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Researching inequalities: lessons from an ethnographic study

Ghazala Mir[1]

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Abstract

Studies exploring health inequalities have often demonstrated the inappropriateness of service provision in relation to the needs of disadvantaged communities. However, the research methods used to explore these issues have been subject to less scrutiny. This chapter considers whether research methods used for a study of long-term illness in a Pakistani community in the UK were appropriate and sensitive to the needs and priorities of Pakistani people. Findings in relation to fieldwork revealed the value of ethnographic methodology in providing context to data from semi-structured interviews. However, attitudes towards research within the Pakistani community, which formed part of this context, indicated that many Pakistani respondents felt disengaged from and cynical about the research process. They also felt vulnerable to exploitation and to abuse of trust from researchers and other professionals. These findings have implications for the methodological approaches adopted during research and their acceptability to research subjects in marginalised communities. Research methods and designs that engage individuals and offer reciprocity through practical outcomes that meet their needs are suggested as more appropriate than traditional qualitative methods.

Introduction

This chapter aims to critically evaluate methods used in an ethnographic study of long-term illness within a Pakistani community in the UK and to draw from these more general lessons about research in socially excluded groups. The study adopted a complex range of data sources to explore whether and to what extent religious identity influenced the processes of communication and decision-making about long-term illness management. This research question was prompted by the high level of certain long-term conditions within this social group (Department of Health/HM Treasury 2002; Acheson 1998), evidence that communication is a particular issue in relation to access to services and management of self-care (Mir and Tovey 2001) and the primacy of religious identity within the Pakistani community (Modood et al 1997).

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[1] Centre for Health and Social Care, University of Leeds, 101 Clarendon Road, Leeds LS2 9LJ g.mir@leeds.ac.uk

The following sections describe fieldwork for the study and draw on findings about these to highlight the strengths and weaknesses of the methodology adopted. These are considered in the context of attitudes to research within the Pakistani community concerned. Possible responses to these weaknesses are considered along with the more general implications for how studies are designed and conducted within this and other marginalised groups.

Ethnographic methodology

Qualitative methodology is particularly valuable when an area is under-researched, complex relationships are involved, and when the life experience of participants is central to the development of knowledge (Ryan et al 2001). Ethnographic approaches provide detailed accounts of the concrete experience of life within a particular culture in order to discover and understand the beliefs and social rules that are used as resources within it. Ethnographic fieldwork combines observation, informal 'interviews' and in-depth case studies as a powerful means of investigating complex questions relating to experiences, relationships and social processes (Hammersley and Atkinson 1995).

Importantly, this methodology recognises the social context of an individual's life and the fact that people are 'patients' for very little of their illness experience. The perceptions of significant others and the personal and social circumstances within which individuals live are recognised as crucial to understanding communication patterns and decision-making processes (Charmaz and Olsen 1997; Donovan and Blake 1992) and necessary to developing effective care interventions (Rybarczyk et al 1999). Triangulation – comparing and combining data from different sources about the same issue – supports researchers to reveal and examine assumptions made by individual research participants or by researchers themselves. This helps to develop a more sophisticated understanding of people's behaviour and beliefs than would otherwise be possible (Hammersley 1992).

The inclusion of diverse data sources during fieldwork for this study (see Table 1), helped build a detailed picture of the context in which long-term illness was managed and the influence of religious identity within this, whilst taking account of other influences such as gender, age and social class. The suitability of specific aspects of this methodology is explored in the sections below, taking account of the data generated, respondents' attitudes towards the methods used and ethical considerations highlighted during fieldwork.

Table 1: Types of data source

Source of data	**Details**
Interviews and contacts with adults recently diagnosed with chronic illness	1-3 semi-structured interviews with 31 respondents and informal contacts over 12-16 months
Interviews with carers/family members	11 semi-structured interviews
Professional interviews and 'shadowing'[2] of appropriate professionals in both practice and community settings	10 semi-structured interviews (GPs, interpreters, community health visitors; diabetes, cardiology, oncology and mental health consultants; specialist nurses; dieticians; podiatrist) and 12 observations of healthcare settings(diabetes clinic, cardiac rehabilitation clinic, community health clinics
Interviews with key informants	13 semi-structured interviews
Community-based ethnographic work	Fieldwork over 27 months
Messages from local, national and international email groups set up for and by Muslims	11 groups with varying levels of mail followed over the fieldwork period
Local information and policy relating to health facilities, ethnicity or the Pakistani community	Documents collected over the period of the study and attendance at related local events.

