Doing participant observation in a psychiatric hospital—Research ethics resumed

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Abstract

Social scientists who employ participant observation methods in medical settings are often held accountable for their research methods, specifically in regard to medical research ethics. However, the medical research ethics tradition rubs uneasily against participant observation and the anthropological understanding of the research process. The underlying premise for considering research ethics in the current case is the notion of the vulnerability of psychiatric patients as a participant group. Based on this notion of vulnerability among psychiatric patients, this article discusses the epistemological grounds for vulnerability in anthropological and medical research ethics. The authors draw on their experience with the Regional Committee for Medical Research Ethics in Norway, and the consequences of the guidelines used for participant observation as a research method in a psychiatric hospital. Social science researchers are required to follow medical ethical guidelines, such as informed consent, the principle of voluntariness, and estimation of risks and benefits. Ethnographers have found these guidelines to be obstructive when doing social science research in a psychiatric hospital. The article suggests the need for reformulation of research guidelines for participant observation in medical settings.

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Introduction

In health research, there is a growing tendency among social scientists and researchers in medical professions to conduct participant observation research within psychiatric institutions (Barrett, 1996; Hem & Heggen, 2003; Hummelvoll & Severinsson, 2001; \textit{van Dongen}, 2004). Social scientists entering the medical field are being called on to comply with ethical regulations, usually enforced by medical ethical review boards, to ensure that ethical guidelines are followed. Social scientists are then held accountable for their research methods, and are questioned with specific reference to medical research guidelines (Fluehr-Lobban, 2003a). The consideration of participant observation research proposals by medical review boards often has uncomfortable consequences for social scientists. The review board's interpretation and proposals challenge the methodological “habitus” of participant observation...
Social scientists such as anthropologists have questioned the role of medical ethics boards, and report uneasiness when trying to follow medical research ethics guidelines (Angrosino & Mays de Pérez, 2000; Mills, 2003; Pels, 1999). Angrosino and Mays de Pérez (2000) claim ethical boards within psychology and biomedicine do not have experience in participant observation research. For that reason, social scientists employing participant observation are caught between two different models of research: the experimental, hypothesis-testing, clinical model, and participant observation, which is intrusive in character (Angrosino & Mays de Pérez, 2000; Hoeyer, Dahlager, & Lynøe, 2005). Wax (1999) claimed that ethical guidelines and the institutional review system are prejudiced in favor of research methodologies that mimic epidemiology, and kindred “objective” approaches that deal with humans as detached social atoms. These approaches do not address the needs or practices of participant observation.

Earlier in this journal, Hoeyer et al. (2005) outlined two different research ethics traditions: medical research ethics and research ethics in anthropology. They showed how differences in central ethical issues can lead to clashes between social scientists and medical staff. Their article addressed the difficulties of measuring one ethical tradition by the standards of the other. In their concluding remarks they suggest building bridges between the two ethical traditions in order to prevent or cope with research conflicts. Their suggestions were made without looking thoroughly at the epistemological paradoxes inherited by both research ethics traditions, or at the practical research problems that arise in participant observation when trying to follow medical research ethics. This article is therefore inspired by Hoeyer et al., and based on cross-disciplinary specific study in a psychiatric setting in Norway by the first and third authors (C.O. and A.S.). This paper traces an ambiguous and paradoxical notion of vulnerability in medical research ethics. Further, the article presents the implications of this notion of vulnerability for participant observation in a psychiatric hospital.

The research case

The main aim of the research was to examine how milieu therapy is practised, organized and experienced by milieu therapists, and patients. In short, milieu therapy is about how daily life activities are organized in a psychiatric ward for the purpose of gaining therapeutic effects (Gunderson, 1978). Activities also include interactions between staff and patients (Ammon, 1993). We planned to use participant observation to observe both milieu therapists and patients, and observe the interaction between them in different settings in public rooms in two different psychiatric wards. We included patients and milieu therapists for different purposes in our study. Patient informants were recruited as recipients of such therapy, to shed light on milieu therapy and to answer the following question: what are their experiences with daily life routines and activities? Milieu therapists were recruited so that researchers could observe how they employ this therapeutic tool. Milieu therapists could be psychiatric nurses, nurses, ergonomists, enrolled nurses, activators, or unskilled staff. For interviews, we planned to recruit primarily milieu therapists who had some experience with milieu therapy to explain the practice of milieu therapy. Included patients would be of any type, independent of diagnosis, with some daily life experience (e.g., routines and activities) within mental health institutions. We planned to use individual-based informed consent forms for interviews with both groups.

