

BRIEF

THE SOCIAL WORKER'S ROLE IN GENETIC COUNSELING

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Genetic counseling is one major aspect of medical practice. It is a recent addition to the medical field that focuses on the etiology of genetic abnormalities.

In the past the emphasis of genetic counseling was on determining the etiological diagnosis and on informing the patient of genetic facts and possible medical options. Areas such as the psychological adjustment and resource location for family support virtually were ignored by the majority of genetic counselors.

For genetic counseling to be effective, the focus of counseling should be on psychological and social adjustment, with an emphasis on therapy, counseling, education, and liaison services for the patient and family. Social work can provide this expertise.

Technological advances in medicine have created an awareness in the medical community that many diseases and birth defects have a genetic basis. Because of these advances more concentrated research is being conducted in the area of genetic diseases. As discoveries are made, the public is becoming aware of the need for federal legislation to research and provide genetic services and education to all. As a result of this increased public awareness and support, Public Law 94-278 was enacted in 1977. This act was an attempt to provide structure and correlate research, training, testing, information, education, and counseling. Title IV of the act is concerned with genetic diseases.

Genetic counseling is one major

aspect of present day medical practice. Genetic counseling involves the complex interaction of medical, psychological, and social factors.¹ An ad hoc committee of the American Society of Human Genetics defined genetic counseling as

a communication process which deals with the human problems associated with the occurrence, or the risk of occurrence of a genetic disorder in a family. This process involves an attempt by one or more appropriately trained persons to help the individual or family (1) comprehend the medical facts including the diagnosis, the probable course of the disorder, and the available management; (2) appreciate the way heredity contributes to the disorder, and the risk of recurrence in specified relatives; (3) understand the options for dealing with the risk of recurrence; (4) choose the course of action which seems appropriate to them in view of their risk and their family goals and act in accordance with that decision; and (5) make the best possible adjustment to that disorder in an affected family

member and/or to the risk of recurrence of that disorder.²

Genetic counseling may be broken down into three steps: (1) evaluation (diagnostic testing), (2) information (facts regarding specific disorder), and (3) immediate and follow-up counseling.

THE NEED FOR SOCIAL WORKERS

The traditional focus of genetic counseling emphasizes diagnosis. The counselor is usually a physician with additional training and expertise in medical genetics or a geneticist with a PhD in genetics. He has focused on research, identification, and treatment of genetic disorders.³ Attendance to psychosocial dynamics played a minor role.

The genetic counselor's training and expertise lies in the highly technical field of genetics, not in human behavior. Because of time limitations and specialized training, the genetic counselor cannot be expected to treat the complexities of psychological disorders or the multiproblem areas of human interaction and family functioning. Often the diagnosis of a genetic condition can precipitate a crisis and leave the family angry, confused, and unaware of viable options.

Genetic counseling involves people. Major psychosocial issues are involved which may have long-

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range consequences for the family and need to be addressed from the onset. Genetic counseling is more than relating an etiological diagnosis of a genetic disorder and probabilities of recurrence and advice giving. It is a process that aids the patient and his family in dealing with and adjusting to an often severe psychological impact that an unfavorable genetic diagnosis may bring. Relating the diagnosis is only the tip of the iceberg. The main focus of genetic counseling should be on physical and emotional adjustment to the genetic disorder. Sheldon Reed, who coined the phrase "genetic counseling," considers the emotional aspects the weakest component of genetic counseling.⁴

The rationale for utilizing social work services in genetic counseling is that clinical social workers are trained and have expertise in dealing with individuals in crisis. Whatever approach the professional social worker practices, he is taught to look at the person in his total environment.

Until recently, social workers appeared to be unaware or uninvolved in the field of genetics. Literature reveals few references to the role of the social worker in this area. The few social workers that do work in genetic situations have not documented their techniques and approaches to the multifaceted problem of delivering social work treatment to genetic patients.⁵

THE ROLE OF THE SOCIAL WORKER

The role of the social worker should be divided into three parts: (1) educator-counselor, (2) therapist, and (3) liaison specialist.

Educator-Counselor

In an educator role, the genetic social worker would educate the

patient and his family about the nature of the genetic disease, its course of development, and possible treatment. Questions and concerns the patient had about genetics, such as possibilities of recurrence in offspring, and inheritance of the defective gene would be discussed. Audiovisual devices are often useful, practical aids in explaining genetic factors in heredity.

