



In the mood for science: A discussion of emotion management in a pharmacogenomics research encounter in Denmark

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ABSTRACT

We investigated the practices through which patients in treatment for depression become research subjects in pharmacogenomics research in Denmark. On the basis of an ethnographic study of research subject participation taking place between May 2006 and August 2007, we conceptualized the efforts made by both researchers and research subjects at the research encounter as *emotion management*, through which the raw material of pharmacogenomics research is created. The study demonstrates that management of emotions in the research encounter is necessary to secure high quality data and simultaneously produces new relations of exchange – exchanges we view as important fuel in the generation of biovalue. In bringing this analysis into dialogue with the bioethical emphasis on altruism, we challenge the assumption that research participation comes about by linking already available, that is, ‘altruistic’, individuals to research institutions. We suggest that the emotion management taking place in the research encounter and the relations of exchange established through it *actualize* behavior we recognize as ‘altruistic’. We conclude that there is no morally relevant conflict between ‘altruistic behaviour’ and the production of exchange relations.

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Introduction

A vital precondition for realizing the often-claimed potentiality of the life sciences is access to human raw material. For clinical genomic research such raw material consists of blood samples, health information from medical records as well as and information about lifestyles and psychosocial issues. Translated into bio-information and banked in large-scale databases, such raw material holds a certain biovalue (Waldby & Mitchell 2006). To create biovalue, biological substances (e.g. tissue) and personal life experiences (e.g. illness narratives) need to be constituted as objects in questionnaires, computers and freezers and subsequently accessed by biomedical researchers. Ultimately, the creation of biovalue relies on the willingness of individuals to donate tissue and make personal information available to research.

In bioethics donations to genetic biobanks are ideally viewed as acts of altruism, in which subjects voluntarily participate in research without expecting anything in return. Born out of historical cases in which scientific experimentation caused harm to human subjects, the wish to secure an autonomous decision and a well-informed research subject has become a driving force in research ethics. In the

case of donations to biobanks this is reflected in the rigorous requirements regarding the formal procedures for donations, primarily informed consent (Chadwick & Berg, 2001; Netzer & Biller-Andorno, 2004; Phillips, Joly, Silverstein, & Avard, 2007; Stegmayr & Asplund, 2002). In social science the literature on subjects’ participation in and donations to life science research has centred on understanding the broader social setting of subject participation in research rather than on formal codes of conduct. Some studies have explored the context of the consent process, highlighting how donation positions donors in relation to larger communities (Barr, 2006; Busby, 2006; Felt, Bister, Strassnig, & Wagner, 2009; Hoeyer, 2002; Svendsen, 2007; Tutton, 2002). Others have investigated the social relations that emerge in the direct alliances of individual citizens with scientists in private and public organizations and the way such relationships contribute to the production of biovalue (Franklin, 2005; Gibbon & Novas, 2008; Rose & Novas, 2005). A recent trend has focused on the economic conditions of clinical trials and the selling of organs and bodily tissue on a global scale and has prompted conceptualizations of research subject participation as labour (Rajan, 2007; Waldby & Cooper, 2008).

In the present study we direct attention to one specific element in the process of biovalue production, namely the research encounter. We followed a pharmacogenomics (PGx) research project in Denmark and examined the practices through which patients in treatment for depression inhabited their roles as

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research subjects and donors. Their research participation consisted in donating a blood sample and volunteering personal information to the investigator through a 2–3-h interview. These research encounters turned out to be highly charged emotional events in which the participants expressed fear, care, consolation, well-being, pressure, irritation and enthusiasm. While their emotional tenor may resemble that of ordinary psychiatric practice, these encounters stand in sharp contrast to the empirical settings typically discussed in both bioethics and social science, where donations to biobanks consist of a blood sample and a completed questionnaire. In our study we explore what may be involved in generating human raw material when the 'life' of life science research is not only a blood sample but also a vibrant human biography. On the basis of ethnographic fieldwork in 2006 and 2007 comprising observations of research encounters and interviews with researchers and research subjects, we ask two questions. First, what characterizes the social dynamics of the research encounter through which research subjects become available for PGx research? Second, how do research subjects experience research encounters and what social identifications are created in the encounters? In pursuing these questions we conceptualize the efforts of researcher and research subject as *emotion management* and explore the relations of exchange constituted through such management of emotions. Finally, we suggest how an analysis of these issues might contribute to the institutionalized bioethical understanding of research subject participation as altruistic.