The Hospital Management Board, in conjunction with the senior nursing officer of two different wards, approved our research plan. In contrast, obtaining research approval from the research ethics committee proved difficult. The committee, both in writing and orally, strongly recommended that we request written informed consent from each psychiatric patient to observe milieu therapeutic practices. The arguments for this demand were various. Firstly, psychiatric patients are regarded as being vulnerable, with impaired decision-making capacity as regards giving informed consent. Therefore, we were to cooperate with the medical staff in charge to decide whether or not each psychiatric patient was capable of providing informed consent. The second argument followed the first one: their vulnerability increases the potential for the study to do harm and creates doubt over how psychiatric patients will benefit from the research. Thirdly, because psychiatric patients are often involuntarily hospitalized, they are vulnerable and not capable of voluntarily giving informed consent. The committee claimed that psychiatric patients who were not willing to participate in the study were...
not able to withdraw from the psychiatric ward whenever the ethnographers were present to observe milieu therapeutic activities. Participant observation as a research method, they claimed, challenges the ethical principle of voluntariness. They suggested two different solutions to this problem: (1) non-participating patients could be transferred to another ward or (2) we could leave the ward and do observations in another ward where everyone agreed to be observed. We discussed different solutions with the committee before, and at the beginning of the fieldwork, because we found the suggestions difficult to comply with. The first suggestion we found very unethical; it would have drastically altered the treatment of patients, and by doing so, “punished” patients who did not agree. The committee’s second suggestion was followed, and most patients were asked for written informed consent to allow us to observe them in the public rooms of the ward. The process of asking patients for informed consent involved asking staff in charge for advice and permission about which patients to ask for informed consent. Most patients gave their consent, and the ones who were never asked or did not give their consent, were not followed as closely as the ones who gave their consent. It was not practically possible to avoid observing situations in which patients who had not given their consent were involved. The committee was not worried about us engaging with milieu therapists, and informed consent to observe them was not requested.

In order to address the committee’s recommendations and follow the medical research ethical guidelines, we were forced to examine and revise our research plan. Following these guidelines, we experienced some obstacles and difficulties when employing participant observation. The obstacles experienced were mainly due to: (a) the opposition of an individual-based informed consent process and a collective-based participant observation method; (b) opposition of the principle of voluntariness and elimination of all influential circumstances and participant observation as an influential-based method; and (c) being able to predict benefits and avoid all sorts of harm, which is a principle that is difficult to follow when the purpose of the research is to scrutinize a therapeutic tool anchored in professional identity. The underlying premise behind these ethical guidelines is the notion of vulnerability among psychiatric patients as a participant group.

