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Lessons learnt from ‘real world’ research

Key words: Research, editorial, field research, lessons learnt, evidence-based midwifery

This special edition of Evidence Based Midwifery (EBM) provides a unique collection of papers illustrating the lessons learnt by midwife researchers ‘doing research’ in the real world where life is complex and human needs are palpable. The insights shared demonstrate what research is all about – challenges to be faced, obstacles to overcome, the sweet fruit of perseverance and the invaluable support from good supervisors.

A common theme addressed in the papers by Chotiga et al (2010) and Kerrigan and Houghton (2010) is one of accessing the sample population and both papers offer a profound and salutary message: ‘Do not underestimate the complexities and sensitivities of research that involves human beings... Communication across different cultures, in different languages with multiple interpreters requires personal commitment, time, dedication and perseverance.’ In addition, Chotiga et al (2010) has a novel presentation style that offers a unique frame of reference, permitting the reader access to the mindset of the research supervisor in her role as teacher, leader, expert and carer.

The inarguable value of discussion and communication between researchers coming from different research paradigms is another insight shared with us by Stenhouse and Letherby (2010). One major reflection in this paper is the concluding comment in which the authors seem to me to be alluding to the potential loss of professional and personal self in pursuit of a shared multidisciplinary team view in which ‘we’ becomes symbolic of a culmination of hidden layers of ‘negotiation, compromise and accommodation’ (Stenhouse and Letherby, 2010). The lasting effect of this reflection may pierce the hearts and minds of those who truly strive to reduce the tokenism of multidisciplinarity and team-work in order to achieve the desired and hard-to-reach ‘shared but collaborative voice’ (Stenhouse and Letherby, 2010).

Marshall et al (2010) illustrate the dimensions and properties of ‘reflexivity’ in the context of undertaking ethnographic research to explore issues of consent to intrapartum procedures. It facilitates a deeper understanding of the processes involved in the real world of field research, where the application of rigour with regard to reflexivity is complex and challenging. It offers an invaluable contribution to our knowledge about process and application of research methodology in clinical practice.

van Teijlingen et al (2010) share lessons learnt from undertaking research in developing countries within Asia and Africa, where understanding the infrastructure, culture and Hawthorne effect of the research process itself cannot be underestimated. In their concluding paragraph they offer much advice, but the last sentence echoes loudly of learned wisdom: ‘...reflect on your experience of doing research and learn from your own mistakes and those of others’ (van Teijlingen et al, 2010).

The reflection by Spence (2010) is one of those rare papers that captures the imagination and conjures images of a secret world lost and found in which the imagination plays havoc with historical information revealed, contextualised and revitalised to produce contemporaneous and synthesised data for multiple usage. The author appeared to revel in her role as field detective and used all means available to access the 50-year-old patient records and live survivors who were born ‘small for gestational age’ in Belfast during the 1950s (Spence, 2010).

Perseverance is a highly desirable trait in any researcher and the paper by Lagan (2010) demonstrates a range of challenges faced by a researcher undertaking novel technological research that posed definitive ethical, technical and methodological issues. Lessons learnt and motivations to persevere are key determinants of the overall experience.

On reflection of the overall contribution to midwifery knowledge, it is worth noting some important points: accessing vulnerable groups for what are often researcher-led outcomes is always going to be an ethically difficult decision, but the results often provide new knowledge or understanding that is meritorious in itself. The cultural and sociopolitical aspects experienced in the research field are contextually binding and cannot be detached from the lifeworld of the participants. Understanding the layers of characteristics in a given sample cannot be described without peeling back the cover and exposing the underlying vulnerability of the people concerned and this is evidenced in several of the papers presented. In essence, protecting the safety, wellbeing and identity of vulnerable participants is a major challenge for the researcher and the supervisor. No amount of forward planning or research training can prepare the researcher for the messiness of real life, in which multiple factors merge and mesh to seal the fate of individuals.

In conclusion, this special edition of EBM offers a wealth of knowledge gained by the researcher in the field of real world research where access, communication, culture, history and ethics are plaited to provide an elaborate and intricate understanding of the research process in action.

References


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© 2010 The Royal College of Midwives. Evidence Based Midwifery 8(1): 3
Including marginalised groups in maternity research: the challenges for midwives

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This research was conducted with funding from Johnson's Baby, Liverpool Women's NHS Foundation Trust and a RCM Mary Seacole Development Award. The authors would like to thank Lisa Baker and Tina Lavender for their supervision and guidance throughout this work and particular thanks must go to the link/community workers and community midwives who assisted with this project and to all the women who gave up their time to participate.

Abstract

Aim. This paper presents and discusses the challenges faced during a qualitative research study, exploring women's views on the information provided during pregnancy. The research was conducted in a large NHS Trust in north-west England.

Findings. A total of 54 women who had recently used local maternity services participated in focus groups held across the city. Several problems in gaining access to women's views were encountered. The success of the study depended on effectively resolving these issues. The challenges included identifying a wide range of participants, communicating with women who do not speak English and obtaining written consent.