If the patient is a child, his education may require a different approach toward developmental expectations, home stimulation programs, and child rearing practices specific to the disability. Understanding genetic factors enables patients and families to adjust easier. By providing information and teaching about the genetic and heredity basics for the disability, the genetic social worker allows for a smoother transition into an often significantly altered lifestyle.

As counselor, the social worker is directly aligned with genetic information and education. Some of the basic information provided will be of genetic risks to the patient's current children and/or the possibility of recurrent risk in future offsprings. This information must be put into the patient's and family's perspective so that they may better understand the genetic implications as these apply to them individually and as a family. The decision to have or not to have children is a major one. All members of the nuclear family may need to be consulted, although the final decision should rest with the parents.

When a childless couple learns that they may be carriers of a serious genetic disease the decision whether or not to have children is greatly influenced by the probability of occurrence of the genetic disease. Severe genetic defects are life-long problems for the person

with the defect and for the parents and families of that person.⁶ Psychological and emotional adjustment is often affected or even impaired by these severe problems.⁷ The genetic social worker can be of service to these parents by informing them of possible alternatives, and aiding them in decision making. The couple is confronted with a number of options and needs to understand and consider each seriously.

Therapist

The therapeutic approaches utilized should take into account the chronicity of severe genetic disorders. Because the genetic disorder affects every member of a patient's family, it is suggested that a family systems approach would be most effective. Severe genetic defects will influence and change the structure of a family. The family will adjust and accommodate to the problem in some way. This adjustment may be functional or dysfunctional. The stress that is precipitated by the realization of a severe genetic disorder is what Minuchin calls "stress around idiosyncratic problems."⁸ Minuchin suggests that idiosyncratic problems can precipitate dysfunctional transactional patterns among family members. But the family will begin to adjust and accommodate to the stress. Some change will occur. New behavior will be learned. One goal of the genetic social worker is to aid the family or individual to learn appropriate new behavior and transactional patterns and make a functional adjustment to the chronic problem of a genetic disorder.

The focus of therapy for genetic disorders will be on the identified patient or affected member with the genetic disorder and his nuclear family.

The rationale for family focused therapeutic intervention is based on a number of factors:

Genetic disorders are inherited from the biological parents. One or both parents may be involved in transmitting the defective gene and are, therefore, "responsible" for their future children.

Genetic disorders have an impact on the entire family. All members, affected or nonaffected, carrier or noncarrier, need to be included. Any decisions or goals made in therapy will have an affect on every members of the family. Every affected member will undergo an adjustment process.

Family members are internal support systems and can greatly aid therapeutic movement or hinder the same.

The chronicity of a severe genetic disorder will occur throughout the lifetime of the affected member. Care of the patient may be passed from parent to child.

Problems involved in genetic disorders are family problems:

1. The genetic disorder threatens and disturbs the homeostasis of the family. The family system must be restructured and readjusted.

2. The family may become patient centered. Family life may be centered around the affected member. Other family members' needs become secondary. The areas influenced might be financial, social, and emotional. This is a burden to the family, often lifelong.

3. Marital problems may occur. If the spouses cannot function adequately as marital partners, their parenting skills will be affected. The parents may function only as parents not as husband and wife. As a result, marital conflict, separation, and divorce often increase.

4. Siblings (if the patient is a child) may be neglected by the par-

ents. Their social contacts may be decreased. The parents may have higher expectations for them to make up for the disabled child.

The genetic social worker should take a goal oriented or problem solving approach to treatment. Initially, he can, with the help of the patient and/or family, determine the problem areas and give a priority to each one. For example, one priority might be physical care of the affected member. A schedule may be negotiated between all members so that care of the patient might be insured. Goals are determined for each problem with the aid of the genetic social worker.

Contracts, either written or verbal, can be negotiated around problem areas and goals developed to correct these problems. Contracts are simple agreements between all parties involved so that each person understands the problem and his role in the amelioration of that problem. A contract may be between family members. It can be between the genetic social worker and the entire family. For example, the genetic social worker may agree to come to all sessions, locate a school placement for the affected member, provide information on genetics, and negotiate with each member on each problem area. The family in turn may agree to come to each session on time and participate. Contracts establish a structure for therapeutic treatment that lets the patient(s) know what to expect, and what is expected of them.