### Medical research ethics committees in Norway, Europe and the US

The World Medical Association’s Declaration of Helsinki in 1964 stressed the importance of establishing Research Ethics Committees (RECs) (called Institutional Review Boards in the US), and stipulated that researchers should not take ethical responsibilities entirely upon themselves (Hoeyer et al., 2005). In Norway, a Regional Medical Research Ethics Committee (REK) was set up in 1985, for each of Norway’s five health regions, in accordance with the guidelines laid down by the Norwegian Ministry of Education and Research (REK, 2003). The committees give advice and guidance based on generally accepted principles of research ethics established and regulated by the Norwegian Medical Research Ethics Committee (NEM) (1990) and international bodies (e.g., the Declaration of Helsinki) (http://www.etikkom.no/REK/english/reference). In addition to the medical committees, there are two independent but coordinated national committees for research ethics to cover scientific disciplines such as Social Sciences and Humanities, and Science and Technology (http://www.etikkom.no/English/about). If the research is carried out in a medical institution, the researchers must submit a research application for ethical review to the REK in their region. Therefore, our research, despite its social science foundation, had to be submitted to a medical research ethics committee. Furthermore, the committee for medical research ethics operates with a descending scale of permission. It suggests that the researcher uses healthy adults as research participants as their first preference, before vulnerable groups. These patient groups are listed hierarchically, with healthy adults at the top of the list, followed by increasingly more vulnerable patient groups: the mentally ill, intellectually challenged, demented, drugged and intoxicated, acutely confused, unconscious, exhausted or marked by a serious disease, and children (http://www.etikkom.no/Etikk-torget/omForskningsEtikk). This does not imply that every person in the latter groups has impaired decision-making capacity. The committee claims that some people with mental illness will be capable of giving informed consent to participate in research. Recently, there has been a discussion within the NEM on how to handle participant observation studies when vulnerable participant groups are involved, mainly focused on impaired decision-making capacity among groups of patients,
the risk of disturbing health personnel in their work, and difficulties in complying with professional confidentiality. Despite these problematic issues, the NEM (2005b) emphasizes the importance of gaining knowledge on how health personnel function when treating vulnerable groups. Furthermore, the NEM has recognized problematic issues when studying vulnerable groups, and therefore suggested in 2005 that researchers should consult user/patient councils (The National Committees for Research Ethics in Norway (NEM), 2005a).

The Norwegian model departs from the more common Research Ethics Committees (RECs) in Europe and the US. Throughout Europe, there are different practices on how RECs are organized. For instance, in the UK, the era of self-regulation ended in May 2004, and RECs became legally accountable to a new government body, the UK Ethics Committee Authority (UKECA). Ethical reviews in social science research depart from medical research, which are still regulated at institutions such as universities (Kerrison & Pollock, 2005). In the US, Institutional Review Boards (IRBs) are independent or commercial, and based at academic or medical institutions, but are regulated by the same federal regulations (Gilbert, 2006). Ethnographic research is governed by federal regulations because human participants are involved, but not all research projects require full IRB reviews—for example, those involving observations of public behavior where subjects cannot be identified (National Science Foundation, 2006). In contrast, projects that focus on sensitive information, where the disclosure of respondents could harm the respondents require full review. This includes research on vulnerable groups such as the mentally ill (Kennedy, 2005). The National Science Foundation (NSF) has questioned IRBs’ reviews and social science methodologies, especially ethnography and the use of written informed consent (NSF, 2006). A request for written, formal consent could seem suspicious, inappropriate, rude and perhaps even fraught with danger in many societies and communities. Therefore, the NSF suggests, the use of “group consent” in such societies (e.g., presenting the project in an open meeting, and allowing questions to be raised and answered publicly) in addition to individual-based informed consent (NSF, 2006).

**Participant observation**

Despite REK’s ethical suggestions and demands, participant observation seemed to us to be a suitable and necessary research method to use, that would allow us to understand how milieu therapy is organized, how it takes place, and how milieu therapists and patients interact, as it is a method used to study daily life activities (Alvesson & Sköldberg, 2000)—also a principal focus of milieu therapy. The method is a mixture of participation, observation, and interviewing (Delamont, 2004), where the purpose is to observe how participants interact with, and influence each other (Atkinson & Hammersley, 1994). Participant observation is a deep investigation of social life and life experience. This process entails becoming involved in social life in order to see and experience how daily life activities are practised (Lincoln & Denzin, 2003; Lofland, Snow, Anderson, & Lofland, 2006). It is undertaken to understand how the studied culture works and what the world looks like for the people involved in the study. Because the anthropologist more or less lives and participates in the studied community, he or she is in a position to interpret the meanings and possible consequences of actors’ behaviors within that specific cultural context (Chambers, 2000). Participant observation then becomes an ongoing attempt to place specific encounters, events and understanding into a fuller, more meaningful context (Tedlock, 2000). Research participants and their knowledge are not essentially unaffected by the research or its circumstances; the research is constructed in a social, cultural and historical context rather than discovered and revealed irrespective of circumstantial factors (Klee, 1997).

