ETHICS IN QUALITATIVE SOCIAL RESEARCH ON MARGINALIZED GROUPS

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Abstract: This paper discusses some ethical issues in qualitative research on marginalized groups, such as intellectually disabled women. These kinds of issues have been brought to the fore through contacts with intellectually disabled women in a recently conducted study. Intellectually disabled women have a particularly low status on account of their intellectual impairment as well as their gender. The principle aim of the paper is to emphasize the need for a continual discussion within the academic community as to the conduct of those engaging in qualitative research on marginalized groups. A self-appointed alliance with such groups risks masking the superior position of the researcher. This has two serious consequences, i.e. it involves running the risk of poor interpretations of the data, as well as of "objectifying" the informants.

Introduction

There is a long tradition in the social sciences that deals with so called marginalized groups. This has meant a number of studies being done on groups which are "on the edge" of society in an economic, a political and/or social sense (see Moore, 1991; Näsman & Eriksson, 1994). Ever since the work of the early Chicago school such studies have been influenced by social interactionism, and as such often use qualitative methods in their ambition to understand the meaning of everyday interaction from the standpoint of the marginalized informant.

Inherent in qualitative social research on marginalized groups is what can be described as a loyal stand. Not seldom, the researcher declares, although not always explicitly, her/his loyalty with the group under study. In qualitative interviewing, for example, the interviewer "lets" the informants tell their stories, i.e. disclose their personal feelings and experiences of the issue under study. The researcher thus gives voice to members of groups who have a low social status and consequently difficulties making themselves heard (e.g. Löchen, 1996).

The reason for disclosing the subjective meanings of the informants is that they are marginalized. The researcher assists in making visible a lived order that would otherwise not be noticed. The powerlessness and oppression of the marginalized group is the underlying assumption. Sometimes the ambition goes beyond just giving voice to those who would not otherwise be heard. In research with an
emancipatory ambition the aim is to liberate these groups from their subordinate social position. But whether the ambition is to reconstruct the subjective world of the oppressed or to create the prerequisites for emancipation, the idea of subordination, marginalization and/or oppression is a presumption for the whole project. This idea, at times theoretically elaborated and explicit and at other times more implicit, is not without problems. Some of these problems can be seen in the way researchers relate to and deal with their informants, as well as in how they analyze the data which have been constructed in these relations. At the root of the problem lies the ambition of the researcher to be loyal with her/his informants, a loyalty that can mask the superior position of power of the researcher. The self-image of the researcher as siding with the underdogs creates ethical problems in relation to her/his informants.

This article deals with ethical problems in qualitative research on marginalized groups. Its principle aim is to bring to the fore the need for a continual discussion within the academic community as to the conduct of qualitative researchers with an interest in such groups. My reflections are based on a qualitative study which I have conducted with intellectually disabled women and men. Instead of asking my informants to complete questionnaires with pre-set questions, I have attached importance to learning of the informants' personal thoughts and experiences in their own words. The women I have interviewed have a particularly low status on account of their intellectual impairment as well as their gender. In my direct contact with these women, as well as when analyzing the data, I have become aware of ethical problems related to my own presumptions about them as powerless and myself as some kind of outside liberator. One way of discussing these problems is raising the issue of what constitutes ethically correct conduct of the researcher.

The emphasis is here not on providing solutions to the issues raised, but rather on bringing to the fore the complexity of some ethical problems which I have been confronted with.

Ethical issues have become a topic of interest in the social sciences since the 1940s, as researchers try to protect the welfare of their research subjects. Ethical decision-making depends to a great extent on the individual researcher's awareness and interpretation of the prevailing collective guidelines (Kimmel, 1988). There appears to be no consensus among social researchers as to what constitutes an ethical problem in their investigations (ibid.).

Since the term 'ethical' is inevitably linked with values, it can be defined as referring to behaviors about which society holds certain values. A distinction can be made between two philosophical schools, i.e. normative ethics and meta-ethics (ibid.). Normative ethics provide moral norms that indicate what individuals should do or
refrain from doing in certain circumstances. Meta-ethics, on the other hand, do not focus on the question of establishing principles for correct moral conduct, but rather on analyzing moral concepts, e.g. the meaning of "good" or "right" (ibid.). With regard to social research on marginalized groups, both these kinds of ethics need to be considered.

