

Whose Body? Whose Voice?

Isabel Dyck

ABSTRACT

This paper discusses the recruitment process of a study concerning women with chronic illness. Tensions emerging among the stakeholders in the research are shown to relate to different conceptions of the body and authentic knowledge.

RÉSUMÉ

Cette présentation examine la procédure de recrutement d'une étude qui a pour sujet des femmes atteintes de maladie chronique. L'auteure montre que les tensions qui émergent entre les intéressés/ées engagés/ées dans le processus de la recherche sont reliées aux différentes visions concernant les concepts du corps et ce qui constitue le savoir authentique.

INTRODUCTION

Feminist methodological debate has problematized the relationship between the researcher and 'researched' and its position within the complex dynamics of research process. Discussion suggests that what constitutes 'the field' in a study is far from simple and is politically located. We are at once straddling the academy and sites of 'data collection' with our usually momentary insertion in the lives of those we study and our embeddedness in social relations that shape the encounter (Nast, 1994). In my research I am interested in how different discourses about a phenomenon enter the research process and influence the course and outcome of a study. I focus here on the specific tensions of working as a social scientist in a medically- defined area. I consider how contradictory discourses about the body shaped access to the subjugated

knowledge of women with disabilities.¹ The paper is an account of the negotiation of authority and credibility in research, which centers on the questions of whose conception of the body will hold and whose voice will be heard in community-based research. In my discussion I highlight the position of the women participants in the study as carriers of valuable knowledge and the different stakeholders negotiating access to this knowledge within the power relations of the research.

EARLY CONSIDERATIONS

The research was conducted with a co-investigator interested in disability policy.² The study was designed to explore the work experiences of women diagnosed with multiple sclerosis (MS), an often progressive neurological disease resulting in a range of

disabilities. There is no known cure, it is usually diagnosed in a person's early to mid-adulthood (20s to 40s), and it strikes women at approximately twice the rate as for men. Because of the typical age of onset, MS commonly affects women while actively engaged in wage labor and/or domestic labor and childrearing. Paid work was central to the inquiry since the existing literature about women with disabilities suggested that many lived in poverty and had higher unemployment rates than men with disabilities. We wanted to know how women dealt with their disability in the paid workplace and hoped to discover some of the barriers to their continued employment.

Key players in the field of disability research have commented on the need to change the social relations of research and to focus attention onto the disabling features of society, rather than on individual limitations (Morris, 1992; Oliver, 1992; Zarb, 1992). Morris (1992:158), who identifies herself as a feminist and disabled researcher, considers emancipatory research important, defining this as an approach based on "empowerment and reciprocity." We therefore wanted to produce an account that would emphasize the social dimensions of the women's subjectively lived disability experiences and were concerned that the study would have relevance for those participating, as well as potentially informing policy. As a researcher working with feminist poststructural theory and a teacher of rehabilitation science students, I was also concerned that we not adopt some of those dominant models of disability which inform professional health care practice and which do not engage with the dynamics of the social and discursive construction of disability.

Neither of the researchers have MS or are disabled, so in-depth interviewing was chosen as a method that would recognize and foreground the 'expert knowledge' of the women research participants. A large-scale mail survey followed up key issues identified in the interviews. The survey would give some guidance in assessing the typicality of these issues, information which would support any policy recommendations. We spent some time exploring avenues for recruiting women. It was during this process of 'gaining access' to our research participants that struggles emerged over 'ownership' of a potential study participant's body and voice, as different parties to the research worked with distinctive cultural constructions of the body in mind.

