QUESTIONABLE REQUIREMENT FOR CONSENT IN OBSERVATIONAL RESEARCH IN PSYCHIATRY

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Key words: acute psychiatry; informed consent; participant observation; power dynamics in nursing care; psychotic patients; research ethics

Informed consent represents a cornerstone of the endeavours to make health care research ethically acceptable. Based on experience of qualitative research on power dynamics in nursing care in acute psychiatry, we show that the requirement for informed consent may be practised in formalistic ways that legitimate the researcher's activities without taking the patient's changing perception of the situation sufficiently into account. The presentation of three patient case studies illustrates a diversity of issues that the researcher must consider in each situation. We argue for the necessity of researchers to base their judgement on a complex set of competencies. Consciousness of research ethics must be combined with knowledge of the challenges involved in research methodology in qualitative research and familiarity with the therapeutic arena in which the research is being conducted. The article shows that the alternative solution is not simple but must emphasize the researcher's ability to doubt and be based on an awareness of the researcher's fallibility.

Introduction

Informed consent represents a cornerstone of ethically acceptable health care research. Research participants in the field of psychiatry are often particularly vulnerable and much thought must be given to research ethics. In this article we will highlight problematic aspects of the requirement for informed consent in acute psychiatry. We will use empirical data from a study conducted in an acute psychiatric department to discuss how to understand and cope with the dilemmas that inevitably arise in such a challenging research field.

The study in question was conducted in a locked ward of an acute psychiatric department in a city in Norway. (The main author ('I'/‘me’/‘my’/‘MHH’) performed most of the empirical work as part of a PhD thesis. The terms ‘we’/‘us’ refer to the main and secondary authors or to all three authors.) The study focuses on how nurses

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use power in their interaction with psychotic patients in ways that either promote
patients’ dignity or have a degrading effect. The study has an ethnographic design and
data were collected by participant observation over a period of 30 weeks and by
interviews with nurses and psychotic patients.6–11

This article was occasioned by an injunction from a supervisory body that
demanded informed consent to be acquired at all times from all patients admitted
to a locked psychiatric ward. It has proved impossible to comply with this injunction.
After several weeks of compliant, doubtful and somewhat unsuccessful attempts to
follow the consent rule, we reached a point where we had to make a choice: the study
would either have to be abandoned in its current form as a research project based on
empirical data, or the method would have to be changed. We chose the ‘non-
compliant’ alternative after consulting the National Committee for Medical Research
Ethics, which is an advisory and co-ordinating body for the regional research ethics
committees,12 and after gaining the support of the hospital and the university institute
management for our decision. The project was continued with the requirements that
general information on the project be made available and that respect be shown for any
patient reservations about being observed.

The empirical basis for the discussions in this article was derived from the ‘non-
compliant phase’ of the project. The purpose is to show why a practice that is governed
by rules, and which has the objective of acquiring consent for research from psychotic
patients, is inappropriate. We also wanted to demonstrate how and with what
problems and misgivings an alternative and more flexible, situation-orientated
practice was developed.

Before we present empirical data in the form of the case studies that constitute the
basis of the discussions, we will first give more details about the reasons for the
injunction we were obliged to contravene.

Supervision

In Norway there are three bodies that are ascribed the task of supervising health care
research. First, there are the Regional Committees for Medical Research Ethics13 that
function as independent advisory and guiding bodies. Second, we have the
Norwegian Social Science Data Services14 that assess aspects of privacy protection in
particular. Neither of these two bodies made any comments on this study. The third
body, the Directorate for Health and Social Affairs,15 takes decisions on cases that
involve access to information that is subject to confidentiality and on dispensations
from the duty to observe confidentiality.

