THE FALLOUT FROM THE CAMDEN JUDGEMENT: HEALTH PROMOTION OR UNHEALTHY COERCION?

What else should be said about the judgement by Justice Wilson over an HIV-positive mother refusing a HIV PCR test for her 5-month old breastfed baby? This article examines several issues stemming from this judgement in relation to the social and professional ramifications of screening.

First, the baby had been medically examined and judged healthy (1). The judgement in favour of testing viewed laboratory screening technology as the ultimate arbiter of health (1). In this case the validity of the PCR for neonatal HIV diagnosis was a key issue. ROCHE, a manufacturer of the HIV-PCR says their AMPLICOR HIV-1 MONITOR PCR should not be used for primary diagnosis of HIV infection (2). In the U.S. such quantitative tests are cited in surveillance case definitions of neonatal HIV infection (3). The limits of screening for any disease are acknowledged by the U.K. National Screening Committee. False positives may receive treatment for non-existent conditions (4). Not every HIV-positive pregnant women in the U.K. vertically transmits, but their babies are likely to be exposed in utero to antiretroviral prophylaxis so risking mitochondrial dysfunction in babies who are HIV-PCR negative (5).

Second, this judgement authorized a police search for a family because the parents disputed the advice of AIDS doctors (6). HIV-positive mothers may now be viewed as dangerous to their babies in situations of no abuse and informed choice. This judgement supports the criminalisation of informed decision-making and so could be challenged by the parents in the European Court of Human Rights. It may be further challenged by midwives, nurses and doctors who see their ethical duty as the promotion of informed consent not enforced compliance. An increasing evidence base opposes blanket application of early antiretroviral intervention and other measures currently advocated for HIV positive pregnant women. For example, harm accrues from antiretroviral interventions e.g. mitochondrial dysfunction (5); negative sequelae accrue from caesarian section e.g. higher complication rates (7); the risk/benefit ratio in breastfeeding is still equivocal (8,9). So, HIV-positive pregnant women must decide upon their own options based on information not coercion.

Third, what I found worrying in this case was the manner whereby professionals engaged with a family and then subsequently distanced themselves from the effects of their decision to force a test. The parents were asked by their G.P. (anxious over breastfeeding not testing) to meet with an AIDS paediatrician and (unbeknown to the parents) an AIDS social worker was present (1). Legal action ensued because the mother had decided to breastfeed, had decided against antiretrovirals and previously had a low-risk vaginal delivery. The professionals judged it right to seek a HIV-PCR test of the baby under the Children's Act in opposition to the parents' beliefs and values. This outcome to pursue a test (but not cessation of breastfeeding) occurred in a situation where parents accepted primary health care services, parents were seen as good parents and where maternal/neonatal illnesses were absent (1). If enforced screening/testing occurs without consideration of the human consequences it must be acknowledged how such actions affect choice and confidentiality.

Fourth, because of this judgement, HIV-positive pregnant women may feel they must 'choose' what AIDS doctors decide is the 'right' choice. This contradicts the ethical tenets of health promotion in relation to disease

screening (10), through enforcing compliance with medical risk appraisal. The wording of the 'Better For Your Baby' leaflet can be seen as a 'doublespeak' where words like 'choice' (e.g. over breastfeeding) actually mean 'no choice' (11). If HIV testing of neonates now comes under the jurisdiction of the Children's Act, so might future decisions by HIV-positive women on caesarian section, antiretrovirals, Septrin prophylaxis and breast feeding. How far should maternal risk appraisal be overruled by medical risk appraisal, backed up by court order? In parts of the U.S., mandatory neonatal HIV screening means blanket antiretroviral treatment without confirmatory testing (12).

Following the Camden case, Blanche et al. reported mitochondrial dysfunction in 8 babies prophylactically exposed to nucleoside analogues in utero. All were HIV-PCR negative. Severe neurological and biological abnormalities and two deaths were documented (5). These facts were circulating well before last year's High Court case. Blanche et al. reported that all HIV-positive pregnant women should be informed about these findings implying HIV-positive pregnant women must undertake their own risk appraisal (5). As antiretroviral therapy is voluntary so is any risk appraisal for screening/testing. Trust in medical professionals was shaken by exposes of the Shipman and Alder Hey debacles. If HIV screening is a technology for promoting health (and not a means for enacting social, sexual or reproductive control), further public distrust may arise from how we deal with those who, like the Camden parents, challenge the authority of biomedical screening technology.

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