Conclusion. The research was successfully completed by recruiting women in a range of community venues, working in partnership with a number of local organisations and by utilising available interpreting services.

Key words: Maternity services, pregnancy, information, research challenges, marginalised groups, language, consent, evidence-based midwifery

Background to the research study

The inspiration for this research came from a desire to improve women's access to information during pregnancy. The purpose of the project was to enhance the information women receive on pregnancy, birth and local maternity services in order to improve access to maternity care and women's experience of services. Earlier research and a local audit identified shortfalls in current information provision. Many women were not aware of all services available to them and many wanted more information on specific aspects of care, including the different places available for birth, how to access antenatal education and how to contact a midwife (Houghton et al, 2008; Baker et al, 2007).

The study area presents many challenges relating to the literacy skills and languages used by the clients accessing maternity services. The NHS Trust is located in the heart of a large, culturally diverse city, serving approximately 8300 women each year from a wide variety of social, cultural and religious backgrounds. In 2006, approximately 12% of women receiving maternity care at the Trust were from ethnic backgrounds other than white. An audit by the local primary care Trust (PCT) (Adebayo and Mitchell, 2004) demonstrated that patients within the PCT spoke 82 different languages, with 48 different languages being read. The study area also includes some of the most socially deprived wards in England (Communities and Local Government, 2007). This may also suggest lower levels of literacy within the population. Providing information to women in alternative ways could therefore improve women's access, uptake and satisfaction with maternity services and meet women's information needs with greater efficacy than other methods.

This research study was designed to explore local women's views on the information provided during pregnancy, with the overall aim being to develop services in accordance with the views of service users. A specific objective was to improve the quality of information for women from marginalised communities, therefore women from a wide variety of social and ethnic backgrounds were included.

Relevant literature

Recent government recommendations state that maternity services should ensure that comprehensive information is available to all women in a variety of formats (Department of Health, 2007). A national survey of women's experiences of maternity care (National Perinatal Epidemiology Unit, 2006) identified aspects of antenatal information that could be improved, such as information about accessing antenatal care, attending antenatal classes and screening procedures. Earlier work also demonstrated that not all pregnant women were aware of all the maternity services available to them (Lavender et al, 2000; Houghton et al, 2008).

Information in maternity care is available in a variety of formats, including leaflets, booklets, video and interactive multimedia. A number of studies have evaluated a variety of methods of information giving in maternity care (Khoury et al, 2002; Browner et al, 1996; Hewison et al, 2001; Kinzie et al, 1993; O'Cathain et al, 2002). However, little attention has been given to exploring and integrating women's views in the development and implementation of these methods.

The challenges that can be encountered when recruiting vulnerable or marginalised groups to research have been previously documented (Smith, 2008; Murphy et al, 2004; Mkandawire-Valhmu, 2009). Smith (2008) suggests that social circumstances, such as low income and poor literacy skills can be barriers to becoming involved in research, and understanding language and vulnerability can significantly impact on the
consent process and may ultimately lead to the exclusion of some groups. Mkandawire-Valamu et al (2009) acknowledge how low socio-economic status, racial differences and power differentials between researchers and potential participants can negatively affect the attainment of informed consent.

The aim of the paper is to highlight the challenges facing midwives when conducting research that includes marginalised groups.

Description of experience
A qualitative methodology using focus groups was utilised. The researchers visited a number of local children’s centres and community groups and women who had used the maternity services at the NHS Trust within the last 12 months were given written information about the study and invited to participate. The research was carried out in community venues, including some of the most deprived and affluent areas of the city. Existing groups of women were specifically targeted, including teenage mothers, women who did not speak English, women living in the most deprived areas of the city and who had recently moved into the area, such as asylum-seekers. Information was distributed by the researchers with help from health visitors and local community workers. Link workers from the Trust also agreed to assist in the distribution of project information to women who did not speak English and assist the research team in exploring the women’s views.

It was initially felt that it may be unlikely that mothers with young children would find time to attend a separate group solely for research purposes. The focus groups were therefore held in a separate room alongside or following existing meetings, as it was felt this would be more convenient for the women who regularly attended. This also allowed women who did not wish to participate to opt out of the focus group. Advanced notice was given as to when the focus groups would be held. Where women spoke languages other than English, several women who spoke the same language were invited to attend, in order to encourage participation. Before each group began, time was taken to reiterate the purpose of the research, what the research involved, the voluntary nature of participation and that confidentiality was assured. All participants were asked to sign a written consent form after an opportunity to ask the researchers any questions. The researchers expected this process to be challenging with women who did not speak English, so interpreters who were peers within that community were recruited to facilitate effective communication between the researcher and participants. The focus groups were audio-recorded and brief notes on the content of the discussions were taken.

Discussion
Engaging women in research – a process of adaptation and change
Service users/research participants from more deprived areas and women who do not speak English can find it more difficult to engage with health professionals and researchers (Lockey and Hart, 2007). Considering the nature of the potential research participants, some problems were anticipated. These included identifying and including a wide range of women to participate in the research and communicating with women who do not speak English. However, while conducting this research further difficulties were encountered and the success of the study depended on the effective resolution of these issues. These are presented below.