The reason we had to contact the Directorate for Health and Social Affairs was
because health care personnel are obliged to prevent unauthorized persons from
gaining access to confidential personal information with which they become familiar
in the course of their work. In this context a researcher is considered an unauthorized
person. In a letter dated 8 September, 2003 (reference 03/3889T7TS LRH), the
Directorate therefore concluded that, pursuant to the Norwegian Health Personnel
Act:

... on the basis of a total assessment of the project as a whole and since Section 29 of the
Health Personnel Act does not provide justification for permitting observation, a
dispensation for conducting this project cannot be granted. In the opinion of the Directorate, any performance of the project must be based on consent from all patients attached to the hospital ward involved.

Three case studies to illustrate reasons for non-compliance

Below we present data that describe in some detail the relationship of the main author (MHH) to three patients, Ida, David and Tom. It was not possible to acquire explicit and informed consent to my presence from any of these three. The use of discretionary judgement from one situation to another was a common feature of the relationships.

Ida: ‘Oh, please! Don’t make me...!’

Ida was acutely psychotic and had delusions and paranoid ideas. She was cautious, did not say much, and was polite and pleasant. I found her somewhat guarded in her contact with co-patients and employees and with me. To a certain extent she kept to her room, frequenting the common rooms for only short periods. However, after two weeks a form of contact had been established between us. I wanted the best for her: she was fragile and this was her first hospitalization. I also thought that Ida could be a significant participant. She was intelligent and reflective. When we came across each other in the corridor or when Ida came into the sitting room to chat with her co-patients, nurses and/or me, there was an instant rapport between us. Two days before she was to be discharged I asked her if she would consider being interviewed. She consented, and we made an appointment for the following day. Ida said she thought she had something important to tell me about her very first frightening experience of being psychotic and being admitted to an acute ward.

However, Ida seemed evasive the following day. When I cautiously reminded her of our appointment, she said she thought other patients would have more to contribute than her. I felt intuitively that I should keep my distance and leave her alone. She was discharged shortly after this encounter. The doubt about what had happened in my relationship with Ida preoccupied me. I recognized my eagerness to obtain information from her, information that I presumed would be extremely valuable, although there was something in her obvious vulnerability and withdrawal that made me also withdraw. I constantly consulted the nurses about those I was planning to recruit as participants; they gave me the impression that Ida would prefer to forget the entire psychosis, get out of hospital and carry on with her life. I did not find this interpretation convincing and I was left with no good explanation or advice about what was the ‘right’ action for a researcher.

Ida was re-admitted two weeks later. She seemed very ill. She talked incoherently and walked restlessly and unsteadily back and forth. She was unkempt and could not manage to dress herself or eat without help, but she remembered that I was a researcher in the department. I did my best to keep my distance at the same time as I tried to send her positive glances that were intended to signal: ‘I’m still here, but I won’t force myself on you.’ I was in doubt about whether my message was understood. Maybe Ida thought I was keeping my distance as a sign of my disappointment over her previous refusal to be interviewed? It could also be that...
my presence in the unit disturbed her. I felt uncertain about how to understand and tackle the situation.

One day Ida came up to me and said clearly and urgently, almost shouting and imploring: ‘Oh please! Don’t make me take part in the research project!’ This episode made a deep impression on me, but it was also a relief. The uncomfortable situation was resolved. Her outburst was overheard by a nurse who told me that Ida was struggling with numerous voices and that she had the feeling of being under surveillance and steered by strong powers. Among the struggle and chaos, the nurse had realized that Ida was also fighting against ‘tests’ and being the victim of an experiment. I was grateful for the nurse’s explanation and Ida’s demonstration. The situation was also relevant to the question of whether participant observation poses an unacceptable additional strain on psychotic patients in an acute psychiatric department.

David: ‘Will I get royalties from the book sales?’

David was a mature man who had been admitted involuntarily for psychosis. He had a long record of illness with several admissions. He functioned relatively well for periods and managed to use his creative abilities in his job. He had seen the notice about the research project and immediately made contact when he saw me. I perceived David’s willingness to participate in the project as unusually intense. I tried to calm him down and to take the consent proceedings slowly. David became irritated and told me loudly and clearly that he really had a lot to contribute to the research. He almost ordered: ‘Write down everything I say!’ He was restless in his movements and disturbed many of the other patients.

