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Motivating Donors to Genetic Research? Anthropological Reasons to Rethink the Role of Informed Consent
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What Is Relevant in Informed Consent?

There has been a striking lack of dialogue between social anthropology and advocates of normative approaches to the medical ethical debates about the use of informed consent in research.

The authors explore donors' motivations for providing blood and data from their physical check-up performed at the age of 40, 50 and 60 in Swedish public health care centres to be used in commercial genetic research. Since the health intervention programme started in 1985, samples and questionnaires were stored in the Medical Biobank at Umea University. After 1999, the University and county authorities established the company UmanGenomics that was granted all commercial rights to the samples of the Biobank. The authors began their research when the company was established and existing consent procedures were strengthened. Interviews with participants and nurses were conducted and 54 medical examinations were observed.

In medical ethics, much stress is laid on informed consent procedures based on autonomy as an organizing principle. Good information enables the intentional and deliberative act of giving consent.

This anthropological research focuses on the non-verbal examination setting and shows that donors often did not comply with the standards for informed consent. For instance, they did not read the information sheet. Sometimes they gave their consent to donate an extra blood sample for research when the nurse was already sticking a needle in their arm. Moreover, the concerns of the participants were not directed towards having enough information, but rather towards societal issues. They expressed fear for possible misuse, and wondered whether all people would be able to benefit. These issues do not enter an informed consent sheet.

The authors argue that the motivation for donation should be understood in the wider context of the Swedish welfare state. Participants were used to the rights and duties attached to welfare state-sponsored health care. They put their trust in a responsible state personified by the nurse. This kind of exchange relationships and mutual responsibilities is known from anthropological studies of gifting. With the commercialization of parts of the health care system, strengthened informed consent comes in as a regulatory principle, while donors have a different perception of what is ethically relevant, assuming responsibility for the ethical consequences and outcome of research. The state, however, merely regulates contractual relations between its citizens and health care institutions.

Comments

The authors raise many interesting questions concerning the changing relations between citizens, health care institutions and the state, as well as concerning the position of scholars studying and regulating these relations. Though they argue that medical ethics has its own merits, they are concerned about a short-sighted restriction to refining consent procedures.

Their issue is the moral responsibility of the healthcare systems that facilitate research for which motivated people give informed consent. They stress that other forms of safeguard are needed to prove the system is trustworthy. Donors seem to place the responsibility for the management of new technologies at a political level beyond the range of the individual. One might argue that the focus on informed consent does not exclude nor run counter to this wider mission. Refining informed consent procedures is still necessary. In the above-mentioned case, for instance, consent might or should have been discussed long before the nurse draws blood. Not only in the case of commercial companies but also, or even especially, in the case of states controlling health care, consent should be paramount. But the authors do have a point that at least part of the ethics community tends to focus on principles and procedures instead of practices and politics. Perhaps autonomy, the cornerstone of ethics, and non-verbal motivation, the focus of anthropology, are merely two aspects of the question of how and why responsible participants contribute to important research. Given the rapid developments in genetics and genomics, both ethicists and social scientists need the best tools of their respective disciplines to enlighten the reconstruction of health care systems.

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Potential for Genetics to Promote Public Health: Genetics Research on Smoking Suggests Caution about Expectations
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Genetics Research on Smoking May Not Be in the Interest of Public Health

The implementation of genetically based prevention in public health was viewed with optimism in the 1990s. Together with currently increasing numbers of DNA-based tests available for use in clinical care, questions have been raised about expectations and research priorities. The authors discuss the current situation of genetics research on smoking.

Smoking-related diseases are major public health problems which can be reduced by cessation of smoking. Current interventions such as counseling, but also bans and taxes have had (limited) success. Research has revealed genotypes that modulate smoking status, initiation, cessation, quantity, treatment response and lung cancer risk. These findings can possibly lead to improved rates of smoking cessation.

However, research reveals that awareness of a genetic predisposition does not facilitate smokers' quitting and may even induce fatalism, feelings of impotence or loss of willpower. Furthermore, no conclusive evidence is available to suggest that nicotine patch therapy can be improved by genotype knowledge.

Genetic testing comes with several risks: knowledge of an adverse polymorphism could cause anxiety and lack of cessation success could be blamed on genetic factors, hence decreasing mo-