**Medical research ethics and the assumption of vulnerability**

The World Medical Association has developed the Declaration of Helsinki (1964) as a statement of ethical principles that provides guidance to physicians and other participants in medical research involving human subjects (WMA, 2002). Medical research ethics is anchored in the Hippocratic Oath, in doing no harm, and tends to take the protection of the individual as its main objective (Hoeyer et al., 2005). Therefore, according to the Declaration of Helsinki, studies should be designed in the safest manner possible and every medical research project involving human subjects should be preceded by careful assessment of predictable risks and burdens weighed against foreseeable benefits to the subject or to others. Furthermore, the participants
in research must be volunteers and informed of the research project to freely give informed consent, preferably in writing. Accordingly, the participants must provide entirely voluntary agreement to participate, with no physical or psychological coercion (Christians, 2003).

The notion of vulnerability among psychiatric patients seems to underlie restrictions on ethical proposals. According to the Declaration of Helsinki, some research populations are vulnerable and in need of special protection. The World Medical Association is concerned about the possibility of exploiting vulnerable groups (see WMA, 2002) for these reasons:

(1) By virtue of their illnesses and common psychiatric symptoms, such as ambivalence, apathy, paranoia, self-destructiveness, and impulsivity, those with mental illness may be prevented from meaningfully participating in the consent process (Osborn & Fulford, 2003). Psychiatric patients are also believed to have impaired cognitive and emotional functioning, as well as a lack of awareness and insight into illness, which implies lack of comprehension and rational reasoning when given information about the research project (DuVal, 2004; Eichelman, Wikler, & Hartwig, 1984).

(2) Institutional constraints apply, which means that in psychiatric hospitals, patients are “captives” and often involuntarily detained, indicating a lack of freedom and autonomy (Regehr, Edwardh, & Bradford, 2000; Roberts, 2002). Patients are often deprived of the facilities required for exercising autonomy (Radden, 2002).

(3) Patients are subject to social factors that arise from stigma, dependence, fractured relationships, fear and discomfort displayed by others, unemployment, homelessness, poverty, loneliness, and other factors primarily brought on by their illness (DuVal, 2004). Therefore, the psychiatric patient is believed to be in a vulnerable position in research, because mental illness impairs their capacity to understand, reason, choose or act (Lützen & Nordin, 1994). Accordingly, psychiatric patients lack the capacity to make acceptable decisions about their participation (Appelbaum, 1998).

All the reasons for seeing psychiatric patients as vulnerable make the informed consent process a challenge. Informed consent means that the researcher gives the participant the fullest possible information about the study and collects a written (or sometimes oral) consent. In recent years, the focus of discussions on informed consent has shifted from the researcher’s obligation to disclose information, to the quality of a research participant’s understanding and decision-making capacity (Leino-Kilpi et al., 2002). Participants should not only be informed, but their capacity to understand, in order to give informed consent, should also be checked.

The medical research ethics tradition draws on different traditions of knowledge in understanding psychiatric patients as being vulnerable with impaired decision-making capacity. First, medical research ethics draws on biological knowledge, such that psychiatric patients are to be regarded as vulnerable due to certain innate biological traits. They have less capacity to understand the information given due to illness, symptoms and medication. Second, medical research ethics draws on an understanding of research participants as basically autonomous, which implies self-determination free of any kind of coercion. The psychiatric patient will, in most cases, not be able to fulfill such an ethical demand, or the ideal of the perfect research participant, due to the influence of illness, the coercive circumstances of institutionalization and by social factors such as stigma, poverty, and dependence. Accordingly, medical research ethics is based on the idea that, as far as possible, research participants should not be under any influence of any kind, including illness, coercion, and institutional, social or relational constraints. The more a research participant is influenced by these constraints, the more he/she is regarded as vulnerable with impaired decision-making capacity and in need of protection by others, including the research committee and medical staff.