Semi-structured interviews

Semi-structured interviews were carried out with 30 Pakistani people, living in the Harehills area of Leeds, who had been diagnosed with a long-term illness in the last year. Twenty-two of these individuals were interviewed a second time six months later and 20 a third time, a year to 16 months after their original interview. The three interviews helped build a very detailed picture of respondents along with an understanding of their most important concerns and values. This approach also enabled tailoring of questions to individual respondents based on previous interviews. All Pakistani people

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[2] 'Shadowing' involved spending time with health professionals in their workplace in order to observe and discuss the detailed processes and practices involved in their day-to-day activities

with long-term illness lived within a two-mile radius of Harehills, which constituted the fieldwork area. Interviews were conducted by two Pakistani researchers in English, Urdu, Punjabi and Mirpuri (a dialect spoken by many respondents originating from the Kashmir province of Pakistan).
Important issues relating to the makeup of the Pakistani community were discovered through recruitment of individuals to this part of the study. Fieldwork demonstrated that the term ‘Pakistani’ is misleading in relation to community membership. A number of people who considered themselves to be part of the local Pakistani Muslim community in fact originated from India and East Africa. Whilst retaining strong and separate ethnic identities, these individuals nevertheless used and contributed to the same social networks as the majority Pakistani population because of their religious identity, which differentiated them from the majority Indian and African populations in the fieldwork area. This confirmed and provided further evidence of the primacy of religious over ethnic identity for Pakistani Muslims (see Modood 1997). A decision was consequently made to include in the sample respondents who identified with and formed part of the social networks within the Pakistani community, even though they were born in India, East Africa or the UK. Their inclusion reflected the geographical and historical diversity that a single Pakistani community may contain.

Semi-structured interviews allowed in-depth discussion of issues such as responses to diagnosis and the meaning of illness, sources of information, communication patterns in family, social and clinical settings, management of illness in daily life and the influence of significant others on communication and decision-making. Interview accounts were compared with fieldwork observations relating to the same themes, providing a means of triangulation. Informal contact and fieldwork observations did not require respondents to dedicate time or effort to the research process and there was no evidence that they were perceived as intrusive. However, as a method, semi-structured interviews raised practical and ethical issues that are considered in detail below.

The need for participatory techniques

Semi-structured interviews generated a good deal of valuable data from most respondents. However, interviewees who had little experience of research could be bemused or perplexed by the process and, despite researchers’ best efforts, some participants did not engage in an in-depth discussion. This was particularly noticeable with respondents who had little formal education. Open-ended questions could generate very little response in these cases and it was clear that respondents were neither engaged by the process nor stimulated to share their feelings or experiences.

Examples of the difficulties faced in relation to semi-structured interviews with some Pakistani patients are given below:

- NS and QL seemed amused and gave joke answers to questions about feelings or family dynamics.
- NC felt that talking at length was not appropriate unless he had something definite to say: ‘There’s no point just saying something for the sake of it’
- In response to specific questions IN and NJ, two elderly people with long-term illness, sometimes began to talk about other issues related to their health or about a certain word in the question but in an unrelated way.

These difficulties indicated that some respondents did not wish to answer direct questions about their feelings or family relationships or felt they had little to contribute to the research. In some cases responses indicated resistance to the process in which participants were being asked to engage. The third example above suggests some people found it difficult to focus on the question being asked, perhaps because of age or illness. In each example, what appears clear is that for a variety of reasons these dynamics prevented interviews from being ‘conversations with a purpose’ (Burgess 1988) since individuals were not always involved in a conversation and interviews became more a question and answer session. In this situation, individuals appeared to be subjected to research rather than enabled to participate in it.