My discussion is based on a normative assumption that research should strive to treat subjects as knowledgable participants. This means being open and sensitive to their experienced situations as well as to the question of how these are affected by their participation in a research project. In a way such assumptions often lie at the heart of the expressed aims of many qualitative researchers. What I am suggesting is that the consequences of these are seldom problematized and openly discussed.

Problematic issues of this kind can thus be made visible when reflecting on one's own role in relation to a particularly vulnerable group such as intellectually disabled women. The issue of ethics is, however, important to consider in research on any group of people.

Deception

Qualitative research is sometimes referred to as being more humanistic than quantitative research. This can be argued due to quantitative studies risk simplifying a complex reality by assuming that this can be understood from a number of pre-set questions, with certain fixed alternatives, e.g. quantitative survey studies, which may have little relevance to the everyday lives of those under study.

But qualitative research is not humanistic per se (see Eliasson, 1987; Barnes, 1992). Qualitative interviewing is based on different interests on the part of the researcher and that of the informant. The researcher, no matter how convinced s/he is about the legitimate "emanicipatory" purpose of her/his research, is primarily interested in attaining information. For the informant, the situation may be, and indeed often is according to my experience, more unclear and unstructured. Not having grasped the specific kind of interest that causes the researcher to visit her/him, or having captured the information selectively as to understand that the visitor is specifically interested in her/his situation, the intellectually disabled informant often understands the situation as being selected for some kind of friendship. And even if the purpose is clear to the informant, the motive for participation is usually not wanting to contribute to someone's articles and/or dissertation, but curiosity in combination with being flattered of the interest shown in one's situation and/or opinions.

An important part in qualitative interviewing is seeing that which the informant discloses from her/his perspective (Taylor & Bogdan, 1984). A warm atmosphere and a sense of closeness between the interviewer and
informant may make the informant feel more comfortable about disclosing some of her/his personal feelings and experiences. For some, such as intellectually disabled women, the feeling of having the undivided attention of someone who listens without judging or evaluating that which is said can be an unusual experience. This closeness is generally viewed as of value (as opposed to the lack of closeness between the informant and the researcher in quantitative research). This situation is of value with regard to encouraging the informant to speak openly. But it means that the informant may be temporarily "seduced" by the warm atmosphere and speak of personal matters which s/he later regrets having revealed to the researcher. I have received telephone calls from worried intellectually disabled female informants after completed interviews. The expressed concern has been related to the fear of me telling parents and/or personnel about that which they have shared with me, i.e. disclose the informants' identities. After again having emphasized that I under no circumstances will do this, these informants appeared reassured. Despite this, their reaction after, in an interview situation, having disclosed, what one informant refers to as, "bad secrets" deserves to be taken seriously. The expressed concern among these particular informants was twofold. It had to do with having disclosed certain information of a sensitive nature as such, as well as with the risk of having one's identity revealed.

Also, the situation of closeness and warmth can be (mis)understood as a promise of something more; i.e. future friendship (see Sjöström, 1994). This promise is not likely to be articulated, but rather inherent in the above referred to interview situation. This has been brought to my attention when some informants, after the conclusion of the interview, have asked when they can make a return visit, i.e. come and visit me in my home.

My point is not that informants necessarily want future contact with the interviewer (or vice versa), but rather that this risk of deception in qualitative interviewing is an ethical problem which needs to be taken into account. Despite the possibility of future contact and friendship between the informant and the interviewer, this is not generally an expected outcome of an interview. The closeness that may come about in the interview situation, which is beneficial with regard to information disclosed, can thus be deceptive by arousing feelings similar to those in a newly formed friendship.

It has been argued that certain kinds of deception are necessary, i.e. ethically acceptable, to gather data in certain settings (Goode, 1996). But this kind of reasoning implies a consequentialism, an ethical argument based on the consequences of action, that automatically puts the researcher "in charge", i.e. as being the one who has
the power to decide what is ethically acceptable or not. As I understand the ethical principle of equality and treating the informant as a knowledgable participant, it is of a categorical nature, i.e. to be adhered to regardless of place and circumstances, and should be discussed as such. The problem of deception is a problem in itself that should be addressed by the researcher without falling back on instrumental arguments about consequences.