THE EMBODIED SUBJECT

The theoretical ideas informing the analysis derive from the intense scrutiny of the body in post-structuralist feminist theory. This work dismantles the mind/body dualism and brings subtle nuances to discussion of how the human (and gendered) subject is constituted through discourses of power. Feminist theorists have elaborated on Foucault's work on the body and its social production and control through scientific discourse (Butler, 1990; Gatens, 1992; Grosz, 1994; Probyn, 1993). They have explored the mutuality of the experienced material body and the body as a surface of inscription, for the body, while given meaning and experienced through social relations and discourses, is understood to be simultaneously biological.³

Elizabeth Grosz (1994), for example, in her extensive discussion of the links between the body and women's subjectivities, comments that the material body cannot be

distinct from its cultural and historical representations. There are, however, different models of corporeality, and dominant conceptions may be contested. The key to her argument is the idea that the 'marking' of the body in different ways is central to how particular kinds of body with particular capacities are constituted through the micro-politics of power. She states, "It is not simply that the body is represented in a variety of ways according to historical, social, and cultural exigencies while it remains basically the same; these factors actively produce the body as a body of a determinate type" (1994:x).

In short, bodies, rather than natural, are understood to be historical and to be culturally constructed within power differentials, as the latter are exercised through discourse and accompanying social practices. The subject, subjectivity, and the body are intertwined. For women with chronic illness and disability, the body is 'marked' with the inscriptions of medical science. It was over the body as a site of inscription that struggles for access to the women's accounts took place, with biomedical constructions of the diseased body conflicting with an approach concerned with women's experiences and knowledge.⁴

ACCESS AND THE BODY AS AN OBJECT OF SCIENCE

We recruited through two settings: a local branch of the MS Society and a medical clinic. We received considerable support from the former. A representative of the local branch of the MS Society facilitated pilot interviews with two women. Talking with

these women and an executive member of the society was invaluable in getting a sense of some key issues for women with MS. As a national organization, the funding practices for research of the MS Society have largely been controlled by medical interests (Blackford, 1993). Our focus away from the medically-defined body to the experiences of living with an uncertain and potentially stigmatizing body was seen to have potential value for the membership. Acknowledgment of the importance of non-medical knowledge in the management of illness was an area of congruence in our interests. We recruited women for our study through an announcement in the branch's newsletter.

We approached a medical clinic in order to broaden the range of women interviewed and to include those currently receiving medical attention. We also requested the assistance of the clinic in recruiting women for the questionnaire survey through their mailing lists. We met most resistance over the interview component of the study. Several factors may have been at issue, but our different understandings of the body in relation to the human subject and what counts as knowledge appeared to be a key concern. The medical interpretation of the 'appropriate' use of the body as a source of knowledge in research collided with our understanding of embodied subjectivity.

The importance of the biomedical gaze in constituting the body, and rendering it as a site of social control, has been well-rehearsed in accounts initially informed by Foucault's ideas. Good (1994), a medical anthropologist who conducted an ethnographic study of

Harvard medical students, provides an account of how medicine constructs its objects through the formative, everyday processes of clinical practice. Good claims that it is through learning to see, write, and talk about the body in specialized ways that it becomes a medical object. Through anatomical investigation, writing up cases, and presenting cases in medical rounds, the medical student enters a lifeworld with a distinctive reality in which a person is reconstructed as one "appropriate to the medical gaze, identified as a body, a case, a patient, or a cadaver" (Good, 1994:73). It was into this lifeworld that we stepped when we wanted to reach women attending the clinic.

We presented our proposal to clinic personnel. We carefully explained our use of interpretive research and our interest in women's own definition of their experiences. Given that the 'objective' knowledge of the scientific paradigm has little in common with interpretive research, we had expected some resistance to our approach. There was no medical body in our presentation apart from the premise of a diagnosis, little evidence of 'objectivity' as understood in positivistic science in our methods, and our presentation lacked the tables, graphs, and other statistical materials common in medical presentations. Initially we received considerable resistance to our proposal, in part, I suggest, because we did not present our potential study participants as cases, patients, or bodies 'appropriate to the medical gaze.' Rather we presented them as women from whom we wanted to learn about their everyday concerns and experiences associated with their disease. It was unclear to the physicians that we would learn anything more than they did in their clinical interviews.

Another concern revolved around 'ownership' of the women's bodies. The physicians were anxious about their patients being over-researched, as many were involved in clinic research projects.