As a way of addressing these problems different ways of eliciting the views of research participants were explored and a more sophisticated approach to data generation adopted. Johnson and Webster (2000) recommend participatory research techniques as a way of involving people from socially excluded, particularly non-literate, groups in a process of which they may have little experience. This approach uses visual stimuli and practical activities to generate data about views and experiences, empowering participants to share their knowledge in a way that traditional research methods do not always achieve. Participatory methods support respondents to take control of their interactions with researchers.

The use of concrete keywords, taken from previous interviews with this respondent group, was an important means of achieving this kind of participation. Three participatory techniques were used in the third interviews:

- A set of cards developed from analysis of previous interviews, which identified problems people could face when trying to manage their health. Pictures as well as Urdu and English keywords were used on these cards. This allowed involvement of individuals who did not speak or read either language as well as those who were literate in one or both languages. Respondents were asked to identify cards which showed problems they faced and then to place them in priority order.

- A second set of cards in similar format was used to ask patients about influences on decision-making. Keywords were again developed from the variety of influences mentioned in the full sample of previous interviews. Respondents were asked to identify the most important influence on their decision-making and place this in a central position. They then placed other cards near or distant to this central card, depending on the level of influence they felt each person or thing had (see Figure 1).

- A map of the fieldwork area used to find out how much people knew about health facilities and community organisations in the area and their views about the quality of services offered. The map was also used to find out about other places in the community that were important to health or social activity and the extent to which individuals mixed with people from other ethnic and religious groups. Places already mentioned in previous interviews, and the respondent's own home, were pre-identified on a personalised map as a starting point for discussion.

Figure 1: Participatory techniques - "Influences on decision-making"

These activities were piloted in two User Advisory Groups established for the study and were well-received. During fieldwork, most respondents who were reticent in semi-structured interviews gradually became familiar with the activities and took control of the process. For example, NL and TBl began to tell the researcher where to put the card after originally feeling the researcher should 'put them wherever you like'.

The words on the cards acted as prompts but the method allowed a greater number of prompts than would be possible in a semi-structured interview. In addition the priority attached to each card was made explicit through the process of accepting or rejecting cards and placing them in a particular order. In contrast, data from previous interviews had reflected needs and problems but often not the order of priority in which they were held by patients. The cards also placed more pressure on individuals to be specific about difficulties they faced. For example, TBl moved from stating a number of times that ‘Nothing is difficult’ to expressing in detail how he felt financial worries contributed to his illness by taking away his ‘peace of mind’ and ability to work less hours. He explained that these worries often occupied his thoughts but were a subject about which he spoke to no-one and this ‘thinking’ was also, he felt, a cause of illness. Comments in relation to a particular card could also help make explicit what respondents saw as the underlying reason for an identified problem:

NL Every thing is difficult for me.
Q Which is difficult from these [cards]? …
NL Walking and talking both have become difficult for me.
Q How? Is it because of the language?
NL No I am old. I am seventy years old. I have breathing problems. The other thing is I am on medication. Doctor gives me the medicine but it doesn’t have any effect.
Q Right, so is 'treatment' a problem then?
NL Treatment means, when somebody doesn't understand your illness then medicine doesn't do any good… The difficulty is in talking, difficulty is in time … Doctor prescribes the wrong medicine
Q Is that your family doctor or the doctor in the hospital as well?
NL All of them… They all just pass their time. They don’t give you the medicine.
(NL - male with coronary heart disease and diabetes)

The extract above is taken from an interview with a respondent who was at times difficult to follow. The use of cards in this interview enabled researchers to identify mobility, speech and treatment as three priority areas of difficulty in relation to this respondent’s condition. The additional comments provide insight into the respondent’s feelings that these were problems partly because of his age but also because the doctors who treated him did not give sufficient time or attention to understanding his condition and therefore could not treat him appropriately. These ideas were supported by evidence elsewhere in this and other interviews with the respondent.

This approach to communicating with respondents was therefore of value in drawing out the views of individuals who generally did not communicate their thoughts and feelings in response to a straightforward question. It was not entirely effective in all cases, however. A small number of respondents who did not speak in any depth during semi-structured interviews were also not stimulated to talk at any length through participatory methods. The use of maps of the area, whilst providing a visual focus for discussion, could also be difficult for people who could not read or people with visual difficulties.

