



Abstract

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PI Title:

Project Title: FAMILY EXPERIENCE OF GENETIC TESTING: ETHICAL DIMENSIONS

Abstract: *DESCRIPTION: (from applicant's description) Genetic testing is becoming more widely applied. Nurses will be offering, reporting results, and interpreting genetic tests to families; in addition they will be caring for families dealing with the complex personal, social, and ethical issues associated with genetic testing. There is little research available to guide practice in this area. The candidate proposes a study combining qualitative and quantitative methods to explore how families define, manage, and reason about the ethical issues that emerge during four different types of genetic testing (triple marker screening for Down syndrome, carrier testing for cystic fibrosis, mutation analysis for Huntington disease [HD], and BRCA1 testing for cancer risk). The Family Management Style (FMS) Model will guide the study. There are 6 specific aims. Numbers 1 and 2 are related to family member's definition, management, and reasoning about moral issues. Number 3 involves comparison of family members from the same family. Number 4 concerns how responses differ according to the type of test. Number 5 involves description of distinct family management styles of decision-making. Numbers 6 is designed to explore management style and psychological well being of the tested family member. Participants will be members of 40 families (10 from each of the four types of testing). Inclusion criteria include having undergone one of the 4 selected genetic tests or being a family member of such a person. The term family is defined and members are self identified. Families will only be studied if both the tested member and at least one other family member agree to participate. An interview guide will be developed based on the FMS model, the literature on genetic testing, clinical experience of the investigator, and Rest's work on moral judgement. The Defining Issues Test (DIT) will be used to assess patterns of*

moral reasoning. The tested family member also will complete Ryff's measure of psychological well being, and the POMS to measure psychological distress. Data will be analyzed following guidelines and techniques of Knafl and Ayers, Knafl and Webster, Miles and Huberman, and Patton.

Thesaurus Terms:

ethics, experience, family structure /dynamics, genetic disorder diagnosis, psychological adaptation

Downs syndrome, Huntington's disease, brca gene, cystic fibrosis, family, genetic counseling, morals

clinical research, human subject, interview

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