The clinic offered its support with the proviso that the study would only include women with a clinical diagnosis of MS. The medical category was of central importance. This view was reaffirmed when it was found that we were simultaneously recruiting women through the MS Society. As we would not know the precise diagnosis of our participants, the research in the clinic's view would be invalid. Another issue concerned the credibility of the women's accounts: that some women might bring personal motives to the research was considered a further factor jeopardizing the study. Once the research was in progress, however, we received considerable help in recruiting women for both the interview and mail survey phases of the study.

It was through these material practices surrounding the access process that claims to knowledge and definitions of what knowledge matters were negotiated. This negotiation occurred in the context of the distinct realities and discourses through which the women participating in the study were positioned by the different stakeholders in the research. While our interests and those of the MS Society were viewed as congruent, access to the women's knowledge in the context of a medical site was mediated by the clinic's claims to some 'ownership' of patients--as material bodies and objects of science--and upheld by their mandate of diagnosis, treatment and research of this medically-puzzling disease. Moreover, the

language of our different research paradigms constrained effective communication.

As Haraway (1988) points out in her discussion of 'objectivity,' we all have a view from somewhere: who we are, where we are, and our views of the purposes of research influence what we see and what is considered credible knowledge. To this point my focus has been on the mediators of the field and their views. I now turn to the central figures in the study to bring into focus their responses to participation in the research and how this may be related to the issue of empowerment.

RESEARCH RELATIONS AND EMPOWERMENT

We interviewed 67 women who responded to our request for volunteers to participate in the study. In the mail-out survey to 812 women, 533 returned questionnaires (a 66% response rate). By virtue of their diagnosis, the women's bodies had already been scripted through the authority of biomedical knowledge and its categories. The women's interpretation of their illness was preframed by a particular cultural (medical) construction of their bodies, despite the large void in knowledge about cause, cure and management of multiple sclerosis. The interviews exposed this void. Participation in the study was, for some women, a way of addressing this absence.

Several women saw their participation in the study as a means of contributing to knowledge that might be useful to others. Other women were isolated and worried and hoped to find information on resources. It was important for some to voice and make public

the particular issues and difficulties they had faced, for example in attempts to access educational or financial resources. The interviews contained accounts of women actively renegotiating 'useful' knowledge as they talked of the specific ways that they contested medical knowledge and practice. These included examples of women using alternative therapies and reclaiming their own knowledge of their bodies in support groups and other arenas of women talking together away from the biomedical gaze. Women also talked of ways they restructured their home, neighbourhood, and work environments in attempts to maintain their performative abilities as wives, mothers, and wage workers.

The extent to which the research facilitated empowerment is difficult to assess, but I suggest that the ways we think about the embodied subject has implications for how we think about 'empowerment' and praxis in research. If the body is understood as constituted through discourses of power and social practices, and experienced through both its materiality and representations, then actions for social change are not restricted to the 'public' arena. Chouinard (1994:3), for example, suggests that seeing the invidious exercise of power through the "multiple sites of experience and practice, in virtually every aspect of our lives" means that "challenging our oppressions requires reinventing ourselves ... and our relations to others." Did our research--where different conceptions of the women, as material bodies and subjects, were at work--contribute to such a reinvention of self and thus empowerment? I focus on one aspect of this question by considering whether

the research fostered the legitimacy of how the women represented themselves when others' representations of the material body tend to infiltrate their lives, often with negative effects. For instance, the study showed that dominant cultural notions of 'normal' bodies, life courses, and gendered activities, mediated by biomedical discourse, tend to threaten the women's employment chances and their heterosexual relationships and also shape the financial circumstances in which they live (Dyck, 1995, forthcoming). The power relations in which such cultural notions are embedded are not readily changed through research, but may be contested.

