New ethical stakes raised since the French nationwide cystic fibrosis newborn screening program was initiated

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Type de publication	Communication
Type	Communication sans actes dans un congrès
Année	2010
Langue	Anglais
Date du colloque	11-17/07/2010
Titre du colloque	Sociology on the move
Auteur	Langeard, Chloé [1], Minguet, Guy [2]
Pays	Suède
Editeur	International Sociological Association
Ville	Gothenburg

Résumé en anglais	Cystic Fibrosis (CF) newborn screening (NBS) has been controversial for many years in France; the long term benefit on pulmonary function test is not yet demonstrated but its median term benefits on nutritional parameters are established as soon as the CF screened infant follow-up is done in a specialized centre. In 2003, the French association “Vaincre La Mucoviscidose” published recommendations addressed at CRCM concerning post-neonatal screening cystic fibrosis diagnosis announcement. **Focus:** Taking the French CF neonatal screening program as a case study, we conducted both a quantitative data survey & a focus groups protocol to gain information on the attitudes, beliefs, & concerns of professionals about newborn screening (NBS) & clinical guidelines, this paper points new bioethical issues from the concrete application of this technology. **Method:** Collective (team) and individual (professionals concerned) interviews in 15 typical centres (historic centres, low practice centres with limited resources, high practice centres with considerable resources). **Results:** • The most important ethical dilemma is the trouble issued of the cystic fibrosis sickness singularity because: **1)** all the children that carry the mutations are not affected with a severe disease; **2)** there is no curative treatment; **3)** parents given information are made anxious, sometimes wrongly if the disease is mild or asymptomatic. • The second ethical issue is located in the distinction between two statuses: on one hand one can observe homozygotes (two mutations), confirmed CF; on the second hand, one can consider heterozygotes (one mutation) healthy carriers. For parents of these healthy infants, the period between learning of the screening result & the sweat test can provoke anxiety, and the long-term impact has not yet been clearly defined. Parents should receive genetic counselling for future family planning, to ensure that they understand the concepts of genetic transmission of CF. (3) However, diagnosis is not always straightforward and difficulties arise when exhaustive study of the gene, following a borderline sweat test (ST), detects a mild mutation or a previously unreported mutation of unknown effect.
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