Interviewees were asked to evaluate these methods after the interview. Some respondents preferred straightforward questions and answers rather than the participatory approach, which they felt demanded more concentration and where the answers had to be more specific:

> 'I did find it harder, I am not sure how I should have answered you ….I have to read myself and then concentrate. I have to think a lot.'
>
> (HX - female with diabetes)

However, others preferred the participatory techniques which they said they did not find difficult. Overall, better quality data was generated through this approach. In addition to encouraging greater participation from individual respondents, these activities enabled data to be gathered that could be compared across the group of people with long-term illness. This made it possible to construct a hierarchy of problems and influences on self-care management for this respondent group as a whole. The map exercise gave an overview of the most important community sites for social and health activities and the level of knowledge about community-based organisations within the respondent group. Furthermore, the process of selecting cards inevitably prompted individuals to talk about their reasons for choosing a particular card and revealed in more subtle detail the reasons why some problems or influences might be more significant than others.

Power relationships

A number of Pakistani respondents expressed feelings of vulnerability and lack of control in their relationships with health and social care professionals. Those with limited English felt vulnerable to having their trust abused by professionals, who might use information against them, or being held responsible for things in which they had unwittingly become involved. Unequal power relationships between Pakistani respondents and health practitioners emerged as an important theme during analysis for the study, affecting those who spoke English fluently as well as others.

Fieldwork revealed that similar dynamics existed in respondents' relationships with researchers. For example, AB initially refused to take part in the research because she had heard locally about a bilingual professional working with Social Services to take the children of Pakistani parents into care. NI expressed similar fears about unexpected consequences after he gave consent to interview his GP. He asked, half-jokingly, "They won't come to take me away in handcuffs will they?"

Greater trust in the aims of the research was apparent in cases where respondents already had knowledge of the researcher through previous community links or where support was provided with health-related issues. Involvement of Pakistani people from the fieldwork area on the Advisory Group and Users Advisory Groups for the project was also helpful in achieving transparency about the research activity and outcomes. Two Users Advisory Groups (male and female, following the gendered nature of groups in Pakistani communities) were also vital to validation of research tools and of findings.

A community-based conference at the end of the project was of further help in terms of increasing the credibility of, and trust in, the researchers. The event was organised so that Pakistani respondents were supported to express their views about service provision directly to healthcare professionals. Feedback from Pakistani participants revealed that this approach was considered very useful and a rare chance to have a voice in discussions about service development.

Triangulation

Triangulation was built into the research design both through the use of diverse data sources and through accounts from different people involved in managing a single individual's condition. In addition to fieldwork in family and community settings, a cross section of primary and secondary care health professionals from various health services related to long-term illness were included in the study (see Table 1).

People with long-term illness were asked to identify a carer and health professional who was most involved in supporting them to gain information and make decisions about their health. Eleven carers were interviewed and ten people with long-term illness gave consent for researchers to interview a professional who had influenced their health behaviour and decisions.

Semi-structured interviews, observations and shadowing activities gave valuable insights into the perspectives of professionals, not just in relation to the healthcare of Pakistani people with long-term illness as a whole but also into their relationships with individuals. Along with 'patient' and carer interviews, this data enabled triangulation of different perspectives on long-term illness management during analysis. However, the balance between different perspectives gained from such diverse data sources as Muslim e-lists and media representations of Muslims raised further issues about how to manage these different perspectives during analysis.

Managing 'regimes of truth'

A particular issue relating to triangulation during analysis for this study was the balance to be achieved between religious and secular perspectives in the data. Exploring the views of Muslims within a secular sociological framework results in a conception of Islam as a social construction and of Muslim understandings of truth and knowledge as functional in nature (Asad 1993). The absence of Islamic interpretations from a sociological framework has the potential to allow interpretations of religious acts and beliefs by researchers that conflict with the way they are presented in Islamic scriptures and understood by Muslims. An acceptance of destiny can consequently be equated with fatalism and the specific roles for men and women in Muslim societies be construed as necessarily oppressive of women (Mir and Tovey 2003; Said 1995).