Emotion management

Our use of the concept of emotion management is inspired by Arlie Hochschild's work. She introduced the concept of *emotional labour* in her study of airline employees (Hochschild, 1983), referring to stewardesses' management of their emotions in order to sustain a facial expression that would produce the required state of mind in airline customers and consequently increase profits (Hochschild, 1983: 7). Since then the concept of emotional labour has been widely used to understand social dynamics in occupational settings in the service industry, highlighting as labour typically unrecognized efforts, such as being responsive, caring and polite towards customers; treating them as individuals; making them feel good and cared for; and creating a smooth interaction with them (Sharma & Black, 2001; Toerien & Kitzinger, 2007). In the context of medical research, seeing research subjects' services and donations as value-producing labour has been suggested in several neomarxist studies exploring the recent off-shoring of clinical trials to Eastern Europe and Asia (Cooper, 2008; Petryna, 2007; Rajan, 2007; Waldby & Cooper, 2008). A central argument of these studies is that the contribution of human research subjects to international drug trials may be seen as a form of exploitation that appropriates the research subject's clinical or experimental labour for commercial purposes. Our point, however, is not to compare the enrolment of poor populations in randomized clinical trials in developing countries with the participation of depression patients in research in a welfare state – or to assume that Danish citizens and research subjects are being managed like customers in the service industry. First, in the research project that we followed no private pharmaceutical company was directly involved, and those who were asked to become research subjects had access to public health care independently of their participation. Still, a certain instrumentalization of the research subjects took place in the research encounters in which a range of institutional expectations were performed. Second, the concept of emotional labour originates in the context of a commercial worker-client relationship in the service industry aiming directly at producing economic value and increasing private profits. Instead, the efforts which we discuss

were exercised in relations of reciprocal responsibility characteristic of citizenship in a welfare state. The term emotion management was originally used by Hochschild to refer both to the management of emotions in private life (emotion work) and the management of emotions for a wage (emotional labour) (Hochschild, 1983:7). As we have explored a setting that is neither directly aimed at a commercial output, nor belongs to private life, the distinction between work and labour is not appropriate here, and we therefore use Hochschild's more general term 'management'. With the concept of emotion management we wish to highlight the exercise of power in the interactivity of the research encounter and suggest that the dual efforts to control the emotional engagement of both research subjects and researchers should be seen as issues of governance. A third issue concerns the object of management and the managing subject. We follow Hochschild in her attention to how the management of customers (i.e. research subjects) requires the self-management of the stewardess (i.e. researcher). Going further than Hochschild, however, we also highlight the research subjects' active engagement in and attempt to control the research process. In the following, then, we wish to shift the focus from the unilateral management of research subjects to dual forms of emotion management performed in a relational practice between researcher and research subject.

To analyse emotion management in the context of scientific experiments we also draw on Vinciane Despret's (2004) work. Despret revisits well-known experiments involving animals and analyses the interaction between the different actors in the experiments (e.g. professors, students, animals). She argues that the embodied expectations and beliefs expressed in the relationship between experimenters make both humans (researchers) and animals (research subjects) 'available' to the research encounter (Despret, 2004: 122). According to Despret, expectations and beliefs have effects by making entities available to events such as an emotionally charged research encounter and thus shape the knowledge produced. Similar processes can be observed in human research subjects. Both researcher and research subject affect each other, adjust to each other and both perform efforts to manage the emotions of self and the other in an intimate, complex and sometimes collaborative, sometimes confrontational practice. In the following we explore the dynamics of the research encounter, focusing on the researcher's emotion management as it contributes to making research subjects available to research. We further explore the emotion management performed by the research subject directed at both researcher and self, focusing on how acts of expressing and objectifying experiences constitute emotional rewards from research participation. We end by discussing our analysis in the context of the dominant understanding of what is formally required by ethical review boards, i.e. that the research subject should act as an altruistic person who cannot expect anything in return for her donation. In contrast to this dominant understanding, we suggest that the existence of exchange relations as an inevitable condition of human subject participation should be acknowledged. We begin by introducing the research setting and our methods.

Field of study and methods

The concept of tailor-made medicine has become a central focus in the psychiatric field, in which PGx-based genetic testing and individualized drug therapy are envisioned as means of matching patients with optimal treatment. In affective disorders such as depression, treatment is hampered by considerable variations in individuals' responses to pharmacological intervention, and 30–40% of all patients do not respond at all. Considerable side effects often occur. While poor efficacy characterizes the medical

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