Research ethics in social science and anthropology

The standards for ethical conduct do not vary fundamentally between medical and anthropological research, even though medical research has been more regulated than social behavioral research (Fluehr-Lobban, 2003a). In the field of social anthropology, it used to be quite common to do covert participant observation (Atkinson & Hammersley, 1994). In psychiatric hospitals, the study of Caudill (1958) is an example of covert participant observation.
observation. Today, neither the American Anthropologist Association (AAA) nor the Association of Social Anthropologists (ASA) permit covert participant observation.

Social scientists continue to discuss ethical standards that will guide their research, but in anthropology, achieving agreement has never been easy (Caplan, 2003). There is currently no common agreement on what such standards should be, although many proposals have been made from various social scientific communities and researchers (Lincoln & Denzin, 2003). Both the AAA, in 1971 (AAA, 1998), and the ASA, in 1987 (ASA, 1999), formulated ethical guidelines for participant observation research. These guidelines are based on the Nuremberg Trials and include obligations of openness and informed consent (ASA, 1999). For years, anthropologists have dismissed informed consent as being applicable only to biomedical research. However, in the last decade, realization has been growing that ethnographers are not exempt from obtaining informed consent in theory and practice (Fluehr-Lobban, 2003a), and that anthropologists should offer the fullest possible information and disclosure for the goals and potential uses of research before it is undertaken (Fluehr-Lobban, 2003b). Furthermore, anthropologists should be sensitive to harmful effects (AAA, 1998; ASA, 1999), especially when it comes to vulnerable research populations (ASA, 1999). These vulnerable groups are often listed as ethnic or religious minorities in danger of being hurt by research due to an uncertain political situation in the country in which they live. In addition to ethnic and religious minorities, Fluehr-Lobban (2003a) regards children, the incarcerated, and the mentally incompetent to be vulnerable, which prevents these groups from giving full informed consent.

Paradoxes in research ethics

The roots of protection lie in the Hippocratic Oath and paternalism; the patient does not know what is good for them (Leino-Kilpi et al., 2002). The risk/benefit ratio has its roots in utilitarian ethics, a calculus of presumed benefits and risks, whereas informed consent becomes a moral obligation (Wax, 1999). Medical research ethics is, then, anchored in different ethical traditions. On the one hand, the protection of psychiatric patients is based on the Hippocratic Oath and paternalism, but on the other hand, the medical research ethics is anchored in absolute respect of patient autonomy and self-determination. We may ask whether the medical ethics doctrine places itself in a dim epistemological landscape, between the human right to voluntarily participate in scientific research, and the human right to protection. The recognition of these paradoxes is deeply rooted in the different humanist-liberal and paternalistic traditions of epistemology. Both traditions imply that participants are, by nature, either fundamentally autonomous or innately vulnerable due to certain biological traits, and therefore in need of protection. The ethical doctrine of informed consent is derived from the recognition of the patient’s vulnerability, as well as respect for the patient’s autonomy, and the enlightenment ideals of humanism, liberalism and human rights thinking (Leino-Kilpi et al., 2002). A mixture of different epistemological traditions in medical research ethics implies paradoxical guidelines when it comes to doing participant observation research. Thus, ethical guidelines, such as those about informed consent, the principle of voluntariness, and estimating the risk/benefit ratio, become substantial challenges when employing participant observation.

Informed consent and participant observation—a challenge

According to medical ethical guidelines, psychiatric patients are potentially considered mentally incapable, with impaired decision-making capacity for giving informed consent due to their assumed vulnerability. Tancredi (1995) claimed that the concept of a patient’s ability to understand is somehow problematic because the notion of what it is “to understand” is unclear. We can further ask: “What is rationality?” “How should we define it?” “What should be the criteria for assessing what is rational?” The concept of vulnerability presupposes the notion that psychiatric patients are incapable of expressing their values, meanings and thoughts of relevance to research (Lu¨tze´n & Nordin, 1994). Our experiences of conducting participant observation research in a psychiatric hospital question this notion. In fact, the majority of psychiatric patients in the wards were expecting us and wanted to tell their stories. Psychiatric patients had several relevant questions and comments regarding research practices. Most were willing to participate, and those who were in doubt provided understandable arguments for not giving their
consent. Those who were unsure of participating were either afraid of offending staff members by gossiping, afraid of sanctions by staff members or concerned that the researchers would violate professional confidentiality.