Diverse interpretations of the behaviour of Muslims was of particular relevance to local, national and international events involving Muslims over the three year period in which the research was conducted. Disturbances involving Pakistani youth in Harehills (the fieldwork area) and the terrorist attack in New York in 2001 had a particular impact on the Pakistani community in the fieldwork area. The significance of these events and the way in which they were interpreted was discussed within community settings, through e-lists organised by Muslim groups and, of course, in the media. Data from elists and community settings often provided alternative perspectives to those in the mainstream media and highlighted the dominance of a secular framework in the UK within which the beliefs and actions of Muslims were interpreted.

The generally negative representation of Muslims presented in the media was often seen as an indication, by respondents in the fieldwork area as well as by e-list participants, of the social position Pakistani people, and Muslims generally, held in the UK. This aspect of fieldwork contributed significantly to findings about adverse influences on the psychosocial capital of Pakistani people (Marmot 2004) and the relevance of this to health inequalities within this community. Stereotypes about Islam and Muslim women were reflected in clinical settings, highlighting healthcare as one arena of many in which the beliefs of Pakistani respondents were undermined on a daily basis.

This context raised questions about how, at the stage of analysis, the interplay between differing ‘regimes of truth’ (Hammersley and Atkinson 1995) should be explored and how to balance differing views about what is true and false. An ethnographic approach went some way towards enabling different constructions of knowledge to co-exist – for example, Islamic and sociological or positive and negative interpretations of the behaviour of Pakistani community members. It allowed the adoption of a framework which attempted to understand Pakistani Muslims on their own terms, emphasising their ‘subjective meanings’ as social agents (ibid).

The approach adopted allowed exploration of the validity of these different views in the context of the empirical data, irrespective of their origin and irrespective of how dominant or marginalized a particular view may be in UK society as a whole. Both frameworks were thus treated as possible ways of knowing the world that may struggle for wider acceptance and resist each other in the process. This approach helped avoid analysis that naturalised and reproduced the inferior position given to Islamic interpretations and the unequal social relations that disadvantage Pakistani communities in the UK

(Said 1995; see also Donnelly 2002). Managing the tension between different perspectives helped increase the credibility of findings at the same time as interpretations that built on the common ground between them were formulated.

Ethical concerns

A further issue raised by the frequent contact with Pakistani respondents in the 'patient' sample highlighted ethical concerns about the benefit of the research to these participants. The author's previous experience of research within this community (Mir et al 2001; Mir and Tovey 2003) had revealed a high level of cynicism about benefits to the Pakistani community from research carried out within it and this view was evident from some respondents in this study:

> So, what's going to happen when you've finished the research – is it going to end up as a big report on a shelf somewhere?
>
> (RS – male with diabetes)

Whilst highlighting the needs of minority ethnic communities, research recommendations over the past two decades have sometimes resulted in few and piecemeal outcomes within mainstream service provision in the UK (Mir et al 2001). It is, perhaps, not surprising therefore that some respondents took part mainly out of politeness and a wish to support the researchers rather than because they expected any benefits from the study itself. Low expectations of research outcomes were a particular problem for this study, which aimed to interview people with long-term illness on three separate occasions and thus drew heavily on their time and resources.

To address the problem, researchers offered to help individuals with health-related issues with which they might need support over the period of the study. This offer was taken up by a number of respondents and the resulting activity contributed to ethnographic data collection. Support activity highlighted a range of issues that people felt were relevant to their health, such as helping to pursue a claim for central heating, referring a complaint to the Community Health Council[3], providing transport and interpreting for people at the diabetes clinic and finding a support group for someone with coronary heart disease.

