

Practice paper

Applied qualitative research in maternity care: a reflection of the barriers to data collection with 'at-risk' populations

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What is known on this subject

- Inequalities exist in maternal and fetal outcomes.
- Patient and public involvement is a central feature of effective healthcare services.
- The exploratory nature of qualitative research methods is suitable for applied research.

What this paper adds

- The needs of the target group must be assessed throughout the research process.
- To ensure that the most suitable data collection tools and methods are used, researchers must be consistently reflective of their own motivations and the needs of their target groups.
- Researchers must be flexible and open to change if an imbalance is found between the chosen research method and the target group.

ABSTRACT

This practice paper discusses the importance of being flexible towards and thoughtful about individual characteristics when collecting qualitative data from 'at-risk' groups in maternity care research. In addition, the valuable contribution of a multi-disciplinary research team is emphasised. The authors (a consultant midwife and a health psychologist) argue that researchers have a responsibility to explore the cultural reasons for the success or failure of certain research methods. Drawing on their experience of researching women's experiences of communication in antenatal care, the authors reflect on

how inadequacies in the selection and use of data collection methods can result in several negative outcomes. These include low levels of identification of participants, low response rates, poor quality and misinterpretation of results. Suggestions for best practice when designing and conducting research are outlined, including the need to use cultural and local knowledge to evaluate the success of selected research methods.

Keywords: 'at-risk' groups, maternity care, qualitative research methods

Introduction

Patient and public involvement in healthcare and healthcare services is a key feature of health policy in the UK. Patients have the right to be involved in decisions about their care and treatment. The Department

of Health recognises that patients are the experts on their own care, and patient satisfaction is a very important factor in ensuring adherence to care and treatment regimes (Department of Health, 2001;

Darzi, 2007). Feedback from patients enables service providers to determine whether services are truly accessible and meet the needs of the population for which they are intended. However, it is not always easy to gather feedback from some service users, especially those most at risk of adverse health outcomes. This group of people are often collectively regarded as 'at risk.' Numerous characteristics can make a person more at risk of adverse health outcomes. Two such examples are area deprivation and ethnicity. There are extensive findings which link relative deprivation (e.g. Marmot *et al.*, 1991; Marmot, 2005; Marmot and Wilkinson, 2006) and ethnicity (Bharj and Salway, 2008) to adverse health outcomes in the general population in the UK.

In maternity services, the term 'at risk' is applied to women who are considered to have a higher than normal risk of adverse outcomes as a result of pregnancy (see Box 1). Several reports indicate that some groups of women are more likely than others to experience inequalities in maternal and fetal health outcomes (Confidential Enquiry into Stillbirths and Deaths in Infancy, 2001; Lewis, 2007). Specifically, individual and area-level deprivations are associated with worse birth outcomes (Luo *et al.*, 2006). The prevalence of adverse outcomes such as gestational diabetes and hypertension has been associated with ethnicity (Shen *et al.*, 2005). For example, maternal obesity is linked to numerous adverse maternal and fetal outcomes. It is highest in women of lower socio-economic status and among some ethnic groups (Kinra *et al.*, 2000). Engagement with healthcare professionals and health services tends to be lower in these at-risk groups of women than for other women (Lewis, 2007). These findings support the extensive literature that links deprivation to adverse health outcomes.

The vision of world class commissioning sees the NHS focusing on 'better care for all' (Department of Health, 2007, p. 4). Patient engagement is central to

world class commissioning because it allows the health service to understand the needs of the public. However, at-risk groups are not generally represented in initiatives that involve collaboration between service users and professionals (Craig, 1998). For example, in a survey of 2406 women undertaken by the Audit Commission, younger women (aged under 25 years), unemployed women and those with no educational qualifications were under-represented (Audit Commission, 1998). As a result, the voice of those women is not heard and their needs are not included in the design of healthcare. To ensure that interventions can target the women who are most at risk of adverse outcomes, healthcare services research must explore why the people who are most likely to suffer from the worst health outcomes are those who are also least likely to engage in research and share their experiences. Only then will researchers and healthcare professionals be able to start to understand which strategies will maximise the participation of these groups in healthcare services. This reflective paper presents a discussion of the authors' personal experiences of conducting maternity care research, specifically collecting qualitative data from at-risk samples, and offers suggestions for best practice when working with these groups.

