The Pastor as Genetic Counselor

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ABSTRACT: The pastor as pastoral counselor in the setting of the church can play an important role on a genetic team. This article explores the role the pastor plays in the definitive stage: delivery of information, educating, supporting, and counseling in human genetics. Problems that are encountered by team members, patients, and families, and dominant feelings that seem to exist in couples or individuals who discover that their children have a birth defect or that they themselves are carriers of a faulty gene are revealed and illustrated through clinical examples and interviews. Further suggestions are given on how a constructive team approach can help provide information regarding birth defects and how pastors can help and participate in this process.

Introduction

My first experience with genetic counseling was a very personal one. When our first child showed symptoms of a tumor several weeks after birth, our doctor referred us to a specialist, who only added to the possibility that the symptoms were of a tumor and said he would talk with another doctor and call us.

We waited, and nothing happened. Our doctor then referred us to the Mayo Clinic in Rochester, Minnesota. Our son did not have a tumor, but X-rays of the skull showed premature fusion of the bones. At the clinic, we were told we could leave the sutures as they were or allow an operation to open the sutures so that the skull could shape more normally. We decided to have the surgery done. Afterwards we asked whether any other children we might have would have the same difficulty and whether the problem was a genetic one. The answer to both questions was "No."

About two years later, after we had another child, we requested her head be X-rayed as a precautionary measure. Our daughter also had craniosynostosis (premature fusion of the frontal bones). Again we elected to have surgery.

Through this experience we were introduced to Dr. James Hanson and Elizabeth Thompson, from the University of Iowa Hospital. Dr. Hanson, a pediatrician, and Elizabeth Thompson, a registered nurse, work in the area of...
genetic counseling and are members of the Regional Genetic Consultation Service. Dr. Hanson helped to clarify our children's problem and fairly stated the problem as a genetic one. We had several sessions with Dr. Hanson regarding the implications of the problem and the decisions we might need to make in the future regarding more surgery and discussed our concerns and questions about the children with Elizabeth Thompson.

The sensitivity of Dr. Hanson and Mrs. Thompson helped us to work through our hurt, fears, and anxiety. Our children, now five and three, are healthy, very active, outgoing children, who are bright, inquisitive, and fun to be with. Our five-year-old will need more corrective surgery in a couple of years. We know what to expect and have the support of Dr. Hanson and Mrs. Thompson. Through their efforts and caring, we have made decisions that will provide the best chances for our children to have normal, healthy lives, physically and emotionally.

My wife and I are both professional people. She is a nurse, and I am a parish pastor and pastoral counselor. Our growing concern over the pastoral role in genetic counseling led to dialogue with Dr. Hanson and Mrs. Thompson. The outcome was a course in genetic counseling and my participation on the genetic counseling team as a pastoral counselor.

This work is the result of insights gained from interviews, class work, counseling with individuals and families at genetic clinics, and working with other pastors regarding their roles in the parish in pastoral care to individuals with birth defects and their families.

**Birth defects and the role of genetic counseling**

This is the darnedest thing. We never expected anything like this . . . When we were younger, people put children away in institutions. People come up to us now and ask if we are going to "put her away." As long as it's not your problem, you can pass it up. As far as we are concerned, we will take care of her . . . I wonder when the other kids want to bring their friends home . . . Maybe they won't because of her.

He looks down. Tears quietly drop. This forty-three-year-old father very tenderly holds "her"—his seven-month-old daughter, Sara, the last child in a family of eight children, who has Down's syndrome.

Almost every one of us knows someone personally or has seen someone born with a birth defect. While individual birth defects are infrequent—occurring in about seven percent of all births—the total number of affected families is well into the millions. Each year about 220,000 American babies are born with physical or mental defects of varying severity. Some of these defects are noticeable at birth; others do not become apparent until months or years later.

Those born with birth defects, and their families, often seek genetic counseling to understand better what has happened, how to cope with it physically and emotionally, and to become aware of the future situations and risks involved. "Genetic counseling provides and interprets medical information based on expanding knowledge of human genetics. Its major goal