

Family Communication about Genetics: Theory and Practice



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Genetics is in all senses a family affair. The diagnosis of a genetic condition affects not only the patient and biological family members who may themselves be at risk, but also "family" more generally as support may be sought from those considered kin and who may or may not be at risk themselves. It is considered best practice in genetic consultations to explore who will be informed within the family when a genetic condition or risk is diagnosed, particularly when the health of other family members is at risk. There is little guidance or consensus on how to achieve the implicit goal of informed family members while respecting patient confidentiality, however. There is a need for practitioners to be aware of the dynamics of family communication and to have guidance about how they may sensitively facilitate communication about genetics within families.

This handbook facilitates the development of clinical practices relating to family communication about genetics. Relevant theories of family communication are summarized and related to a clinical genetics milieu and, from this, frameworks for practitioners are presented. A book of this nature is particularly timely as the completion of the Human Genome Project will result in an unprecedented amount of information about genetic constitution and health risks becoming available to individuals and their families. The presence of a potential genetic condition in a family is not a new phenomenon. However, the growth in testing for genetic conditions, common complex conditions and variants that may influence health as well as drug metabolism means that a greater number of individuals will face decisions about communicating this information to their relatives. Many health professionals in all levels of health care will be confronted with issues of responsibility and practice in family communication about genetic information as they become providers of this testing.

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