I experienced many dilemmas resulting from his intense wish to take part in the project. I tried to withdraw by sitting elsewhere or talking to others, but he followed me and urged me once again to listen to everything he said about Norwegian psychiatry and his experience as a patient. I tried to keep my distance and reminded him that it was not primarily the patient’s life I was focusing on but the nurses’ work with patients. Aggressive and forthright, David replied: ‘Them – the nurses – they don’t work at all.’ It was without doubt an interesting patient experience, and I followed it up in different ways that provided valuable data about David’s experience of being pathologized and ignored.

Some days later he was again excessively eager about his commitment to the project. I now noticed that his interest was more positive and more factual. Applying the consent I had obtained, I started a new conversation with him. He proved to be skilled in writing and he had several intelligent questions about the research project. We sat in the common room in the unit and chatted for almost half an hour about psychiatry, nurses and research. He wanted to discuss how the doctoral thesis was to be written. He visualized a best-seller that would bring in a large income. I explained that I was going to write articles. He saw that as a poor solution and argued strongly for a book in which his experience could be given focus. When he had decided that a book must be published, he suddenly asked in total seriousness: ‘Will I get royalties from the book sales?’ My attempts to correct him seemed only to reinforce his opinion and he repeated it continuously. He became more insistent in his arguments and did not let me out of his sight. His behaviour towards me illustrated the problem of power dynamics and setting limits in psychiatry (the actual subject of the research project).
His ‘quest’ for the researcher’s attention provided me with valuable data while also making me uncertain about whether it was right to include him in the research out of consideration for his own good (he was in a locked ward in order to regain his peace of mind). It was also annoying to be exposed to David’s intense and persistent interest. It was a relationship from which it was almost impossible to escape. I noticed that to cope with the situation I activated the knowledge and experience I had acquired as a psychiatric nurse. My role varied between that of therapist and that of researcher. I activated a knowledge base that gave me power in the situation and that also enabled me to handle David’s persistence. For a person researching the power dynamics of nursing care, this mixture of roles provided data and was interesting in itself, but it was also unpleasant and problematic.

**Tom: ‘Damn nosey status seeker!’**

Tom was also very interested in the research project that he had read about on the notice in the corridor. His interest developed differently. I had heard at the morning meeting that Tom was unstable and that his behaviour towards women often emphasized sexual aspects. Tom appeared as I entered the sitting room. We introduced ourselves, and he said that the research project looked interesting and he would like to participate. He thought he had experience to contribute as he was older than me. He gradually became more interested in me than in the research. He was seeking contact. One day when we sat in the corridor he stroked my arm gently and made a comment about the jacket I was wearing. Suddenly he said, ‘You really are nice-looking!’ I thanked him for the compliment, sat there calmly and did not regard his interest as disagreeable or sexual, but rather as his way of making contact. We talked a lot, and he told me about his difficult life in and out of psychiatric institutions. He told me about his sadness at not fulfilling his own and others’ expectations of his career. He appeared to be a gifted man with artistic talents. This changed shortly afterwards.

For some days there was considerable unrest in the department, with several new admissions, aggression, piercing screams and vandalism in the sitting room. Tom could not tolerate the changes in the environment and became disturbed and very anxious. One day when I entered the unit he shouted: ‘You just walk around here snooping. Damn nosey status seeker! You don’t know anything! You’re a careerist! Just keep away from me with your research!’ I was upset because the accusations were crass and I found them unreasonable, but I did not have the ‘right’ to argue. My task was to observe, converse and make notes. I was there primarily to do a job rather than to take on the function of therapist, even though I once again experienced that it was difficult to make a distinction between the roles. I thought Tom’s reaction should be understood in the light of my having unlimited development opportunities while he had ended up fighting for his mental health and regretting an abandoned career. He saw that I was upset and suddenly expressed concern about having been so angry. He apologized again and again; he assured me that the project was important and that he would do all he could to support it.