The discussion is based on issues arising from qualitative approaches, which are frequently used in midwifery and health services research and which are well suited to examining why certain groups of people are at risk for certain adverse health outcomes. Qualitative methods allow people's experiences to be heard directly from them and in their own words. Reflexivity is an important feature of qualitative research, as it enables researchers to reflect on possible ways in which they have influenced the research (personal reflexivity) and possible ways in which assumptions that have been made during the research process (e.g. research questions) have affected the data and results (epistemological reflexivity) (Willig, 2001). This paper includes discussion about the outcome of both authors' reflexivity at key points in the research process.

Box 1 Women at risk in pregnancy

- Non-English speakers
- Asylum seekers
- Travellers
- Refugees
- Substance misusers
- Victims of domestic violence
- Women with mental health problems
- Victims of sexual abuse
- Women who are HIV positive
- Teenage pregnancy
- Black and ethnic minorities

Source: Lewis (2007).

Highlighting the sample and designing a recruitment strategy

The first stage in research is to highlight the target sample and design a sample frame that will be productive in identifying and recruiting participants. Reaching at-risk groups and involving them in research requires tenacity and a more proactive approach than when recruiting other sample groups. Researchers may have to invest a lot of time to gain an understanding of the culture of the population and thus be able to

successfully engage them in research. Purposive sampling is often used to ensure recruitment of participants from each target group. The best way to do this, according to Steel (2001), is through the use of local networks, including local councils, community voluntary services, local libraries, community centres, local gatherings and word-of-mouth networking (see Box 2).

The authors of this paper were both recently involved in a study examining the antenatal experiences of at-risk pregnant women (Raine *et al*, 2010). The study took place at one NHS Trust (i.e. hospital in Central London, England). The study aimed to recruit a sample that reflected the populations identified as at risk in the NHS trust (see Box 3).

English- and non-English-speaking groups were recruited for the Bengali and Somali groups because, when English-speaking women attend mixed-language focus groups with non-English-speaking women from the same ethnic background, the English speakers tend to dominate the responses and attempt to interpret the responses of the other women (Richens, 2003). Moreover, the experiences of healthcare services differ greatly for women who are unable to communicate in English, especially in terms of the way that they are treated by healthcare professionals (Richens, 2003).

Box 2 Ideas and recommendations for reaching marginalised groups

- Reaching marginalised groups will require time and careful consideration.
- Tapping into existing community networks, both formal and informal, is often effective if done with sensitivity and respect.
- Be aware that marginalised groups may not use the methods of communication that you are used to.
- Offer to meet people informally on their own ground, and take time to build trust. Be open and learn from them.

Source: Steel (2001).

Box 3 Characteristics of the women who were recruited to the study

- Black African (Somali), exclusively non-English-speaking
- Black Caribbean, exclusively English-speaking
- South Asian (Bangladeshi), exclusively English-speaking
- South Asian (Bangladeshi), exclusively non-English-speaking
- Socially disadvantaged white, exclusively English-speaking

Women were recruited to the study using the framework suggested by Steel (2001). Community midwives were viewed as the key gatekeepers, so a series of meetings was arranged to inform them about the aims and objectives of the study. This also helped to make contacts, build relationships and identify possible facilities, such as rooms for focus groups and crèche facilities.

The midwives were asked to inform women of the purpose of the study and explain what participation would involve. The plan was that women who were interested in taking part would then meet with one of the researchers, who would explain the study in more detail, and if the women were still interested in participating, their preferred contact details would be taken. Both the information sheet and the researcher informed the women that transport would be provided in the form of a pre-booked taxi or reimbursement of a day travel card. Approval from the NHS Research Ethics Committee (REC) required that women were given a minimum of 24 hours before consenting to participation in the study. The women were asked to indicate when it would be convenient to attend a focus group, and were told that they would be contacted by a member of the research team with focus group dates. To ensure that the women received all of the relevant information to enable them to make an informed decision about their participation in the study, the information sheet and invitation letter were translated into Bengali and Somali. Women who could not read were contacted by telephone by a member of the research team who spoke Bengali or Somali. The research team attended antenatal clinics on a regular basis, and had a good relationship with the community midwives. In addition, posters and information sheets about the research study were displayed in antenatal clinics and Sure Start children's centres.

