PATIENT'S RIGHT TO BE INFORMED IN DIAGNOSTIC GENETIC TESTING

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Introduction: According to The Finnish Act (785/1992) patient is entitled to know any information collected about his or her health. **The purpose** of the study was to describe how the patients's right to be informed is realized in the pre- and post-analytic phases of diagnostic genetic testing according to adult patients, parents and personnel.

Methods: The data were collected at three Finnish university hospitals from adult patients (n=33) or the parents of children under 15 years (n=73) undergoing diagnostic genetic testing as well as from personnel (n=162), ingluding nurses and midwives (n=107), physicians (n=20) and clinical laboratory scientists (n=35). The data were collected between April 2003 and July 2004, using a structured questionnaire, rated on a five-point scale. The higher values represent the better realization of the right. Pre-analytic section consisted of the following 6 items concerning information about purpose of test, benefits and risks, voluntariness, validity, getting the result, and the meaning of the result. Post-analytic section consisted of 4 items concerning information about; effects of disease to patient's life, prognosis, possibilities to treatment and risks to relatives. The data were analysed using the SAS 8.1 statistical software. The Cronbach alpha values ranged from 0.81 to 0.96, indicating that the instrument was reliable.

Results:
In the pre-analytic phase in patients/parents the highest mean was obtained for item concerning voluntariness of participation (mean 4.02) and the lowest mean concerning benefits and risks of genetic test (mean 3.25). In personnel the highest mean was obtained for item about the purpose of genetic test (mean 3.78) and the lowest mean concerning benefits and risks in genetic test (mean 3.37). *In post-analytic phase* in patients/parents the highest mean was obtained for effect of a possible genetic disease on the patient's life (mean 3.35) and the lowest mean was for information about prognosis relating to a genetic disease (mean 3.18). In personnel the highest mean was obtained for information about treatment possibilities (mean 3.96) and the lowest mean for information about risks posed by a genetic disease to relatives (mean 3.70). Patients/parents considered that receiving information in post-analytic phase was less consistent with their expectation, compared to views held by personnel (mean 3.28 v s. 3.80 $p<0.0001$).

Conclusion: In the training of the personnel more attention should be paid to the informing the patient before the test about the benefits and risks especially to the relatives and after the test about the prognosis of the genetic disease, which according to this study got less attention in the genetic counselling.