The present study focuses on the introduction both of genetic screening and testing and of the related counselling in Finnish health care during the 1990s, i.e. clinical genetics. In addition, the formation of medical ethics as it pertains to clinical genetics is analysed from 1970 onwards. The study consists of five original publications and a summary.

The material consists of data collected by means of questionnaires (conducted among lay people, public health nurses and midwives), semistructured interviews (of physicians, public health nurses, midwives and psychologists) and text material collected in connection with four genetic screening and counselling projects carried out in Finland.

In general, Finns approve of gene tests, but this general approval is combined with disapproval of certain aspects and prospects of such tests. Furthermore, clinical genetics creates agonizing situations where all options have undesirable consequences. Abortion because of a disorder of the fetus is an especially perplexing issue reflecting the ambivalent status of the fetus.

Within the field of medicine, problems related to the increasing number of applications of clinical genetics have been addressed to an increasing extent by developing ethical guidelines and recommendations, by establishing ethics committees and by encouraging public discussion on ethics. In the guidelines, voluntariness and autonomy are repeated principles, and they are also widely accepted principles among lay people and professional groups. Choice may even be regarded as an imperative. What is feared is its opposite, concretized in the fear of eugenics. The situation is paradoxical, however, and characteristic of modern societies: On the one hand there are constant demands for more ethical rules; on the other hand these rules cannot but remain superficial, since they have to be open and flexible in the face of new scientific discoveries and individuals' life situations. A contradiction exists between modern ethics setting the rules for advancing genetic technologies and the real-life situations of clients seeking genetic screening and counselling. Individuals are at the same time struggling to form their own choice and influenced by a plethora of expectations, interests, medical determinants and technological conditions.

Avainsanat-Nyckelord-Keywords
genetics - ethics
morality - prenatal diagnosis
abortion - morals
screening - genetic counseling

Säilytyspaikka-Förvaringsställe-Where deposited

Muita tietoja-Övriga uppgifter-Additional information