Reflection on the recruitment strategy

The recruitment strategy was successful to the extent that a small number of women expressed an interest in participating and were keen to give the researchers their contact details. However, the majority of the women who provided their contact details were from white, educated backgrounds, and there was a lack of response from women in the at-risk groups. The research team were very aware of the need to be reflexive throughout the research process, and scheduled regular meetings to enable this to occur (as supported by Mauthner and Doucet, 2003). Reflecting on the recruitment strategy indicated two possible reasons for the lack of interest shown by the majority of the women who were approached about the study, and in particular the at-risk women. First, the REC

required the researchers to give the women at least 24 hours to consider participation before consenting to the study and taking part in a focus group. A number of women reported being busy with work and family responsibilities. They were keen to take part in the study while waiting for their appointment, for which they had made work and childcare provision, but were not willing to return to participate at a later date. Secondly, in order to identify women who could be approached about the study, the research team had to rely heavily on the help and support of the midwives and other key gatekeepers, such as community group leaders. The midwives and direct contact with the research team in maternity clinics were found to be the most successful recruitment routes. This finding is supported by a recent UK study which found that UK-born migrants are less likely than non-UK-born migrants to be recruited through community groups. Rapport and the relationship between the researcher and the UK-born migrants were more important in successful recruitment (Twamley *et al*, 2009). However, midwives are extremely busy in their clinical roles, and are not always able to fulfil the added responsibility of identifying prospective participants for researchers. They may view the extra work negatively, which means that recruitment may take longer (Kinnunen *et al*, 2008). Following these reflections, the consultant midwife (YR) became involved in the recruitment process. Initially she had not been involved, as it was generally felt that her role at the hospital from which women were recruited might create a bias and deter women from taking part. These changes led to successful recruitment of women from all ethnic groups.

In a subsequent maternity care study, one of the authors (DS) has experienced successful recruitment rates due to the employment of full-time research midwives. Using full-time research midwives to recruit women for maternity care studies has three advantages. First, the research midwives understand the maternity care pathway and the logistics of the clinics in the hospital and community setting. Secondly, they are sensitive to women's unique pregnancy needs, and pregnant women are more receptive to research midwives because they perceive them to be the most appropriate people to care for them during their pregnancy. Thirdly, midwives tend to have good links within the hospital and clinical setting, and midwives working in the clinical area and community teams are more receptive to research midwives, due to their shared interests and knowledge.

The data collection method: focus groups

Another aspect of recruitment was the use of focus groups as the data collection method. A focus group consists of an in-depth, open-ended group discussion that explores a specific set of issues associated with a predefined topic and a homogenous group of participants. A distinguishing feature of the focus group method is the group dynamic and interaction between participants (Kitzinger, 1994). Focus groups are convened under the guidance of a facilitator, who allows a free-flowing discussion to occur between the participants (Howard *et al*, 1989). Focus groups provide direct feedback and can be used as a way of obtaining rich information within a particular social context. The focus group method has been used for many years to elicit people's experiences of disease and of health services (Barbour and Kitzinger, 1999). During the discussion the participants hear other focus group members' responses to the questions, and make comments of their own (Chui and Knight, 1999). The groups are not required to reach any kind of consensus, but simply allow a group of individuals to clarify their views and thoughts in ways that would not be possible in a one-to-one interview. This process of sharing, comparing and justifying viewpoints that spontaneously occur between participants adds a level of context, depth and self-interpretation that is difficult to replicate via other qualitative data collection methods.

Focus groups can facilitate the identification of cultural values, and they have been identified as being useful when researching ethnic minority groups (Hennings *et al*, 1996; Duff, 1999; Wilkins Winslow *et al*, 2002; Richens, 2003; Dorset County Council, 2006). They are commonly used to collect information or to investigate individual responses to different situations or policy initiatives, particularly those of a sensitive nature (Grbich, 1999). They are particularly useful for encouraging participation by people who are reluctant to be interviewed on an individual basis or who feel that they have nothing to contribute, and for tapping into a given cultural context (Kitzinger, 1995).