This activity also revealed that some respondents needed help with longstanding problems in which a number of other professionals had already been involved without success. The perseverance and time needed to help solve these problems was considerable and the lack of skilled support available to

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[3] an independent body within the NHS, established to represent the interests of health service users in localities across the UK

Pakistani people in the fieldwork area became apparent. If researchers were not prepared to do anything about these issues, their reasons for asking about problems was called into question:

> Q Do you want to ask any thing uncle?[4]
> NE No we don’t want to ask anything.
> NE’s wife No we don’t want to ask anything.
> NE We don’t have any other demand. Our demand is to get us a house. If you could do that then thanks to you. If you can't do that then coming repeatedly is useless. Otherwise it is waste of time for you and us. The questions are fine but the illnesses don’t go away with answering these questions.
> (NE - male with asthma and coronary heart disease)

Similar concerns about the benefits of research were apparent in many of the thirteen community organisations which were also included as data sources. Involvement in community groups was undertaken during fieldwork to gain an understanding of how community networks operated in relation to health. In addition information and literature was gathered to gain an overview of how Pakistani community networks fit into the wider network of community activity.

Community groups were selected as a focus for fieldwork activity because of a link to health or else to faith. Researchers gathered data through volunteering, attendance at regular meetings or one-off events and informal contact with group members or facilitators. Involvement through volunteering was validated as a mutually beneficial means of gathering data a number of times during the fieldwork period. One group organiser contrasted this method with her experience of other research projects, which had expected her to organise women to be interviewed, on top of everything else for which she was responsible, without offering any extra resources. Not only did volunteering build in an element of reciprocity to the research design, it also enabled collection of valuable data, through the role of participant observer, about group dynamics and about interactions between Pakistani individuals and community-based services. Much information about the quality and type of service people with long-term illness were receiving from overstretched community-based organisations was gathered in this way.

Discussion

My aim in this chapter was to highlight practical and ethical problems in the use of research methods commonly used for qualitative studies in Pakistani communities. The research methodology adopted

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[4] this extract is translated from Punjabi: the term ‘uncle’ is used to show respect for an elderly person

for this study was complex and presented numerous opportunities for reflexivity and for drawing lessons about the appropriateness of the approach. In some respects findings can be seen to support those of previous studies about research in socially excluded communities. However, in other areas the findings present fresh insights into the dynamics of researcher-respondent relationships.

This chapter began by outlining the value of ethnographic methodology in providing context to the experiences of Pakistani respondents. Evidence from fieldwork confirmed that lack of support to address unmet needs, unequal power relationships and low social status form part of this context for many people in Pakistani communities. The evidence presented here demonstrates that research methods are capable of reinforcing this context and that researchers will need to specifically address these issues both in the design and implementation of fieldwork and during the process of analysis and dissemination. As with research in other disadvantaged groups, care is needed to ensure that Pakistani respondents are not perceived simply as the objects of study, that they can contribute effectively and that they are empowered by research projects (Hill 2004).

The potential for exploitation has been highlighted by writers and activists in the fields of feminism and disability studies and greater accountability demanded to avoid studies that primarily serve the interests of researchers themselves (Hill 2004; Barnes 1996). In studies of ethnicity and health inequalities there has been less consideration of these issues, though research on minority ethnic women has sometimes drawn on feminist research perspectives concerning power relationships (Mulder et al 2000; Egharevba 2001). Whereas standards of professionalism and problems with communication have been highlighted in relation to health and social care practitioners by numerous studies on ethnicity and health, particularly in relation to respondents who do not speak English well and who do not understand professional systems (see Mir and Tovey 2003), findings presented here suggest that these issues are no less important in relationships between researchers and respondents in minority ethnic communities.

Perhaps the principal finding of the research relating to methodology, and one in which the significance of researcher-respondent relationships is evident, is the need to take account of the priorities of people from Pakistani communities at all stages of the research process. As Mulder et al (2000) note in their research with Bolivian women, constant checks are needed to ensure that the desire to obtain specific data does not take precedence over the interests of research participants and damage the ability to work fairly or collaboratively with the community being studied. Evidence presented here demonstrates that respondents may agree to take part in studies for a variety of reasons, including politeness or a wish to support researchers. They may also give consent to researchers even though they are fearful of unintended consequences or feel vulnerable and powerless. Without a negotiation of the diverse interests and agendas of participants, and support to become engaged, the response of some respondents may be tacit resistance to the process. Furthermore, unless researchers respond to the critiques of research and concerns of respondents from socially excluded groups, they become guilty of mirroring and perpetuating the social disadvantage that members of this group already experience (Mulder et al 2000).