To illustrate the complexity of the issue of deception, we can take as our point of departure one of the collective guidelines with regard to the conduct of the researcher and the rights of the informants, i.e. voluntary informed consent (see Löchen, 1996). This particular guideline is generally considered as the central norm governing the relationship between the interviewer and the informant (Kimmel, 1988). But what if the researcher is unable to introduce the aim of the study, the conditions for participation, etc. to the prospective informant in a way which s/he fully grasps? I have shown above that despite my informing intellectually disabled female informants that their identity will not be revealed, there has later been some expressed concern with regard to this issue. In other words, is it ethically acceptable to include those in social research who do not fully understand what the involvement entails?

One way of dealing with this complex issue is to simply state that this is indeed ethically acceptable since the situation of vulnerable groups, such as intellectually disabled women, needs to be exposed. It can be argued that this exposure can in turn lead to improved living conditions for underprivileged groups. But then we are back into consequentialism again; an all too easy way for a researcher to use her/his position to avoid discussing the problem in light of her/his ambition to be loyal and to view the informant as a knowledgable participant.

The trap of goodwill

There are a number of studies which deal with oppression of disabled people (see Munford, 1995). Parents (particularly mothers) tend to be described as overprotecting their disabled children. Service-providers are criticized for making the decisions for disabled people and thus ignoring the individual requirements of the latter. These, often normative, studies are important in making visible unequal power relations and in emphasizing the importance of equality and the empowerment of disabled people (e.g. Oliver, 1996), not least the empowerment of disabled women (e.g. Morris, 1991).

But there is, however, a tendency to overlook the researcher's own position of power. The power of the researcher does not have the same far-reaching and totalizing character as the power that protective parents and professionals often have. The researcher is not in a position to directly affect the
daily living situation of her/his informant the same way. But the former has a power position in that s/he has the resources and competence to impute her/his own meanings and interpretations on the informant, thus deviate from the norm of treating informants as knowledgable participants. Basically the position of the researcher is therefore the same as the one of professionals. Qualitative interviewing is about close social interaction where the interviewer has the role of professional as well as sympathetic fellow being (Näsman & Eriksson, 1994). While there has been some discussion, particularly in Anglo-Saxon literature, as to the role of the researcher in social research on disability (e.g. Oliver, 1992), studies dealing with the imbalance of power between disabled and non-disabled members of society tend, however, not to emphasize the imbalance of power between the (non-disabled) researcher and the disabled informant. I understand this lack of reflection over one's own position among researchers as linked to the above referred to sidetaking, i.e. being on the same "side" as the disabled informants.

This insider/outsider distinction, where the researcher sees her/himself as being on the same "side" as the disabled informants, masks the imbalance of power between the researcher and the informants (see Naples, 1996). The power of the interviewer is also linked to the fact that the informant's voice is generally filtered through the researcher's account (Hertz, 1996). Shifting between data and theory involves making decisions about the voices and placement of the informant within the text (ibid.).

The research process has not been subject to the same sort of scrutiny as other social processes with regard to unequal power relations (see Wenger, 1987). One consequence of this is that the issue of what ethically correct conduct entails on behalf of the researcher tends to be neglected. With regard to social research on disability, I argue that this approach can be understood as related to what can be described as "the trap of goodwill". It is as though being interested in the everyday lives of disabled people as such is viewed as involving some kind of humane act. Then, bringing to the fore an issue such as ethical conduct of the researcher does not fit this image of oneself as "a good samaritan".

We can thus see that by a self-appointed alliance with marginalized groups, the researcher risks masking her/his own position of power. This has, as I see it, two serious consequences.

Firstly, it involves running the risk of poor interpretations of data. Not taking into account one's own position of power and the possible consequences of this position might make the researcher less open to the nuances and possible interpretations of that which the informant discloses. It thus risks limiting sociological imagination and theoretical sensitivity.
Secondly, masking the imbalance of power here discussed demonstrates an approach which comes close to violating the ambition of "the good samaritan" and thus treat the informant as a knowledgable equal.