The problem solving, goal oriented family approach can also utilize a variety of treatment modalities, depending on the needs of the family or individual. Supportive therapy may be needed during the initial crisis brought on by the genetic disorder diagnosis. At this time the individual or parents may

experience emotional disorganization. The diagnosis may be denied and other professional opinions may be sought. Later, confrontation may be needed for the individual or family to accept the reality of their situation. A series of contracts with appropriate goals geared to each major problem area may be negotiated.

Treatment approaches for the individual and family with genetic disorders are limited only by the genetic social worker's knowledge, skill level, and imagination.

Liaison Specialist

The genetic social worker, as a liaison specialist, will be concerned with aiding the individual's and/or family's adjustment through resource location. Often the individual or family will need help in meeting basic needs for food, clothing, and shelter. Basic needs must be met before one can deal with other problem areas.

Families with severe genetic disorders often have great financial burdens related to the disorder. The genetic social worker can place the family in contact with various public and private agencies that can help them manage financially. The genetic social worker must be aware of all available resources within the community so that patients' needs may be met.

Either educational, vocational, or institutional placement will need to be provided for the severely handicapped. It is often helpful to parents for someone aware of the various programs to counsel them regarding appropriate placements for their child. Parents need current information on available placement options to make the best choice for their child.

After receiving a diagnosis of a severe genetic disorder, there is often confusion with the individual,

parents, and family. This confusion occurs before functional adjustment can take place. During this period of confusion and initial adjustment the genetic social worker can be of great service to the individual and/or family by putting them in contact with appropriate resources, whether financial, medical, or educational. One of the first steps in social work treatment is to provide a situation where the client has some degree of success. Placing the individuals in contact with vital resources (1) gives them initial success and movement (they are beginning to work on the problem); (2) makes them aware that there are people to help (this provides some support at a time when it is most needed); and (3) it lets them know that someone cares about their plight.

The genetic social worker is also a liaison between the patient and/or family and the genetic counselor. The genetic social worker may have close contact with the family over a long period of time. He is in a position to evaluate the individual and family. The genetic social worker can aid the genetic counselor (1) by alerting him or her about unexpressed fears of the patient(s); (2) by obtaining factual data for genetic appraisal about parentage, incest, etc; (3) by informing about possible social and emotional difficulties present in the patient and/or family; (4) by providing information regarding various physical and social needs of the patient and/or family; (5) by planning therapeutic intervention and follow-up; and (6) by initiating necessary referrals to available resources. By working together as a team, the genetic counselor and the genetic social worker can provide more effective genetic counseling services.

The genetic social worker is a

beginning support system for the individual and/or family during an initial crisis. He attempts to stabilize the family at a time when equilibrium is in a state of upset. He does this through counseling, therapy, education, and liaison services. The end goal is for the family to function well independently.

CONCLUSIONS AND RECOMMENDATIONS

Social workers in direct service positions have a unique opportunity for early identification of genetic disorders and other handicapping conditions. The majority of these direct service practitioners, however, have little or no training in recognizing the most apparent handicaps; they also lack the knowledge to take action. Two suggestions may remedy this situation: First, the National Association of Social Workers, the Council on Social Work Education, and undergraduate and graduate social work programs need to be encouraged to develop courses in genetic disorders and handicaps. Second, for those social work practitioners already in direct service positions, workshops on recognizing genetic disorders and other physical and mental handicaps could be provided.

Recommendations for genetic social work training include: (1) the need for clinical social work training and education; (2) the need to know basic principles of human genetics and genetic and congenital defects; (3) the need for additional knowledge of human growth and development other than what usually is required in human behavior core course work; (4) field practice in the second year at a genetic clinic, where intervention and education strategies would be geared toward genetic patient problem areas; and (5) specific skills and

training to ensure recognition or licensure as a genetic social worker. Thus, genetic social work could claim status in the professional community and insure quality social work services thru licensure.

A proposal is being considered by the American Genetics Society that appropriate social workers and other professionals be certified in genetic counseling. This indicates that genetic professionals have begun to recognize the need for social workers in genetic counseling.

Social work knowledge of human behavior and experience in dealing with individuals in various crisis situations can contribute to genetic counseling as they have to other areas of medicine. It is important for genetic counselors and social workers to be aware of the role that social work, as a helping profession, can play in genetics. Genetic counseling effectiveness can be enhanced by the utilization of professional social workers.

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