

Informed consent in the newborn screening practice

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Since 2004 the amount of diseases for which babies are screened in the Netherlands in the first week of their life has augmented to 17 diseases. This screening takes place in the form of a short prick in the heel of the infant, and the withdrawal of a few drops of blood. This blood is researched for a broad variety of metabolic diseases, sickle cell disease, phenylketonury and hypercholesterolemia.

Informed consent has been the generally accepted way of making this type of screening publicly acceptable, and ethically legitimate. However, in this paper I want to ask the question whether informed consent is suitable for this screening practice. Next to practical difficulties in carrying out informed consent –such as parent's difficulty in understanding the implications of the broad variety of diseases for which is screened, and the parent's difficulty to concentrate on this decision in the first busy period after the birth of a child- the question should be asked whether informed consent is the appropriate way to legitimize screening in general, and this newborn screening in particular.

Originally informed consent was introduced in the medical world in doctor-patient relationships. These relationships were characterized by a patient who suffers symptoms of a disease and who requests help from a physician. After this, the patient has to give her consent to the treatment that the physician proposes. In this patient-physician relation, informed consent has helped to counter paternalism and to protect the autonomy of the patient in deciding how far she wants to go in treating her disease. It has made patients more able to manage their own lives in the face of the overwhelming possibilities for further treatment that medical specialists sometimes offer.

Informed consent, however, has now also been transported to other types of relationships, and is expected to offer the same type of legitimation there. In screening programs, for example, the relationship between the stakeholders is quite different than the patient-physician relationship. Usually screening is offered to the whole population, such as in this case; newborn babies. This screening is not an answer to a question of a patient who suffers a complaint; it is offered to healthy individuals who do not ask for medical assistance. The benefits of screening are also often difficult to determine at an individual level. They are determined at the level of the population. The health of a population as a whole is thought to benefit from screening.

In my paper I would like to analyze the discrepancies between these relationships and show how informed consent is able to protect the autonomy of the patient in the patient-physician relationship, and how its function to protect autonomy is difficult to grasp in the screening-context. Consequently, I want to show that it is hard to use it in the same way as a legitimation in the screening context. The conclusion of my paper will be that the well-known ethical language of informed consent is unfitting for contexts of public health ethics, which involves not individuals but groups of people.