followed by health professionals and MS Society staff. Small group discussions were the favored manner of presentation. All of the topics received higher scores for small group discussion, but some topics received 20-30% of the responses in favor of a one-to-one conference.

Twelve respondents had received some type of sexuality education or counseling in the past. Of these twelve, nine had their questions answered by doctors and nurses. Three people reported seeking help from private counselors or rehabilitation centers. All assistance was rated fair, very limited, or not really helpful.

Twenty-five people reported having one or more sexuality problems or concerns. The most frequent of these were: exhaustion, problems with body image, psychological ups and downs, role as spouse, and sexual functioning.
All of this information was compiled to form a generalized sexuality program for individuals in Franklin County with multiple sclerosis and interested friends and relatives. One such program will be held in autumn. You will be receiving more information about it later. I hope you will be able to attend. Most of the people in this study said how much they would like to talk with other individuals with MS and this will be a good chance.

In closing, I would like to repeat an old Irish saying that expresses my sentiment.

May the road rise up to meet you,
may the wind be always at your back.
May the sun shine warm upon your face, the rains fall soft upon your fields, and until we meet again, may God hold you in the palm of his hand.

Sincerely yours,

Ann Teske
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