Ryan et al (2001) establish acceptability of the research to respondents as a criterion for evaluation of qualitative research on health. Innovative methods of engaging and empowering people at all levels of a research project, such as the participatory techniques used in this study and the User Advisory Groups, go some way to addressing these challenges and identifying the priorities of people from such communities. However, adapting existing techniques is not the same as fundamentally changing the relationship between researchers and respondents. Evidence from Pakistani respondents suggests that the absence of reciprocity in their relationships with researchers diminished the acceptability and thus credibility of both research and researchers. As Egharevba (2001) points out, shared ethnicity does not automatically bestow credibility or trust in researchers, whereas willingness to engage with the needs of respondents may help prevent exploitation in these relationships and raise the standing of research within this social group.

If acceptability to respondents is a standard for the quality of a methodology, evidence from this study suggests that approaches in which reciprocity has not been considered can be deemed methodologically weak in relation to the Pakistani community. Studies that take up the time and energy of people from this community, whilst offering no tangible benefit to them, risk reinforcing the existing perception that research is carried out primarily for the benefit of researchers.

The nature of what can appropriately be offered to respondents when considering reciprocal arrangements can not be assumed. Whereas Hill (2004) found that emotional support and willingness to engage in ‘mutual disclosure’ was important to women prisoners, evidence from this study suggests that support to meet immediate and practical needs was the priority of many Pakistani respondents. Egharevbar’s (2001) study of South Asian female students indicates that this priority is not necessarily restricted to those with limited English and may be a reflection of limited social capital and capacity to meet practical needs within South Asian communities.

Findings indicate that helping to meet the needs of Pakistani respondents impacts positively on their relationships with researchers and increases acceptability of the research. This dynamic highlights an important issue in researcher-respondent relationships that was mirrored in relationships between Pakistani people and healthcare professionals - the process of identifying need was often not considered a worthwhile activity unless linked to outcomes that improved people’s lives. The means by which such outcomes may be achieved during the research process needs further exploration. Both

Hill (2004) and Egharevbar (2001) made use of their own skills to provide benefits to respondents but how far this contributed to their data for analysis is unclear.

Attempts to incorporate the priorities and concerns of Pakistani people into the research process for this study affected methodology in a number of ways. The tools used to engage with Pakistani respondents developed from traditional semi-structured interviews to more participatory techniques, which were combined with practical support for health-related needs. All these became methods for collecting data which shaped not only how data was generated but also the kind of data gathered.

The practical support was not only of direct benefit to research participants but also highlighted the way they conceptualised their health needs and the process, if any, through which particular needs could be met. In a social group that consistently experiences unmet need, findings that indicate how needs can be met more effectively are perhaps more relevant than a more sophisticated understanding of what those needs are. This approach may be understood as translating ‘practice into research’ and findings suggest that this may be more appropriate within Pakistani communities than methodologies which result in research recommendations that struggle to find their way into practice.

Conclusion

Lessons highlighted for research in marginalized communities through this study converge on the quality of the relationship between researchers and respondents and the impact of this relationship on research design. The evidence suggests that culturally competent researchers should identify the priorities and concerns of people from marginalized communities and ensure that they respond to these. The use of participatory methods can empower individuals, who may feel unwilling or unable to respond to abstract questions, to engage in the research process. An opportunity to influence this process can also be offered through User Advisory Groups. These can help to increase transparency and address the lack of trust in research that may exist within some communities.

The importance of reciprocity in culturally competent research has also been demonstrated by findings from this study. Evidence suggests that building this into research design can enhance the quality of data gathered and go some way to establishing more equal power relationships between researchers and respondents. This shift in power needs to be carried through to analysis and writing up of research and can involve managing the tension between different knowledge frameworks.

Interpretations that have been formulated in collaboration with all stakeholders will not only be more valid but are likely also to increase the credibility of research itself amongst those taking part. Such credibility is particularly important for researchers working with communities that feel they have benefited relatively little from past studies. Establishing the value of research within these communities will involve ensuring that they are empowered through the research process and that dissemination strategies promote their voice in ways that influence policy and practice.

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