L.Culley, N. Hudson, F L Rapport. Contact: lac@dmu.ac.uk

Recruitment and Reciprocity: focus group method in health research with minority ethnic communities

Introduction - This paper discusses the focus group phase of an exploratory study examining the provision of infertility services to South Asian communities in the UK (Culley et al 2006). It comments on two of the methodological/ethical dilemmas which faced the researchers in carrying out focus groups with members of 4 main South Asian communities, across 3 English cities. The paper discusses recruitment of participants and the issue of the obligations inherent in the relationship between researcher and researched within a critical social research paradigm (research reciprocity).

Background to the study - Inequalities in health between and within ethnic groups in the UK have become an increasing focus of research (Johnson et al 2000). National surveys of mortality and morbidity have demonstrated significant variations by ethnic group (Ehrens et al 2001), inequalities in access to health services have been established by a number of studies, and differences in the quality of care received by majority and minority ethnic groups have been demonstrated (Ahmad 2000) though few studies have explored the reasons for these differences. Involuntary childlessness and its social impact is an under-researched area. Most studies tend to treat the 'infertile' as a homogeneous group. As a consequence the social characteristics of participants are not always clarified, though in general research has focussed on white, middle class treatment seekers. Studies have consistently ignored non-treatment seekers, those accessing treatments other than IVF, those in lower socio-economic groups and those from minority ethnic communities (Griel 1997). This project aimed to start to fill these gaps by exploring the social meaning of involuntary childlessness in British South Asian communities and the experiences of those having difficulties conceiving.

Methods - The first phase of the project included over 20 interviews with key community informants and 14 focus groups (10 female only and 4 male only) with 93 members of the Pakistani Muslim, Bangladeshi Muslim, Gujarati Hindu and Punjabi Sikh communities. There was no attempt to recruit those experiencing fertility problems, but to access to view of 'ordinary' people, young and old, male and female. The objective of the focus groups was to explore community constructs of involuntary childlessness and community responses to infertility and its treatments, prior to interviews with infertility patients in the second phase of the project.

Recruitment – Though research recruitment has received relatively little published comment it is crucial to a study's success. It is a complex process, often remaining hidden, yet there may be community differences in response to research recruitment, reflecting the reality of peoples' lives within different socio-cultural entities (McLean & Campbell 2003). It was acknowledged that the social identities of the two main researchers (white female academics) placed them as cultural outsiders potentially affecting successful access to and recruitment of participants. A small team of male and female community facilitators were employed in order to assist with recruitment and to co-facilitate groups who preferred to speak in community languages. The project's aim was to explore the highly sensitive topic of infertility. As a sensitive and potentially stigmatizing condition we were concerned that, despite the fact that we

were not asking for personal testimonies in the focus groups, people might be reluctant to take part in group discussions about infertility and its treatment.

It has been reported elsewhere that assumptions about ease of access to minority ethnic groups, based on holding 'insider status' in terms of ethnicity and gender, have been misjudged. Both Bhopal (1995) and Mirza (1998) in their research with South Asian women assumed they would be given free access based on their own identities as South Asian women. However, in both cases this was not the case, with insider status being judged in terms of other factors (social class, educational status and membership of a geographical community). In relation to our study, we presumed that our social identities as white women might *inhibit* access, but found that in some cases it *facilitated* access. The 'placing' of us as *experts* became the social identity of most significance for our initial contact with key gatekeepers, and our status as 'outsiders' was regarded by these individuals as making it more likely that people would speak with us about infertility as we were not members of the immediate community and would not threaten confidentiality.

We decided to conduct single-sex groups based on previous research experience and knowledge of communities concerned. We worked with pre-existing groups held in women's centres, playgroups, community centres and gurdwaras, with personal contacts with community workers and other 'gate-keepers' crucial to recruitment. These individuals had a wider 'political' interest in the topic, since several reported that they were aware of difficulties within their communities around the issue of infertility and were keen to have this topic 'opened up' to discussion. 'Gate keepers' were also vital to our being accepted as researchers and several acted as initial conveners of the meetings where our focus group interviews were carried out. Gaining access to participants was, therefore, a lengthy and complex process, requiring considerable preparatory fieldwork. The ethnic identity and, importantly, the gender of the main researchers was a more pertinent issue when trying to recruit groups of South Asian males to discuss infertility. Here it was necessary to use personal contacts with knowledge of the communities concerned. It is difficult to determine whether the difficulties in recruiting males was influenced by the sensitivity of the topic, or the fact that it was very much seen to be a 'woman's issue'. In most communities there are fewer occasions when men meet as a group and the need to specially convene male groups, taking into account working hours and other commitments added to recruitment difficulties. Once convened, the male groups were very successful, with remarkably open and frank discussions.