This episode was a new challenge for me. I wondered how to handle Tom, the course of his illness and his consent to the research. Should I take into account the fact that at his most anxious and insecure time he had turned his back on me and withdrawn his consent? Could I regard it as an episode and an exception that confirmed his ‘yes’ to the consent? Was his consent to participation merely a fulfilment of his wish for contact?
with a person who had time to sit and listen? Was this an ulterior motive that was acceptable from the viewpoint of research ethics?

I was present the day Tom was discharged. He felt calmer and was ready to leave. He shook my hand and thanked me politely for the time and attention I had given him and hoped that his contribution would be useful for my research.

Summary

The case histories leave an impression that the research was conducted in a field where both the patients and the ambience are characterized by great despair, sadness, rapid changes in atmosphere, insecurity and aggression, but also by pleasure and new opportunities. The unreliability of informed consent is clear and the patients’ fluctuating capacity\(^2\) to assess what they are being asked about is striking. The above descriptions show how demanding it was to relate to these patients and how I repeatedly had to activate my skills as an ethically conscious researcher, participant observer and psychiatric nurse. My doubt about what was right and what was wrong is clearly conveyed.

Discussion

With empirical data on problems concerning research ethics as our starting point, our discussion will now cover three different standpoints. We start with the most extreme solution to the dilemma facing us: that the project should not be carried out because it was impossible to obtain informed consent. We then discuss the practice that was established and study more closely the research ethics issues that arose, particularly the consent problem. In the third and final part of the discussion we outline and argue the necessity of the researcher applying discretionary judgement and a flexible, more situation-orientated approach to the ethical challenges linked to vulnerable patients’ integrity.

No research without consent

One consequence of the injunction to obtain consent and the subsequent problems in the research field was the conclusion that the injunction from the supervisory body (the Directorate for Health and Social Affairs) made correct practice impossible and that the project would therefore have to be terminated. The Directorate underlines the importance of protecting psychotic patients owing to their vulnerability. This is a standpoint we support. Furthermore, the Directorate claims that psychotic patients are so vulnerable that it is unacceptable to involve them in schemes in which a researcher participates in the field for a long period. Does the patient’s vulnerability therefore preclude the researcher being integrated into the therapeutic arena? The practice that was developed in this research project indicates a negative reply to this question.

The descriptions of Ida, David and Tom show, as the Directorate points out, that psychotic patients are vulnerable owing to their vague and to some extent flawed understanding of reality. They are afraid, and they probably experience existence as unpredictable and fragile. The descriptions, however, likewise show that, despite their vulnerability, they are brave and ‘strong’: they interact with the people around them,
they are humorous and they dare to express their opinions, often with great force. The descriptions also show that the researcher was in doubt when she met both the patients’ strength and their vulnerability, and she activated different types of competence to handle the situations. We consider the doubt to be positive, and so far have restricted ourselves to stressing that vulnerability is a complex phenomenon. There are grounds to question whether the perception of psychotic patients as vulnerable contributes to devaluing them and deprives them of their legal capacity, with the result that they are not expected to be able to take decisions and be rational in certain areas.\textsuperscript{2,16,17} We do not rule out that it may be a positive experience for patients who have limited autonomy to meet a researcher who has interest in their experience because they are then approached with expectations of having their own opinions.\textsuperscript{18}

Conducting the type of research described here is closely connected with cooperation in the workplace and gives employees an insight into how a researcher handles situations with patients/research participants. When we decided to continue the project despite the fact that it was not feasible to implement the injunction, the decision was influenced by support from professional circles both within and outside the department where the project was conducted. Solid backing from the practice field, the university and the research ethics bodies inspired us to continue collecting data. This meant that individuals with wide and comprehensive expertise in research ethics, professional ethics, psychiatry and qualitative research methods considered the research ethically acceptable and did not agree with the public supervisory body’s instructions.

