The Amish: Perceptions of Genetic Disorders and Services

Jill D. Brensinger,1,3 and Renata Laxova2

Previous studies of the closed Amish population have proven to be valuable in the field of genetics, however they have not explored the Amish parents' opinions and attitudes concerning genetic conditions and services. This exploration is necessary in order to provide culturally sensitive health care to a population at an increased risk for certain genetic conditions. The purpose of the present study was to examine the Amish population's general knowledge of genetic disorders, services, and the terminology used in describing inherited conditions, as well as their attitudes toward medical care and ethical and reproductive issues. Information was obtained from 17 Amish families, 12 who had an incidence of a genetic condition and five who had one or more children with other special health care needs, during personal interviews conducted in their homes in Lancaster, Pennsylvania. Results of the interviews showed that the birth of an affected child did not deter subsequent reproduction, that the majority of the parents were never offered genetic counseling or prenatal testing, and that the parents are interested in understanding the cause of their children's problems and recurrence risks.

KEY WORDS: Amish; inbreeding; cross-cultural genetic counseling.

INTRODUCTION

The Amish are a conservative Christian group who originated in Switzerland in 1693. They are direct descendants of the Swiss Brethren (Anabaptists). The original sect, the “Old Order Amish,” left the Swiss

1Genetics Counseling Program, University of Wisconsin, Madison, Wisconsin.
2Clinical Genetics Center, University of Wisconsin, Madison, Wisconsin.
3Correspondence should be directed to Jill D. Brensinger, The Johns Hopkins Hospital, 550 N. Broadway, Suite 108, Baltimore, Maryland 21205.
Brethren church in 1693 because of a doctrinal dispute. (The shorter generic term “Amish” will be substituted for “Old Order Amish” in this report.) Severe persecution forced the Amish to move to Alsace-Lorraine, eastern France, the Palatinate, and finally, the United States (Cross and McKusick, 1970). The first group of Amish settled in Pennsylvania between 1727 and 1771, subsequent immigrants settled in Ohio, Indiana, and Illinois between 1815 and 1860 (Wiggins, 1983). Currently, approximately 100,000 Amish reside in the United States (Kraybill, 1989).

Despite the Amish sect’s separation from the Swiss Brethren church, they continued to uphold the Anabaptist nonconformist way of life. The Amish are well-known for their agrarian lifestyle, plain clothing, avoidance of “worldly things,” such as telephones, electricity, and automobiles, and strong emphasis on living their everyday lives according to Biblical standards (Wiggins, 1983). Although the Amish live in areas called settlements, non-Amish families and towns are interspersed within the Amish communities (Adams and Leverland, 1986).

The Amish are an extremely interesting and appropriate population for genetic studies for three reasons. First, there is a high degree of consanguinity within the group because marriages with non-Amish individuals are forbidden (Hostetler and Huntington, 1971) and the mobility of the Amish is quite limited. At the time of the 1973 census, all except three of the 1850 married Amish couples in Lancaster county were demonstrated to be consanguineous (McKusick, 1978). Second, United States Amish communities represent genetic isolates due to their limited number of ancestors and negligible number of converts into the Amish faith. Finally, the high birth rate in the Amish community allows more informative genetic studies (Guyther, 1979). In 1986, the average number of live births per Amish family was approximately seven, as opposed to 3.27 children per rural non-Amish family in the United States (Adams and Leverland, 1986).

Previous studies of the Amish have focused on their demography (Cross, 1970), general medical attitudes (Adams and Leverland, 1986; Guyther, 1979; Wenger, 1991; Wiggins, 1983), and pregnancy outcomes (Resseguei, 1974). In addition, Amish families have been invaluable in studies of rare conditions such as cartilage hair hypoplasia, Ellis van Creveld syndrome, and bipolar disorder, all of which are found at an increased frequency within the Amish population. (McKusick, 1978). The majority of these studies, however, have been descriptive and the population is treated as “subjects” with genetic disorders. In order to provide culturally sensitive health care to a population at an increased risk for certain genetic conditions, professionals must begin to consider the opinions and attitudes of individuals within that population. Only one previous study is known, the