Recruiting through pre-existing groups raises challenges for informed consent. In effect, delegating the passing on of information to a group of conveners was essential, particularly when the group was not going to be held in English. In some cases, however, it was difficult to determine to what extent all members were aware of what was going to be discussed, although the purpose of the group was always explained at the outset. In theory it was possible for women to leave before the discussion, but in practice they may have felt pressure to remain.

Reciprocity – Issues of power between researchers and participants are complex and may be particularly pertinent with marginalized groups. There has been considerable debate about whether minority ethnic communities have benefited from the increasing levels of research interest from health and social care providers. Whilst rejecting the

discourse of empowerment, we felt strongly that we would like to repay in some way the time and effort of those who helped to recruit participants and the participants themselves. One such opportunity arose in responding to information needs. It was evident from the first group that many women were concerned about the impact of infertility but had little knowledge of causes and treatments available. In some cases it was clear that misinformation was being provided during the course of the group, which might be legitimized by the presence of the researcher, and we felt that it was unethical not to try to address this during the sessions. To meet this need, we produced basic written information about infertility and about local sources of support and treatment for infertile couples and spent time at the end of the group interview answering questions. We also offered follow-up workshop sessions for community groups, with interpreters if necessary, where infertility could be explored in depth.

Conclusions - Focus group research is currently very popular, though relatively little has been written on the methodological and ethical issues vis-à-vis use with minority ethnic communities. We have briefly reported on 2 issues relating to the complex process of recruitment of South Asian men and women and the ways in which we offered to repay some of the time and effort given freely by our participants. A diverse range of recruitment sites was required to reach a cross section of communities, in terms of ethnic identity, age and gender. Gatekeepers, in form of local community workers and leaders, were vital in accessing existing groups, they themselves having a keen interest in the topic and in it being opened up for discussion. Recruiting male groups was particularly challenging but they proved very successful in eliciting men's views. In all groups it was not always clear that enthusiastic group conveners had passed on all relevant information about the purpose of the group, which raises significant ethical issues. In addition, the researchers were faced with unanticipated requests from the groups to provide basic information about the topic under debate or in some case, practical support. However, it was felt that a reciprocal relationship requires a positive response to these requests. Researchers need to be sensitive to the expectations of participants and the potential effects of their research presence. Discussions of focus group methodology need to include socio-cultural contexts of recruitment. In designing projects, researchers need to address the fact that cultural values and social norms may play a part in the motivation of participants and their expectations of participation.

Ahmad, WIU. (ed) (2000) *Ethnicity, Disability and Chronic Illness.* Buckingham: Open University Press

Bhopal, K. (1995) 'Women and feminism as subjects of black study: the difficulties and dilemmas of carrying out re-search' *Journal of Gender Studies*, 4 (2): 153-68

Culley, L., Hudson, N, Rapport, F, Johnson, M, Katbamna, S (2006) British South Asian Communities and Infertility Services. *Human Fertility* 9(1):37-45

Ehrens, B. Primatesta. P. & Prior, G. (eds) (2001) *Health Survey for England. The Health of Minority Ethnic Groups '99 Volume One.* The Stationary Office London.

Griel, AL. (1997) 'Infertility and psychological distress: a critical review of the literature' *Social Science and Medicine*, 45 (11): 1679-1704

Johnson, M. Owen, D. & Blackburn, C. (2000) *Black and Minority Ethnic Groups in England: the second health and lifestyles survey.* Health Education Authority, London.

McLean, C & Campbell, C (2003) Locating Research Informants in a Multi-ethnic Community: Ethnic Identities, Social Networks and Recruitment Methods. *Ethnicity and Health,* 8(1), 41-61.

Mirza, M. (1998) ''Same voices, same lives?': revisiting black feminist standpoint epistemology' in *Researching Racism in Education*: *Politics, Theory and Practice,* (eds) P. Connolly and B. Troyna. Buckingham: Open University: 79-94

L.Culley, N. Hudson, F L Rapport. Contact: lac@dmu.ac.uk