It is also worth mentioning the need to develop knowledge of what takes place in psychiatry. For some time, acute psychiatry has been the frequent object of strong criticism, partly because it is regarded as a field that is closed to access. Research can help to bring to light both critical and constructive aspects of therapeutic practice. There is clearly a need for knowledge about what happens on a daily basis in an acute psychiatric department: what creates dignity and what degrades patients?\textsuperscript{19} An interesting example from our material that shows the ambiguity of care concerns the setting of limits for David. Setting limits for patients’ behaviour can be degrading, even though it is necessary to promote dignity at that moment and in the long term. The way in which limits are set may appear demeaning, but the process can also create dignity and must be interpreted in the light of the specific context. Knowledge of this type of process between patients and employees cannot be acquired if the researcher does not participate and try to understand what is happening.

**Consent is not only consent**

At the very first meeting with the department/research field, MHH was struck by how data on the field flowed in continuously, even though the intention at the start was only to obtain consent. Being shut in and locked up, hearing shouts and seeing bed restraints etc provides information about power in therapy. The point is that collecting data cannot be separated from requesting consent in this type of research.\textsuperscript{2,3,5,20-22} MHH’s attempts and investigation to determine how far Ida, David and Tom should be involved in the research shows how important it is to establish a relationship that can form the basis for assessing what is in the best interest of the participant. Establishing relationships with psychotic persons takes time and is demanding. It is inevitable that information is acquired in the process of obtaining consent, and in this
type of research it is therefore not possible to distinguish between procuring
information and being present, which entails the researcher having access to
information that is subject to confidentiality.

The fact that there is a connection between achieving information about patients and
that negotiations about consent may take time also sheds light upon another issue that
has been a focus in qualitative research for the last 10–15 years, namely, ‘process
consent’ or ‘ethics as process’. These concepts have been discussed in several
ways, based on different kinds of research projects. A common trait, however, is
that there seems to be a growing awareness of the dynamic qualities of qualitative
research (especially participant observation). An understanding that consent is given
once and for all is both insufficient and misleading. From the stories of Ida, David and
Tom we would like to point out two issues. First, it is obvious that their consent was
invalid because of their rapid shifts of opinion about whether or not to participate in
the research project. Their consent had to be continually negotiated. Second, the
relationship and communication between the patients and MHH was at times based as
much on MHH’s therapeutic skills as on her research competence. Her professional
background in psychiatry was of vital importance for her ability to interact with the
psychotic patients and take into consideration whether or not she could rely on their
willingness and abilities to be part of her research.

The three narratives from the ‘non-compliant phase’ illustrate that, in different ways,
these patients had a somewhat unclear understanding of to what they were consenting. Ida, for example, wanted to relate her experience even though it was
frightening for her to talk about what she had been through. However, she had
consented and MHH could have exploited the situation and maintained that ‘consent
is consent’. (Those who were interviewed signed a consent form. At that time Ida had
not given her written consent to being interviewed.) Ida was in an extremely psychotic
state on her second admission, thus research would have seemed the same to her as
‘tests’. She may also have presumed that tests and observations of her would be made
secretly. A common problem with psychotic patients is that they feel they are being
monitored and recorded. Ida was worried about having contact with a researcher she
thought would make records and carry out tests. MHH experienced ambivalence
between not burdening the patients with information and explanations on the type of
research she was conducting while realizing that patients like Ida could develop
‘crazy’ and disturbing associations such as that research in psychiatry involves tests
and perhaps manipulation. The ambivalence reinforced the doubt about whether her
daily collection of data in the department was too stressful for the patients. Would the
knowledge the project provided in the long term justify the strain expressed directly or
indirectly by the patients?

A dubious feature of researchers who comply with the rules is that they follow
standards and procedures rather than endeavouring to exercise discretionary judge-
ment in their assessments. It is tempting to simplify the complex and difficult aspects,
and thus claim that the research is safe and ethically acceptable, even though this is not
necessarily the case. How can consent show that no persuasion, inveigling or coercion
occurred? The point of consent is that it is intended to prevent those taking part in
research being deceived or exposed to coercion; but full consent is an illusion. MHH
felt relieved on the days she had obtained consent from all the patients (in the
‘compliance phase’), but there was still a nagging doubt because she knew that several
of them had signed a document without understanding what it implied. She therefore
felt she had behaved unethically, even though in formal terms she was in the right. The fact that she chose to be ‘non-compliant’ did not make her daily work less complex. On the contrary, throughout the ‘non-compliance process’ she was constantly aware that she should check and appraise the value of any consent. Ida provides an example of obtained consent that soon became refusal to participate.