When interviewing intellectually disabled women, I have become aware that some of them strive towards answering my questions in a "correct" way. This can, for instance, entail describing one's relationships with others as overwhelmingly positive and then asking whether this kind of description was correct. Despite ensuring the informants that I am interested in their own feelings and experiences and that there are no correct answers, this situation has in some instances prevailed. My immediate interpretation of this problem was that the subservient approach of these female informants demonstrates an everyday life of being tested and corrected by those around them, such as parents and/or personnel. I was thus quick to identify the superior power position of parents and/or personnel. I was thus quick to identify the superior power position of parents and/or personnel as one reason for this particular approach among some of the women. As "a good samaritan" I had thus identified "the villains", i.e. those who because of their superior position of power may serve as an obstacle to autonomy, i.e. influence in everyday life, for disabled women.

While this interpretation is not necessarily irrelevant, it nevertheless neglects to take into account my own role as interviewer. Despite the women's accounts indicating that their subordinate position is not only linked to gender, but also to them having an intellectual impairment, I at first neglected to take into account my own superior position of power.

Emancipatory research

Research on disability has been criticized for alienating disabled people by seeing "the problem" as located in the individual, or rather the disability, instead of in society (Oliver, 1992). Inherent in this kind of critique is a view which emphasizes that it is the social obstacles, which people with impairments come up against, that are disabbling rather than the impairment as such. These kinds of studies take a definite stand against discrimination and oppression of disabled people. In fact, it has been argued that the sole aim of disability research is to study oppression (Barnes, 1996). Colin Barnes means that researchers have to choose sides: that of the oppressors or that of the oppressed. According to this approach, research on disability should thus be emancipatory and the researcher must be loyal to the research subjects. The researcher should join with disabled people in their struggle to overcome oppression (ibid.).

It is not difficult to see the value of the above mentioned approach. What could be more important than joining in the struggle for equality and human rights for marginalized groups, such as "the disabled"?

But the question remains
whether this should be the principal aim of social research on disability (see Shakespeare, 1996). The researcher is placed in a situation of choosing "sides", i.e. that of oppressed disabled people. This indicates a somewhat oversimplified view on society as consisting of two "sides"; the disabled and the non-disabled. As social researchers on disability, we need to acquire knowledge about the social processes which create the need for this oversimplified view of society. By knowing "the whole truth" before beginning a study, we can thus lose sight of social phenomena that are important in understanding social reality. Distinctions become problematic when they are "frozen", i.e. understood as given and inevitable (Håkanson, 1988).

Apart from demonstrating a strong belief in the impact of research with regard to social policy making, it means that the researcher has a certain image of society and views disabled people primarily as victims of discrimination. This preconceived image tends to divide members of society into "them" (the disabled and discriminated) and "us" (the non-disabled and not discriminated). Inherent in this dualistic image of society is the understanding that there are different "sides". One consequence of non-disabled researchers viewing the disabled women and/or men under study as those (discriminated) "others", i.e. as passive victims, can be that the researcher simply reinforces a predetermined understanding of social reality. This approach does not necessarily further the understanding of social reality nor assist in the struggle for equal opportunities for marginalized groups, such as "the disabled". While we know that marginalized groups, such as "the disabled", are subject to oppression, social research needs to strive towards asking new questions in order to learn more about the mechanisms behind different kinds of oppressive practices.

A not uncommon topic in research on disability is prejudice towards disabled people. In line with the above discussed image of society, the particular prejudiced views discussed are those of non-disabled members of society towards disabled people. It is interesting to note that we as researchers generally tend to view ourselves as an exception to the rule, i.e. as not prejudiced or put differently as having the "right" attitudes to disability. (I have come across a similar approach in some research on youth where the (not so young) researcher appears to identify her/himself with the young in opposition to the adult world.)

Another point of interest is that of prejudice among disabled people towards others; disabled and/or non-disabled female and male members of society is an issue which has attracted little attention. Despite emphasizing the importance of seeing disabled people as individuals with different characteri-stics and living conditions,
i.e. as anyone else, disabled people are, in social research, generally viewed as a homogeneous group of asexual victims of prejudice. When the informant is seen exclusively as a representative for one category, the relationship between the researcher and the informant is characterized by personal distance instead of closeness (see Lochen, 1972).

