Ethical Issues in Genetic Counseling: A Comparison of M.S. Counselor and Medical Geneticist Perspectives

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New technologies available in the field of medical genetics have increased the importance of responsible ethical decision-making among genetic counselors. A 1985 national survey of M.D. and Ph.D. genetic counselors assessed ethical attitudes using case scenarios designed to simulate dilemmas faced in genetic counseling (Wertz and Fletcher, 1988b). The current study focuses on attitudes of M.S. genetic counselors using similar scenarios, allowing for effective comparisons. M.S. counselors were more willing than M.D. and Ph.D. counselors to maintain patient confidentiality when screening for Huntington’s Disease and occupational diseases, and a greater number would agree to counsel patients pursuing prenatal testing for sex selection. A majority of M.S. counselors would disclose an XY karyotype to a phenotypically female patient. M.S. counselors reasoned that respect for patient autonomy and patient confidentiality justified their decisions in many cases. The importance of these principles is discussed and questioned.

KEY WORDS: ethical issues; medical ethics; genetic screening; genetic counseling; ethics.

INTRODUCTION

Rapid growth in the area of medical genetics is providing a wealth of new options for dealing with genetic disease. These technologic advances

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often pose unique and significant ethical dilemmas which must be resolved by providers of genetic services and individuals who receive those services, as well as society in general. Reproductive options such as artificial insemination by donor, genetic screening, *in vitro* fertilization, sex selection via prenatal testing, surrogate motherhood, fetal tissue transplantation, and gene therapy have generated considerable ethical concerns. As genetic counselors relay important genetic and reproductive information to families at risk and to the public, they often play an important role in the way these ethical issues are understood and acted upon.

Major ethical principles which govern the attitudes and actions of counselors include (1) respect for patient autonomy, or the patient's right to information and his/her right to make his/her own decisions, (2) non-maleficence, which is defined by Fletcher *et al.* (1985) as one's "duty to minimize or prevent the infliction of harm on individuals and families," (3) beneficence, or taking action to help benefit others and prevent harm, and (4) justice, which requires that services be distributed fairly to those in need. Other moral rules include veracity, the duty to disclose information or to be truthful, and respect for patient confidentiality.

Nondirective counseling, a hallmark of the genetics profession, is largely in accordance with the principle of respect for patient autonomy and incorporates the other ethical principles as well. Despite an overall respect for patient autonomy and the value of nondirective counseling within the genetics community, it is virtually impossible to be completely nondirective, especially when the counselor has a particular bias. Factors such as order of presentation of information, amount of time spent counseling about an option, voice inflection, and body language can all influence a patient's perception of information.

Three groups of professionals currently consider themselves genetic counselors: M.D. clinical geneticists, Ph.D. medical geneticists, and M.S. genetic counselors. Although two thorough studies were done on attitudes of genetic counselors in the United States, these surveys were directed at M.D. and Ph.D. counselors (Wertz and Fletcher, 1988b; Sorenson *et al.*, 1981). Wertz and Fletcher (1988a) omitted M.S. counselors because there were few outside of the United States and Canada, and their survey was intended to be comparable across nations.

In the present study, M.S. genetic counselors were surveyed using case scenarios designed to simulate ethical decision-making. Many of these cases were identical to those presented to M.D.s and Ph.D.s in 1985 by Wertz and Fletcher (1988a,b). Identical cases were used in order to facilitate effective comparisons between the two groups. It was expected that a survey of M.S. counselors would yield significantly different responses to some ethical questions given that (1) they counsel patients more frequently, (2) a