The whole question of consent seems strange in a department where limits are strict and clearly defined by the staff and where the patients are largely deprived of the authority to decide for themselves. Ida’s reactions illustrated that the practice created anxiety and insecurity among the patients. Tom’s frequently ambivalent attitude to the project also shows that he was not competent to give informed consent because he regarded MHH as ‘damn nosey’. Both the employees and MHH found such conduct unnecessarily disturbing for a treatment unit where the key concepts were security, calmness and structure. David was unambiguous in his desire to participate and he undoubtedly had extremely valuable experience to contribute. The reason MHH was reticent was that she did not consider him competent to give consent. His interest in the project also faded as he became less psychotic and regained greater control over himself, but MHH could have taken his consent as given and thus placed less emphasis on his failing competence.

Flexible and extended perception of consent

So far our discussion has focused on a dual standpoint: ‘yes’ and ‘no’ to consent. The message is that it is important to consider psychotic patients’ vulnerability and consent, but this must be negotiated depending on the situation and by using a complex knowledge base. It is neither feasible nor acceptable to found actions only on rules.

Several authors have disputed the view that qualitative research methods are ‘harmless’ compared with research that involves trials of new types of treatment, and that the rules for consent are less stringent for this type of research. Research involving the researcher participating actively in the field/department poses a major risk of offending the patient’s integrity. For example, the concept of a mutual relationship between researcher and patients conceals the fact that research exploits others for the purpose of creating knowledge. Ida is an example of a participant who agreed to be interviewed only to withdraw her consent vigorously later. She appeared to be troubled by MHH’s presence and by her possible participation in the research. Indeed, she misunderstood the type of research involved and refused corrective information. MHH was in doubt about whether Ida was harmed by her presence. Similarly, one can also question whether David and Tom (who were respectively indiscriminately persistent and ambivalent to the project) were so disturbed by MHH that their disquiet and insecurity increased. We are left with doubt, and we give the researcher the benefit of the doubt. Here, as well, assessments from the staff were critical for MHH remaining in the field. We believe that MHH’s knowledge of psychiatry and her experience with psychotic patients’ insecurity were of help and ensured respect for the patients’ integrity. We believe that in general the risk of distress was low. Nonetheless there is a danger of following the customary power patterns that can degrade patients. Contact with patients/participants constitutes a continuous challenge that must be interpreted and
handled according to the situation, and it demands ‘a wide and robust concept of reflexivity’ (p. 134).22

We argue that it is appropriate not to view research ethics in isolation but to consider which other sources of knowledge a researcher can use to ensure good and acceptable research practice. Further discussion therefore includes professional knowledge and qualitative research competence as relevant knowledge bases.

Clinical competence and research ethics

Requirements regarding ethical awareness and safeguarding patients’ integrity are basic concepts in psychiatry. MHH’s professional background enabled her to behave with sensitivity and respect. For instance she withdrew (not exerting pressure on Ida when Ida retracted her consent to the interview) or accepted verbal attack (‘damn status seeker’, ‘you just walk around here snooping’) in a matter-of-fact way and calmly. MHH’s response was founded on clinical experience from psychiatry, where developing skills in accepting what patients express represents a major form of competence. Managing specialized knowledge is ultimately dependent on the person in question. The researcher’s individual aptitude – and ability to exercise good professional judgement – is therefore vital for participant observation to be carried out in an ethically acceptable manner. However, professionals with a high degree of ethical awareness may still behave unethically in their research. Researchers with qualifications in psychiatry who are accustomed to frequenting the power structures of an acute psychiatric arena may be blind to their own exercise of power and offensive behaviour. This is a major argument against the importance of specialist knowledge. Nonetheless, MHH’s clinical experience and theoretical knowledge of psychosis may also have been an advantage in enabling her to manoeuvre her way around the acute ward in the best possible manner. Several authors have maintained that treatment providers have relational skills that can be used in research.33,34