The point of argument is here not to suggest that disabled people may not be subject to prejudice. On the contrary, studies show that this is indeed the case (e.g. Turnham, 1992). Instead, I argue that research on disability risks reinforcing, not only a stereotypical view on, but also, the marginalization of, disabled women and men by the exclusive interest in them as victims of prejudice. A consequence of this image of society is that it risks bring about an understanding of women and men with different characteristics and living situations, who happen to have an impairment, as passive recipients.

My point is here not to argue for objectivity as such in social research on disability. Generally there is a common view among social scientists of today that the researcher cannot be objective but always has a certain subjective view on that which s/he examines. I argue, however, that in qualitative social research on disability it is nonetheless of importance to be as openminded about that which is under study as possible. Otherwise we may, instead of exposing myths through which we understand social reality, simply reinforce prevailing ones (see O'Brien, 1993).

**Superior knowledge**

Qualitative interviewing thus generally aims at understanding that which the informant discloses in her/his own words, which has been referred to as gaining entry into her/his world (Marshall & Rossman, 1989). The informant's understanding of that which is under study, i.e. her/his truth/reality is in focus. After having gathered this information, it is up to the researcher to analyze the given image, i.e. interpret that which the informant has disclosed. The emphasis is on how the accounted for personal experiences can be understood. This is a complex process where the informants' image must not be questioned, i.e. assessed as true/false or right/wrong, but rather problematized and analyzed. With regard to research on disability, this process raises a number of ethical questions dealing with the impact of the social construction of normality.

Despite striving to be as openminded as possible about that which is under study, the researcher has a certain understanding as to what constitutes a "normal" situation, e.g. a "normal" adult life. Interviewing intellectually disabled women brings to the fore the complexity of seeing that which is disclosed from the informants' perspective. In order to illustrate this, we can ponder on the question as to what is the most reasonable
interpretation of the situation of an intellectually disabled female informant, whom I have come in contact with, who is most contented with her everyday life and who has virtually no say with regard to her own living-conditions?

Is it that she is contented because she has such unreasonably small demands on life generally (i.e. not the demands that I, as a non-disabled researcher, would define as "reasonable")?

While this seems a valid way of interpreting this particular informant's contentment with regard to her everyday life, this interpretation is nonetheless problematic. To put it simply, my definition of reasonable demands with regard to decision making is closely linked to my understanding of a "normal" adult life. Instead of learning from the informant in question as to what can constitute a good life, I thus evaluate her situation in terms of my preconceived understanding as to what constitutes a good life. My definition, as a social researcher, of a good life, which comprises individual influence and decision making, is thus viewed as superior.

The wish to make visible the lack of autonomy of intellectually disabled women takes precedence over acquiring a deeper knowledge as to the meaning of a good life. The informant's "truth" has become a means of demonstrating the subordinate position of intellectually disabled women, i.e. to verify this preconceived understanding of intellectually disabled women's living situations. The dilemma, or paradox, is here that while this exposure is important in order to make visible the lack of autonomy of this particular marginalized group, it nevertheless corresponds poorly with the emphasis in qualitative studies on treating informants as knowledgable participants in social research (see Tössebro, 1993).

Thus, the ambition to emancipate builds on assumptions that, if not kept under control in form of professional distance and readiness to question one's own assumptions, can result in objectifying the informants as passive victims, interpreting everything they do and say in those terms. The challenge should be to find a way of balancing the insights into subordination with an open mind to what the experienced reality of the informants is like and include both aspects in the analysis.

Conclusion

The argument presented in this article has suggested that also qualitative social research runs the risk of "objectifying" informants. The voice of the informants in qualitative interviewing risks being obscured as in quantitative research. In fact, this ethical problem is more obvious and thus easier recognized in quantitative research. While providing some assurance that prevailing requirements will be met, ethical guidelines in social
research are not guarantees for ensuring that informants are treated as knowledgable participants.

Ethics in qualitative research on marginalized groups, such as intellectually disabled women, is a complex issue which needs to be brought to the fore. Exposing this complexity does not mean taking a stand against research on marginalized groups as such. Instead, the point of argument is here to emphasize the importance of recognizing the researcher's superior position of power when in contact with marginalized informants as well as when analyzing the data.

