What Predicts the Use of Genetic Counseling Services After the Birth of a Child With Down Syndrome?

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In the state of Victoria, Australia, a government funded genetic counseling service exists to meet the needs of families. An audit showed that many families do not use this service after the birth of a child with a genetic problem. To investigate this we surveyed families of children born with Down syndrome over 2 years in Victoria. Questionnaires were completed by 74 mothers, of whom only 18 had received genetic counseling between the birth and the time of the study (mean 3.5 years). Of those not receiving genetic counseling, 71% said they were not offered or had not heard of it. Mothers who had genetic counseling were younger than those who had not, and were more likely to have attended University. Those who had genetic counseling indicated less “satisfaction with care at the diagnosis” and were more likely to perceive their child as “unwell at birth” than those who were aware of genetic counseling but did not have it. Of those who did not have genetic counseling, over half were unclear about what it is, although 74% agreed with the statement “genetic counseling is most useful when planning to have another child.” Of those who had heard of genetic counseling, 73% said they were not sure how it could help. Many families with children with Down syndrome are not aware of the existence or functions of genetic counseling. With greater awareness, some may still choose not to have genetic counseling, but others enunciated needs that could be met by this service if it were offered to them.

KEY WORDS: genetic counseling; genetic services; Down syndrome.

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INTRODUCTION

An important function of genetic counseling is to assist parents who have had a child with a genetic disorder to deal with the implications of the diagnosis for the child, the family and future children, and for parental concerns to be addressed (Fraser, 1974; Harper, 1998; Kelly, 1986). Since 1988, in the state of Victoria, Australia, a government funded genetic counseling service has been available. All parents with a child with a genetic disorder are eligible to receive genetic counseling but an audit of the use of the service in 1993 showed that only about 50% of parents of babies born with a serious birth defect used the service within 3 years of the birth (Halliday et al., 1997).

The reasons for such a high proportion of families not having genetic counseling are not clear. The Victorian audit showed that older women were more likely to use the service than younger and the presence of the service in the hospital of birth predicted uptake (Halliday et al., 1997). A small interview-based study in the Netherlands compared data on couples who sought, or did not seek, genetic counseling after the birth of baby with a congenital anomaly (Hobus et al., 1995). Two major predictors of seeking genetic counseling were identified—whether the couples had been informed correctly about the availability of genetic counseling, and whether, shortly after the birth, the parents considered genetic counseling might be useful in their particular case (Hobus et al., 1995).

A conceptual framework for understanding reasons for uptake of health services that has been used in a variety of health settings is the Health Belief Model (HBM) (Janz and Becker, 1984). The model describes four domains that are likely to be predictive of whether an individual will undertake a health behavior: (1) perceived susceptibility to the health condition; (2) perceived severity of the health condition; (3) perceived benefits of the health behavior; and (4) perceived barriers to taking up the health behavior. The model predicts that greater perceived severity and susceptibility provide the impetus to perform the health behavior and the balance between perceived benefits and barriers will ultimately determine whether the action is undertaken. Sociodemographic variables and cues to action will modify the effect of the domains of the HBM (Janz and Becker, 1984). Cues to action can be either internal (e.g. symptoms) or external (e.g. referral from a health professional) (see Fig. 1).

The HBM has not been used explicitly in studies assessing the uptake of genetic counseling but findings from studies of genetic screening programs might be useful to consider. The uptake of carrier testing for cystic fibrosis (CF) (Decruyenaere et al., 1998; Fang et al., 1997), community carrier screening for Tay-Sachs disease (Becker et al., 1975), prenatal screening for hemoglobinopathies (Rowley et al., 1991) and prenatal diagnosis for cleft lip/palate (Sagi et al., 1992) have been assessed in light of the HBM. These studies have generally validated the HBM by demonstrating associations between the HBM domains and intentions...