Considerations concerning how close or distanced MHH was to be at any time are expressed in the descriptions and analyses of Ida, David and Tom. One example is her anxiety about having threatened Ida on the question of her being interviewed. Managing knowledge of psychosis includes attempting to interpret patients’ statements – both spoken and unspoken – about how much close contact they can handle. It was also necessary to check one’s personal interpretations by talking to the employees and listening to the professional discussions they held. Even if specialist knowledge and clinical experience are important, thoughtful researchers should also have a conscious relationship with the psychiatric context of which they are part. The knowledge one acquires is developed in a certain area and has certain assumptions about the person and the mental disorder. However, it is difficult to imagine that a project such as ours could have been carried out if MHH had too greatly disregarded the prerequisites on which her work was based.

Consideration of knowledge interests can also obscure the researcher’s ethical awareness. The compromise between knowledge acquirement and personal protection is demanding. Good management of specialized knowledge is therefore hardly a satisfactory prerequisite for ethically acceptable research.
Methodology competence and research ethics

Research methods are related in complex ways to research ethics and professional practice. Qualitative approaches are often justified by an interest in researching for meaning, subjectivity and experience. Qualitative methods are characterized as phenomenological and sensitive to context. The distinctive characters of various research methods are connected to positions of scientific theory, where the relationship between researchers and the persons and contexts to which they link their research is perceived as mutual and dynamic. Emphasis is given to the researcher as a creative person. Researchers’ reflectivity is connected to their consciousness of how they create themselves through interaction with the field in which they are conducting research. The perception that the relationship between the researcher and those researched is intersubjective breaks with the norm of researchers’ neutrality.

The shift in method towards the dialogical relationship between participant and researcher is of importance for research ethics. The requirement for researchers to have reflected on their own self-awareness can promote a clearer consciousness of their responsibility to take care of the research participants’ well-being. In our project, MHH’s self-reflection and consideration for the participants were expressed in several ways. She tried to be aware of the impact her presence had on the patients. With David and Tom it seemed that the expectations they created as participants were exaggerated compared with MHH’s intentions. The extent to which her awareness of how they perceived her should have guided her towards assuming a more distanced position can be discussed. The main reason for being in the common rooms with them was that she felt she was not harming them. When they were anxious and afraid, MHH – just like the employees – was given a misunderstood role. It may well be that the patients were exposed to no greater ‘risk’ through MHH’s presence than that they would have experienced anyway as a result of their current state. When they improved, their reactions were somewhat different: David was no longer particularly concerned about her, while Tom continued to be curious, perhaps because of his great need for contact, which was largely satisfied by MHH. This shows that, through being part of what they are studying, researchers take on a normative role. The role of researchers is not objective; they therefore bear a special responsibility.

Concluding remarks

In this article we have shown that the principle of obtaining informed consent is extremely problematic and does not guarantee ethically acceptable research practice. One-sided monitoring of the requirement for patients who participate in research to give informed consent can appear directly opposed to the good intentions and can give the researcher an unjustified free hand to collect data. Based on experience of qualitative research in acute psychiatry we have shown the ways in which psychotic patients daily challenge researchers to take responsibility and to think carefully about the extent to which patients can and should be included in research.

We conclude that a reasonable criterion is that those involved are given information and have the right to refuse. This is not sufficient, and researchers must take continuous responsibility for assessing what is in the best interest of patients. The assessment is demanding and has no standard solution. Good research judgement is
needed and this must be exercised in the context of each situation. Discretionary
assessments require the researcher to possess high ethical awareness, good insight and
experience of qualitative research methods, combined with specialist therapeutic
competence. This is no simple prescription. It rests on an awareness that doubt must be
respected and that researchers’ assessments and their understanding of situations may
be erroneous.

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