Challenges were presented by the necessity of collecting informed consent forms when doing participant observation from one group of participants (psychiatric patients) and not the other group (milieu therapists), when individuals of both groups were present in the study. In doing so, we communicated to psychiatric patients that we must be more careful in our interaction with them, be more considerate, show more respect, and be more careful than in our interactions with milieu therapists. Our interaction with psychiatric patients became in a way “unnatural”—being very considerate and careful, asking again and again for permission to stay with them, and being overly pleasant. In doing so, we undermined their mental capacity, and, in a sense, communicated distrust in their capacity to make their own decisions. After we had informed one of our participants several times about our study and asked for his written informed consent signature on two different forms, he commented: “You know, I am not stupid, I understand the purpose of the study.” If, as researchers, we do not give psychiatric patients the opportunity to participate in the research, we may cause or maintain their feeling of unworthiness and confirm their stigma and lack of self-determination. Furthermore, researchers are in danger of maintaining the view of psychiatric patients as vulnerable, and further stigmatizing this specific group. Such research is in danger of representing the professional’s point of view at the expense of the patient’s point of view (Van der Geest & Finkler, 2003).

Punch (1994) was strongly critical of recommendations of informed consent and stated: “... gaining consent is quite inappropriate, because activity is taking place that cannot be interrupted. In much fieldwork there seems to be no way around the predicament that informed consent—divulging one’s own identity and research purpose to all and sundry—will kill many a project stone dead” (Punch, 1994, p. 90). Therefore, obtaining informed consent becomes inappropriate, because activity that cannot be interrupted is taking place, even though the mere presence of a researcher does change the situation. This is known as the “observer’s paradox.”

The principle of voluntariness and participant observation—a challenge

The principle of voluntariness and the elimination of all extenuating circumstances seem to rub uneasily against participant observation, which is an influence-based method. As we have seen, according to medical research ethics, all participants must voluntarily agree to participate without physical or psychological coercion. Accordingly, one of the main reasons for assuring voluntariness is to avoid exploitation and harm (Kottow, 2003).

Psychiatric patients are not wholly free to choose when it comes to activities such as leaving the hospital, and cannot choose when visitors enter or leave the ward (these are some reasons for regarding this group as vulnerable). Nor are milieu therapists wholly free to choose when it comes to being participants in a participant observation study, despite reading information sheets and signing informed consent sheets. Some members of staff did not consider themselves to be entirely free to make a choice, which was been recognized by others (Moore & Savage, 2002).

Medical research ethics guidelines have not incorporated an understanding of participants as members of a social community, where participants are shaped and reshaped in social interaction. On the contrary, participants are seen as solitary individuals who are supposed to choose freely with minimal constraints or influence of any sort. Participant observation has been understood as an intrusive method (Angrosino & Mays de Pérez, 2000), because participants can hardly escape the context of discovery. As mentioned earlier, in the social sciences, participants and their knowledge are understood as being created through social interactions and settings, rather than being discovered and revealed in isolation from circumstantial factors. Therefore, employing participant observation means interacting with, getting to know about, and being involved in events and participants’ lives to learn about their social life and cultural ideas. Only by being involved, can the researcher gain knowledge about daily life matters in different social settings.

Estimating the risk/benefit ratio when employing participant observation—a challenge

As mentioned earlier, according to medical research ethics and the Helsinki Declaration,
researchers should estimate the potential risk/benefit ratio. Social scientists employing participant observation methods have expressed concern over how to predict possible risks and benefits (Akeroyd, 1984; Christians, 2003). First, any benefits that the informants should expect from the research and the researcher, as well as the obligations of the researcher to informants in a participant observation study, are not clear (Jokinen, Lappalainen, Meriläinen, & Pelkonen, 2002). Second, the ethical principle of avoiding all sorts of harm and minimizing risk seems somehow vague; what kind of harm and risks are relevant when doing participant observation? According to Labott and Johnson (2004), we are talking about psychological and social risks in daily life research, even though what might be understood as minimal social and psychological risks is a bit unclear. Du Toit (1980) suggested that possible risks include the danger of embarrassing or causing pain to once-trusted participant friends. According to Angrosino and Mays de Pérez (2000), participant observation implies being involved in the lives of the participants and thus is fraught with all sorts of possibilities for harm and risks. In our study, the potential for harm is unclear, but we have observed in the field how participants of both groups have reacted when we have been present doing participant observation in terms of expectations, ambivalence, embarrassment, worries and unpleasantness.

