13 It Runs in the Family: Lay Knowledge about Inheritance
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Genetics concerns families and kinship. It is the study of the ways in which inherited characteristics are passed from parents to children through the generations. As the new genetics (genetics based on recombinant DNA technology) develops, the ability to characterise the genes that individuals may carry increases dramatically. Almost daily there are announcements of the identification of genes related to specific disorders. This allows new possibilities of genetic testing. So, for example, for many genetic disorders, a foetus may be tested and aborted if it is found to carry the disorder that runs in the family. Or in the case of diseases that have an onset in adulthood, individuals can be tested before symptoms develop and so discover whether or not they are likely to get the disorder. There are many questions about such testing and how it should be deployed (see Marteau & Richards 1996 for a more general discussion).

Our approach to these issues has been to investigate the knowledge and beliefs that family members may hold about genetic disorders that may run in their families, and more generally about inheritance, and to describe how information about such matters is communicated among family members. We have suggested that lay beliefs about inheritance, which may be incompatible with a Mendelian view, are a major determinant of reproductive choices, uptake of genetics services and other actions of members of families which carry a genetic disorder (Green et al. 1993, Richards 1993, Richards & Green 1993, Richards et al. 1995).

Our work does not involve cross-cultural comparison (at least in its current phase) and so might not seem very directly related to the theme of this volume. I want to argue to the contrary, however, as it is my hypothesis that lay knowledge about inheritance is closely related to ideas about kinship and the social relatedness of family members. If this proposition is correct, lay knowledge about inheritance would be expected to vary between cultural groups with their different
concepts about kinship, marriage and family relationships more generally.

Another point needs to be made about cultural diversity. In genetics, as in many other spheres, the issue of cultural diversity is usually addressed by looking at minority groups whose culture differs from that of the mainstream. Thus we find studies of minorities who have particularly high frequencies of certain genetic disorders (such as sickle cell disorders in Afro-Caribbean communities or Tay-Sachs disease in Jewish communities) or have cultural patterns, such as cousin marriage, that may be held by some to constitute a genetic problem. Such approaches take for granted, or regard as normal or usual, the knowledge, beliefs and practices of the mainstream culture. But, of course, the mainstream culture is as much a part of ethnic diversity as the beliefs and practices of any other group. It is part of our research programme to examine knowledge about inheritance and its possible association with concepts of kinship within our own culture. We would expect the descriptions we can provide to be culturally specific, and similar research is needed for other cultures, including those of ethnic minority communities in the UK.

My aim in this chapter is to sketch out some of what we know about certain genetic disorders from a family point of view (for a further discussion, see Richards 1996) and then discuss the issue of lay knowledge of inheritance. As yet, research is limited, and much of what I say is necessarily speculative, more in the way of a research agenda than a research review. However, one clear conclusion from what has been done so far is that such issues can be very different for different genetic conditions depending on such matters as the nature of the disorder, the age at which symptoms develop, treatments that may (or may not) be available, the mode of inheritance, the availability of genetic tests, and the penetrance of the gene (the likelihood of individuals who have inherited the faulty gene developing the condition). This variation makes it very difficult to make points relevant to genetic disorders in general. I shall discuss two specific disorders to illustrate certain points.

HUNTINGTON’S DISEASE

Huntington’s disease is a degenerative disease of the central nervous system which usually first develops in middle age. Its symptoms