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ETHICS IN DIAGNOSTIC GENETIC TESTING

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ABSTRACT

The purpose of this study was twofold. First, the aim was to identify ethical issues in diagnostic genetic testing, and second, to describe, to compare and to explain the realization of ethical principles, autonomy, privacy, equality and beneficence in diagnostic genetic testing. The purpose was reached by describing and comparing the perceptions of patients or parents of tested children and personnel and by determining the factors associated with the realization of ethical principles in pre- and post-analytic phases and in consequences. Furthermore, based on the results and the literature, suggestions are made to improve the ethical quality in diagnostic genetic testing. This study was performed in three stages at three Finnish university hospitals. In research stage I a literature search (n=270/80) was carried out on the Medline database for the years 1991-1998. In research stage II, the data was collected through face-to-face focused interviews (n=30) in 2000 and in research stage III through a structured questionnaire (n=268) in 2003-2004 from adult patients or parents of tested children under 15 years and from personnel.

Among ethical issues concerning diagnostic genetic testing, three main categories emerged in different testing phases: personnel characteristics, realization of ethical principles and consequences of the testing. Generally, ethical principles were followed fairly well. The means of patients' and parents' answers on the realization of autonomy and beneficence in consequences were higher compared to those of the personnel. When comparing different testing phases the perceptions of patients and parents were poorer in the post-analytic self-determination and equality compared to the pre-analytic phase. Further, no difference was observed between different testing phases in the group of patients and parents who had received a positive test result. The perceptions of the personnel were poorer in the pre-analytic information receiving, self-determination and privacy compared to the post-analytic phase. Comparing respondent groups there was a significant difference between respondent groups in pre-analytic self-determination and in pre-analytic protection of privacy, higher ratings being given by patients and parents than personnel. Likewise, personnel tended to have more negative perceptions of the consequences in each area of a patient's life, compared to the patients' and parents' views. The correlations between the realization of ethical principles varied from low to moderate in both respondent groups. In the patients/parents group, in particular, the providers of genetic counselling/information, world view, level of education, informed consent, result of test, the way of informing test result and purpose of test explained significantly the variance of the realization of ethical principles. Respectively, in the personnel group, age, training in ethics and genetics, profession and medical speciality of work unit significantly explained the variance of the realization of ethical principles.

Based on the results and the literature several suggestions can be made to be applied in the clinical practice of diagnostic genetic testing, administration and for staff education. Furthermore, some suggestions for future research and improving the nursing science are also proposed.

Keywords: ethics, diagnostic genetic testing, autonomy, privacy, equality, beneficence, patient, parents, personnel