Notes:
1 This referred to study deals with the quality of life for intellectually disabled people. In this particular article, I will not however account for this study as such. Instead, the discussion focuses on the issue at hand; i.e. the imbalance of power between researchers and intellectually disabled female informants. This problematic issue has been brought to my attention through my contact with intellectually disabled women in the actual interview situation, and when analyzing their personal accounts.

2 A similar approach has been identified by Lien (1991) with regard to studies on immigrants. It is here referred to as 'the moral paradigm'.

References:
Barnes C. (1992). Qualitative research: valuable or irrelevant?, in Disability, Handicap & Society, vol. 7, no. 2, pp 115 - 123.
Barnes C. (1996). Disability and the Myth of the Independent Researcher, in Disability & Society, vol. 11, no. 1, pp 107 - 110.
Eliasson R. (1987). Forskningsetik och Perspektivval. Studentlitteratur, Lund.
Goode E. ( 1996): The Ethics of Deception in Social Research: A Case Study, in Qualitative Sociology, vol. 19. no. 1, pp 11 - 33.
Hertz R. (1996). Introduction: Ethics, Reflexivity and Voice, in Qualitative Sociology, vol. 19, no. 1, pp 3 - 9.
Håkanson K. (1988). Den skapande tomhetens bild. Om kunskap och kärlek. Prisma, Stockholm.
Kimmel A.J. (1988). Ethics and values in applied social research. Applied Social Research Methods Series Volume 12. Sage Publications.
Lien I.L. (1991). En god forsker eller en godt menneske, i Nytt Norsk Tidsskrift 2.
Löchen Y. (1972). Sociologens dilemma. Vetenskaplig distans eller samhällsförändring. Wahlström & Widstrand.
Löchen Y. (1996). "De funksjonshemmete". Rådet för funksjonshemmede. Oslo.
Marshall C. & Rossman G.B. (1989). Designing qualitative research. Sage Publications.
Moore S. (1991): Investigating Deviance. Sociology in action. Collins Educational.
Morris J. (1991). Pride against Prejudice: transforming attitudes to disability. London, The Women's Press.
Munford R. (1995). A position of marginalization or inclusion? The experiences of women with disabilities, in New Zealand Journal of Disability Studies, no. 1, pp 29 - 59. Massey University.
Naples N.A. (1996). A Feminist Revisiting of the Insider/Outsider Debate: The "Outsider Phenomenon" in Rural Iowa, in Qualitative Sociology, vol. 19, no. 1, pp 83 - 106.
Näsmann E. & Eriksson B-E (1994): Inledning. Att nära sig samhällslivet, i B-E Eriksson & E. Näsmann (red.), i Samhällsvetenskap och vardagserfarenhet. Teori, praktik, etik. Liber Utbildning, Stockholm.
O'Brien M. (1993). Social research and sociology, in N. Gilbert (ed.), Researching Social Life. Sage Publications.
Oliver M. (1992). Changing the Social Relations of Research Production?, in *Disability, Handicap & Society*, vol. 7, no. 2, pp 101 - 114.

Oliver M. (1996). *Understanding Disability. From Theory to Practice.* Macmillan press Ltd.

Shakespeare T. (1996). Rules of Engagement: doing disability research, in *Disability & Society*, vol. 11, no. 1, pp 115 - 119.

Sjöström S. (1994). Professionell vänskap, i B.-E. Eriksson & E. Näsman (red.), i *Samhällsvetenskap & Vardagsetfarenhet. Teori, praktik, etik.* Liber Utbildning, Stockholm.

Taylor S.J. & Bogdan R. (1984). *Introduction to qualitative research methods: The search for meanings.* John Wiley & sons, New York.

Turnham M. (1992). Supporting special needs in further education, in T. Booth, W. Swain, M. Masterton & P. Potts (eds.) *Policies for Diversity in Education, Learning for All 2.* The Open University, Routledge.

Tössebro J. (1993): Gode levesteder for psykisk utviklingshemmete. En paternalists dilemma, in B. Gjaerum (ed.) *Kunnskap og ettertanke. Psykisk utviklingshemning som flerfaglig utfordring.* Universitetsforlaget, Oslo.

Wenger G.C. (1987): Introduction: the Problematic Relationship, in G.C. Wenger (ed.) *The Research Relationship. Practice and Politics in Social Policy Research.* Allen & Unwin.again.

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