We have identified three different conditions that cause what some would call emotional or social harm or possible benefits to participant individuals, either patients or milieu therapists, when employing participant observation as a research method. First, the very purpose of this study is to scrutinize a therapeutic tool through the method of participant observation, which can be experienced by milieu therapists as an unpleasant form of surveillance. As ethnographers, we followed milieu therapists in their daily work and life. Doing participant observation in a psychiatric hospital means that the milieu therapists allow access to their professional life and work. This includes access to formal and informal meetings, where they discuss patients, routines and different forms of milieu therapeutic efforts. In these settings, the milieu therapists discuss matters that are delicate and difficult, sometimes with a great deal of despair and distaste. They also let us follow them in different forms of interactive activities with patients, which included attempts to calm patients, set limits, deliver unpopular messages, and be strict or harsh in some way—tasks that many of the milieu therapists find uncomfortable. Afterwards, milieu therapists tried to explain or make excuses for not coping. We did not only observe and map interactions, activities and episodes, but we also requested professional explanations and recorded these in writing. Participant observation then became an inquiry in which milieu therapists’ professional identities were scrutinized.

Second, when doing participant observation, the researcher becomes a mediator between or benefactor to different groups, which is a well-known experience in the field (Atkinson & Hammersley, 1994; Wax, 1999). Patient participants, in most cases, expected us and were often anxiously waiting for days in the smoking room to tell their stories about daily life matters inside and outside the institution. Most patients saw an opportunity to be seen, to be listened to, to have someone to whom they could explain their misery, and not least, to use us as mediators between themselves and staff or the rest of society. Some milieu therapists also saw the opportunity to use us as mediators between themselves and hospital management. There were also those who wanted the study to map and document their practice, which they were confident in and proud of, for the professional community. On the other hand, milieu therapists worried about how we interpreted their practice, whether we liked their practice, and how we would write about it. Some were afraid of being presented in an unfavorable way or being tested, e.g., “Are you here to test how much knowledge we have about milieu therapy?”.

Third, in participant observation studies, participants of both groups obtain glimpses of the translation process by means of curious ethnographers observing and asking questions. The principle of participant observation is obtaining the “native’s point of view,” whilst at the same time keeping a distance so as not to “go native,” or fully acting as a participant, in order to keep one’s eyes open (Behar, 1996). Participant observation is then deeply paradoxical. Acting as natives, we would communicate understanding and friendship to participants in our bid for a trustworthy relationship. Simultaneously, they knew “we had our eyes open” in order to record information about them. Potential emotional harm inflicted on participants can be understood as anchored in this paradox. Here lies our power as
researchers, of potentially causing harm to professional souls.

The question of vulnerability and research ethics resumed

An important mission of research ethics, either medical or anthropological, is to avoid the exploitation of, to protect, and to do no harm to, research participants, as researchers learned from the experiments by Nazi physicians. Therefore, we will argue that research ethics is an important issue to be formulated, reformulated and discussed for the appropriateness of the research methods used and for the research situation at hand. However, in Norway, social scientists are being questioned with specific reference to medical research guidelines when doing participant observation in a medical setting.

Participant observation in a psychiatric hospital will necessarily involve informants of different categories, in our case, they are patients and milieu therapists. Medical research ethics has classified the participant category of psychiatric patients as vulnerable, without looking at the reasons for including this group in the study. The purpose of including psychiatric patients in our study differs from the purpose of including milieu therapists in the study. While psychiatric patients are primarily included to shed light on a therapeutic tool, milieu therapists are included to observe how they “use” and explain this therapeutic tool. In this case, who is to be regarded as vulnerable is predefined. Medical research ethics, then, assume that psychiatric patients are more exposed to potential harm than other participant categories.