Focus groups are well suited to exploration and discovery when little is known about the beliefs and attitudes that are held by individuals about a particular topic (Morgan, 1998). Since little is currently known about the reasons why some pregnant women use or access antenatal care suboptimally, the focus group method was considered to be the best option for the London study.

Reflections on the data collection method

The successful use of focus groups: example of research with young parents

Young parents are a socially isolated and at-risk group. As a result, there is a lack of understanding about available support services for young parents, and many barriers to accessing antenatal and postnatal care have been described by young parents (Smith and Roberts, 2009a). The importance of specialist antenatal clinics and support services that address young parents' individual needs has been reported several times (Peckham, 1993; Drife, 2004; Wiggins *et al*, 2005). Focus groups were successfully used in previous research by one of the authors (DS) with young parents (Smith and Roberts, 2009b). In that study the research question examined young parents' experiences of antenatal and postnatal support in order to ascertain the reasons why they did or did not adhere to medical advice and attend antenatal and postnatal services. The main aim of the focus groups was to collect qualitative data in order to clarify the findings highlighted in survey data collected from the same group of young parents. A focus group format was chosen to enable the young parents' cultural beliefs and perceptions of antenatal care to be heard.

Recruitment took place in one London borough through several gatekeepers, such as teenage pregnancy coordinators and health visitors. It became evident that the researcher needed to meet with the young parents several times before inviting them to attend the focus group. These meetings helped to build rapport and trust between the researcher and the participants, and were deemed to be a success, as the required number of participants attended each focus group. In addition, as many young parents experience financial hardship, young parents were given £15 in ASDA vouchers to thank them for giving up two hours of their time to take part in the focus group. The focus groups were designed in an informal and semi-structured manner to encourage discussion and comfort, and were run by a female researcher (DS). A topic guide, including key questions and prompts, was designed to ensure that important topics raised in the questionnaire responses were addressed. As they were an at-risk group and not likely to attend antenatal and postnatal groups, precautions were taken to make the parents feel at ease in the group and to encourage discussion. This was achieved by dividing the participants into smaller groups for the first question of the focus group. They were then asked in their small groups to write down their views on a piece of flipchart paper. Subsequently these responses were displayed to the whole group in order to facilitate discussion. The researcher read out a few points from the paper and participants were told that they could

comment on or discuss these points at any stage. This method was very successful, and the young parents started discussions about the points as soon as these were displayed to the whole group. This method also helped the researcher at the analysis stage, as some of the key themes were already written down on the flipchart paper along with descriptions and quotations from the young parents. Similar success with the use of activities in the focus group setting with young people has been reported by Colucci (2007). She describes the use of activities such as the one highlighted here as a way to collect in-depth data on sensitive subjects, by enabling the participants to feel more at ease with the focus group topic. In addition, a beneficial effect on recruitment was suggested, as the participants were more likely to recommend the study to friends when these activities were used.

Barriers to using focus groups in the London study

In the London study of antenatal experience, women were recruited from a number of different community groups and clinics throughout the hospital catchment area. Therefore it was decided that smaller focus groups of 4 to 6 participants, instead of 10 to 12 group members, would be used. However, the main problem that arose involved trying to get women from the at-risk groups to attend the focus groups in the first place. Attendance was very low for these groups, despite the enthusiasm of participants at the time of initial recruitment. On one occasion this resulted in the cancellation of a focus group for English-speaking Bengali women. In contrast, the recruitment of 'educated white' women was completed within one week. The low attendance by members of at-risk groups led the team to re-examine the recruitment strategy. On reflection, there were a number of reasons for the low consent and attendance rates.

First, women were not keen to return to participate in the focus groups because of the time constraints and childcare issues associated with this research method. They were not able to commit to attending the university for two hours because of busy schedules and the need to care for their other children. Reflections on this limitation resulted in changes to the protocol, and an amendment was submitted to the NHS REC to enable women to consent to participate at any stage after they had been given a written and verbal explanation of the study and had had time to consider their participation. This recruitment strategy was very successful and resulted in a large number of women, of all ethnic groups, consenting to participate in the study within a short period of time. In addition, recruitment rates were highest when women were asked to participate in the study by their midwife, rather than merely being given the study information to read.