The interviews made some space for the women to voice their experiences and concerns between the interstices of power, which is not confined to the relationship between the researcher and 'researched' but operates among the various potential players in defining the research. The interviews and participation in the mail questionnaire act to legitimize the women's knowledge, validate the importance of the non-medical dimensions of illness, and acknowledge women's continuities in their identities. The analysis, which includes these experiential accounts, represents resistance to the biomedical (and dominant) way of thinking about the 'diseased body.' During the interviews, women as individuals could reclaim their own reality--as distinct from the biomedical 'script'--through recounting their everyday experience of living with MS as experts. Many women commented on the positive experience of participating in the interviews or survey and the value they felt this type of study had. Response to conference presentations and publications has also stressed the importance to women of their

own, everyday knowledge of living with their 'failing' bodies being recognized when decisions affecting their lives--such as in the allocation and management of homecare--are made. Although each woman talked of an individual experience, the accumulation of many women's accounts and responses to the questionnaire provided a rich data source that--in the form of an overview summary of the study--was returned to the study participants. This is not action for radical change, but produces knowledge about women who are marginalized in society that defines the women's difficulties as common problems to be dealt with, rather than simply individual concerns.

The research also brings the women's interpretation of their experiences into a larger dialogue, through the positioning of the researchers at the interface of social and medical science. In writing for health professional and policy audiences, participating in the continuing education of professionals, and through teaching students who will be service providers, we aim to use the women's words and descriptions of their experiences to reinterpret dominant ways of thinking about and practicing health care. Foregrounding the experiences of women living with a 'marked' body, rather than continuing the isolated scrutiny of the physical limitations of the material body, I hope can suggest ways of looking at health care issues in a collaborative way which includes an active engagement with the 'patient' as an expert knower.

CONCLUSION

In our exploration of both the women's expressions of their experiences of their 'lived

subjectivity' and the social relations and discourses of power shaping these, we have gone some way forward in meeting criteria for disability and feminist research that are concerned with issues of empowerment, reciprocity, and voice in constructions of knowledge. Our methods have provided a forum for women to construct themselves as holders of expert knowledge useful to other women in a practical sense and in contesting the dominance of biomedical discourse in understanding the 'diseased body.' We have also examined the micropolitics of the research and we represent the women in an alternative way to that predominant in health and health care research. These are features that Bhavnani (1993) views as critical to feminist research practice. The women of the study, however, are the key players in the process of beginning to challenge taken-for-granted, dominant constructions and ways of looking at and doing things.

If we work with the notion that the embodied subject is not only constituted through social reproduction, but is also part of constitutive processes, then individual action can be understood as having the capacity to influence dominant representations. Our research documents spaces of resistance--such as those of the household and social networks--which are away from public political arenas but are places where women may 'reinvent' themselves, negotiating their self and social identities and their relations to others. Our study, however, also suggests that many women remain isolated with their feelings of lack of control of their bodies and their lives and are caught within different

interpretations and representations of the body and their subjectivity. It is these women who are harder to reach and for whom the outcome of research practice has a more tenuous link. I am left with the question of what models for change are most appropriate for such women, who often are severely constrained on a number of axes in the ways in which they can participate in society, whether or not this includes political action.

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ENDNOTES

1. Terms within the disability field of research and health care professional practice are politically nuanced. In the U.K. the term 'disabled' is preferred as congruent to the notion that disability is socially constructed within sets of social relations and physical barriers (the social model of disability), while in North America the term of choice is 'people with disabilities' to suggest the importance of focusing on the individual, rather than their

impairment. Here I use the terms interchangeably to indicate the problematic. In the disability literature individual writers refer to themselves in different ways, sometimes as a political strategy (see for example Zola, 1991).

2. Co-investigator was Lyn Jongbloed, School of Rehabilitation Sciences, University of British Columbia. Ann Crichton, Professor Emeritus, University of British Columbia, and a policy analyst provided consultation on the grant proposal. As principal investigator and the one researcher engaging with social theory I take responsibility for the analysis presented here.
3. See Shilling (1993) for a study of the contribution of different social theories of the body to understanding the body as constantly in process. The notion of the embodied subject is central to understanding the body as both material and social. That is, the effects of social relations, inequalities and oppressions are experienced corporeally, and the social reproduction of 'appropriate bodies' is part of the ongoing social reproduction of society.
4. In focusing on women with MS we faced something of a conundrum; by relying on medical labels we vindicate them while simultaneously recognizing them as cultural constructions (albeit with a biological

base) 'marking' the body in a particular way. Critical medical anthropologists and sociologists have also noted the tension in interpretive work concerned with the objects of scientific medicine.

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