

Chapter 14 New bodies, new selves: genetics and biotechnology

CASE STUDIES

Case study: a commercial biobank in Umeå, Sweden

Høyer²⁶ described the activities of a large, commercial *biobank* – a collection of stored human tissue – in Umeå, Sweden. It currently holds 11 000 blood samples from about 85 000 people, making it one of the largest research biobanks in the world. Donors of blood samples to the biobank also have to answer a detailed questionnaire on their lifestyle and previous medical history. He described two different views of 'personhood' among the donors: some think of it as residing primarily in the information about their lifestyle (the 'narrative'), while others

see it as residing in their blood (or genes). For some in this latter group, selling information on their genetic code to other parties thus 'amounts to selling the very person'.

The biobank functions to convert blood from a substance – a part of a person – into a tradable commodity: *information*. The biobank redefines genetic codes derived from the blood sample as information and then sells this information on to medical researchers, pharmaceutical companies and other enterprises. In this way, the medical biobank 'becomes an important intermediary between human life on the one side, and economics on the other, as even the term "biobank" seems to denote.'

Case study: genetic counselling for inherited disorders in Riyadh, Saudi Arabia

Panther-Brick^{38,39} in 1988 studied the parents of children with inherited disorders who had been brought to a specialist hospital in Riyadh, Saudi Arabia. Eighty-one percent of these couples were first or second-cousin marriages, and while one-third of them had experienced one to four infant deaths as a result of inherited disorders, two-thirds had had one or two affected births but no previous infant deaths. In explaining the origins of the disorder, they invoked a mixture of scientific ('genetics'), religious ('God's will') and folk explanations ('Evil Eye' or *ayn*). All attributed their child's condition to 'God's will', and Panther-Brick suggests that religion helped them to overcome feelings of helplessness, to care for their child with serenity, and even to pray for its eventual recovery. It also made possible the denial of responsibility for the disorder and, unlike in the West, only a minority of the parents acknowledged guilt for having given birth to a child that would suffer. Although two-thirds of the parents did acknowledge a possible genetic basis (*wiratha*) for the disease, only one-third were sure of this.

Only a very small number could accurately remember the risks of recurrence mentioned by their doctors, or understood the precise link between inherited tendencies and actual diseases. For example, several could not understand why an inherited condition did not affect all births in the family, or affect children immediately at birth. Some knew of other cousin-marriages among their relatives that had not had affected children, and this also undermined the link between inheritance and disease. Unlike in the West, their coping strategies did not include therapeutic abortions, but did include both divorce and polygamy (in both cases, taking a new wife who might bear them healthy children). Despite the presence of inherited disorders, 36 per cent stated that they would still prefer traditional cousin marriages for themselves or for their children, though 39 per cent rejected this option. Such differences of opinion therefore 'reflects the position of Saudi families in a society undergoing rapid change.' Overall, Panther-Brick concludes that genetic counselling 'may have very little effect if consanguinity is not widely discouraged'. However, this practice is still deeply rooted in Saudi culture.