Secondly, the women were deterred by the amount of time that was required for the focus groups, and by the venue. The focus groups were scheduled to take place at the university, a venue with which the women were not familiar and which was some distance from the community clinics where they were recruited. Moreover, the distance travelled by the women to get to the clinic and hospital may differ according to both level of personal deprivation and ethnicity, and this may explain the reluctance of the at-risk women to attend the focus groups. For example, in an American study, the time that it took to travel to receive health-care was significantly greater for African American adults than for white Americans (Probst *et al*, 2007). To overcome this barrier, taxis were arranged to collect the women and, where possible, focus groups were conducted in community centres that were familiar to them.

Thirdly, following on from the difficulties involved in arranging a time and location that were suitable for a whole group of women, it was decided that interviews would be included as an amendment to the NHS REC. This overcame the obstacles of location and time, as it allowed interviews to be conducted in women's homes and after their hospital appointments.

Fourthly, as suggested by Singer and Kulka (2000), incentives were introduced to thank the women for giving up their time to take part in the research, as a way to increase participation. In this instance, Mothercare vouchers were given to the women at the end of the interview to thank them for giving up their time. The women were found to respond positively to this token of gratitude, and consequently the recruitment rates for women from all ethnic groups increased.

Finally, the gender of the researcher was important to certain groups of women, and the research team had to be sensitive to this. In the London study, the necessity of a female researcher was demonstrated at several points early in the study, and was therefore adopted throughout the data collection phase. For example, the Bengali and Somali women were not comfortable with a male researcher being present at recruitment, which resulted in low recruitment rates at these times, nor were they comfortable with a male researcher making the follow-up phone call, which was seen as critical to recruitment (MacDougall and Fudge, 2001). Finally, interpretation is very important to ensure that questions and answers are correctly translated. Misinterpretations of meaning in data can occur for many reasons. A bias may arise due to the motivation of the interpreter or to differences in dialect. This was the case with the Bengali and Somali women. In the cases where the interpreter also recruited the women, several leading questions were evident during the interviews, despite the fact that training

had been given. A similar finding has been reported by one of the authors in a previous study (Richens, 2003).

Conclusion

In conclusion, research with at-risk populations is essential if inequalities in maternal and fetal outcomes are to be addressed by maternity care. Qualitative data collection is a suitable research method for applied research, as it produces detailed and descriptive data on the views and experiences of the sample. However, engaging at-risk samples in qualitative research is a challenge to researchers, and involves a greater investment of time than research with other populations. Researchers must understand the cultural and environmental needs of their target group and use this knowledge to constantly evaluate the success of their recruitment strategy and data collection method. The process of reflexivity is vital for understanding the influence of the researcher and the research design on data collection and analysis, and for highlighting any imbalances between the participants and the current research design. We must be mindful that our views and motivations as researchers may differ from those of the individuals we are trying to recruit and the clinicians whose practice we are hoping to inform. If we are aware of these differences, we are more likely to be open to the needs of all involved in applied research and to design a successful research protocol. This was true of all the experiences of the authors as shared in this paper. In addition, researchers must be aware that in many healthcare service studies and qualitative research studies the participants are self-selected and may therefore have an extreme experience to share. Thus caution must be exercised when analysing such results.

The need to be reflexive at all stages of the research process was highlighted in this short paper. This reflexive practice enables researchers to identify barriers and examples of best practice and design, and to conduct effective and efficient research. The authors believe that researchers have a responsibility both to their study sample and to their research to explore the cultural reasons for the success and failure of their research method. They then need to share detailed information about these successes and failures, to ensure both that the evidence base for the research method grows, and that examples of best practice are available for all target populations, especially those at greater risk of adverse health outcomes. Researchers also need to find a strategy for communicating with healthcare professionals in order to ensure optimal recruitment of participants.

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CONFLICTS OF INTEREST

None.

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