This article has tried to challenge such an assumption by drawing on participant observation experience where participants of two different groups, patients and milieu therapists, are included. Participant observation often affects the lives of those studied, because of the researchers’ continual presence. This can lead participants to see themselves in ways that they feel are disrespectful, or in other ways they do not like, through the interrogation process, and so, in these respects, either produce or invoke vulnerabilities or harm. Participants representing both groups showed glimpses of doubt, ambivalence and unpleasantness on the one hand, and expectations and trust on the other. In our study, it seemed that more was at stake for milieu therapists, than for psychiatric patients. We have not argued that milieu therapists should be regarded as vulnerable per se, but we have argued that participant observation is capable of producing vulnerabilities and hurting professionals when the purpose of the study is to scrutinize a therapeutic tool anchored in professional identity. Therefore, researchers employing participant observation should give an account of what is at stake. What is at stake is not an exact branch of knowledge that fits a utilitarian model—to predict harm and benefit ratios—in any exact way, but more a way of giving an account of what might be at stake for the different participant categories involved. Predefined notions of who is to be regarded as vulnerable, due to different traits or capacities, should be replaced by providing accounts of what might be at stake for those involved to an ethics board or committee.

Participant observation creates a problem for obtaining informed consent, because informed consent is an individual-based ethical guideline and participant observation is based on observing interaction between participants, which makes it a collective approach. When doing participant observation we will often observe participants interacting when one or more participants are believed to have impaired decision-making capacity, or have not yet given their consent to be observed. In our study, we were bound to follow medical ethical restrictions. Participant observation became a practical, as well as a scientific, research problem of informing, inviting and collecting consent on entering the field for the purpose of observing human activities. In doing so, there is a risk of radically altering human activities and interaction.

As informants in participant observation research, both groups were subjected to the continual presence of the researcher, which is the very core of participant observation. Neither milieu therapists nor patients could escape the context of discovery. Being informants in a participant observation research project implies it is almost impossible to hide from the eyes of a curious ethnographer. Both groups are in difficult circumstances, created by the institution. While patients can withdraw to their private rooms, staff members do not have any private rooms that are inaccessible to the researchers.

We suggest that the individual-based ethical principle of informed consent and voluntariness seems utopian when employing participant observation, which is a method based on how informants
and researchers influence and construct each other. Therefore, we concur with the NEM (National Committees for Research Ethics in Norway, 2005a), which recently suggested that researchers should consult user/patient councils. Furthermore, we suggest that the user/patient council should be composed of potential participants at the institution where the research is carried out and should also include members of staff and patients. Permission to carry out participant observation should be given by a research council at the institution, consisting of researchers, staff members with different occupational backgrounds, and patients.

**Conclusion**

In Norway, medical research committees question social scientists, with specific reference to medical research guidelines, when the social scientists are doing participant observation in a medical setting. In our study, the regional medical research committee recommended that we ask each psychiatric patient to sign individual-based informed consent forms for permission to observe them. The committee’s suggestions were attempted, but proved difficult. It was not practically possible to avoid observing situations that involved patients who had not given their consent. The underlying premise for the committees’ recommendations is a predefined notion of psychiatric patients as vulnerable.

The notion of vulnerability is anchored in different epistemological traditions in medical research ethics, which leads to paradoxical guidelines when it comes to doing participant observation research. Therefore, ethical guidelines, such as informed consent, the principle of voluntariness, and estimating the risk/benefit ratio, become substantial challenges when employing participant observation. As long as participant observation projects are carried out in medical institutions, informed consent, the principle of voluntariness, and predicting risk/benefit ratios in medical ethical guidelines need to be reviewed. We have therefore argued that the ethical question of vulnerability in participation observation research at psychiatric institutions requires a nuanced reformulation. Predefined notions of who is to be regarded as vulnerable are not suitable when doing participant observation. However, that vulnerability is a condition that must be understood as a construct of the purpose and context of the study.

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**References**