Community venues
Recruitment was originally planned to take place from existing groups in the newly developed children’s centres. At the time, most children’s centres were located in areas of high social deprivation and it was thought that this would ensure involvement of women from a variety of social backgrounds. However, while undertaking the initial focus groups, it was felt that the small number of women who accessed the weekly structured groups, like ‘tea and toast morning’ and ‘stay and play’ were already well informed about local maternity care services and were highly motivated to seek out information and access community services. Many women would travel between the centres to access several groups of their choice. The views of these women were obtained and were invaluable; however it was felt that a wider sample was needed.

At this time, children’s centres had only recently been established and being a relatively new innovation, it was felt that it may only have been well-informed women that were aware of them. A proactive approach is recommended when wishing to involve marginalised and vulnerable groups in research (Smith, 2008), therefore other ways of obtaining women’s views had to be considered, in order to obtain a more inclusive sample. Baby clinics were well attended by a wide range of women and appeared a more appropriate forum to engage with women who had recently used local maternity services. The initial plan was to attend the baby clinic one week and hold the focus group the following week, allowing enough time for women to decide whether or not they wished to participate. Although the clinics were busy and well attended, women did not attend every week. This problem was identified and an effort was made to attend the baby clinics on several consecutive weeks, with the focus groups planned several weeks in advance. This allowed as many women as possible to be informed about the planned research and have an opportunity to attend the focus groups.

Involving women who do not speak English
Each week, the Trust held an antenatal ‘link clinic’, that was attended by women who do not speak English. Link workers who assist with interpretation and support at the clinic are loaned to the hospital by the local PCT. In view of their close links with the community, the link workers were asked if they would assist with the recruitment of women who do not speak English and the majority were agreeable. The link workers and some community midwives assisted in arranging meetings with Somali, Arabic and Polish women. Initially, the Somali women requested payment for their participation in the research, stating they had previously received payment for participating in research. However, as we had already conducted focus groups with other women and had not provided any payment and it was not stipulated on the ethics agreement that payment would be made to participants, it was
considered inappropriate and unethical. The situation was explained and a small number of Somali women agreed to participate if the group could be held locally, with a nice lunch and special cakes provided. To acknowledge the value of this group’s contribution to the research, the researchers agreed to provide this small gift.

Research incentives and gifts are acceptable as long as they are approved by an ethics committee, however, the value of the gift can pose an ethical dilemma for the researchers. An expensive gift has the potential to be viewed as coercive, whereas a gift of low value could imply the researchers view the contribution to the research to be of little value. It is recommended to specifically tailor gifts to the population of participants (Mkandawire-Valhmu et al, 2009).

Accessing women who spoke French and the Chinese dialects proved more challenging. No link workers or community midwives were able to assist with this, due to time constraints of current workloads and an absence of any formal community groups for these women. To overcome this, the help of a local community worker who works with women seeking asylum was sought. Her work is predominantly based in a local church hall and involves regular, informal social meetings where support and companionship is offered. With her assistance, two very successful focus groups with women whose first languages were French, Mandarin or Cantonese were held.

It is suggested that using a professional who is already well known to a group to act as mediator is particularly useful when recruiting marginalised groups into research, as it helps establish contact and trust between the researchers and participants (Wright et al, 1998). The researchers’ experience of working with the local community worker supports this. The groups were held in the church hall and Chinese and African women from within the community who spoke English volunteered to act as interpreters for the purpose of the groups. However, during the focus group discussions, often several dialects were being spoken concurrently, making conducting the groups a complicated and lengthy process. The researchers ensured that each woman had an opportunity to speak and enough time was allowed for interpretation. This gave the researchers valuable insight into women’s experiences of needing to rely on an interpreter to communicate and the difficulties they can face when they access local services.

Obtaining consent
When conducting ethically sound research, the provision of informed consent acts to protect potential research participants. It is recognised as an essential component of the research process (National Research Ethics Service, 2009). It requires that potential participants are provided with clear and comprehensible study information, a period to consider the information and opportunities to ask questions before deciding whether or not they would like to be involved. Obtaining formal written consent is usually the final stage in this process. Stevens and Pletsch (2002) suggest, however, that current ethics procedures that require detailed information sheets and consent forms, negatively affect the consent process, shifting the emphasis away from clarity and understanding the information.

It was important that women who most often experience communication difficulties during maternity care were included in this research. To engage these women in the project, a considerable amount of effort was required to ensure attention was given to all of these important steps in the consent process. The process for obtaining consent and the ethics surrounding this have been acknowledged as a barrier when including vulnerable groups in research (Smith, 2008). Mkandawire-Valhmu et al (2009) specifically identify low socio-economic status and racial differences between researchers and potential participants as factors that can negatively impact upon achieving informed consent.

To communicate details of the study, information sheets were produced and disseminated to each potential participant. As the written research information sheet was produced in English only, this highlighted a definite power difference between the researchers and potential participants who did not speak English. Mkandawire-Valhmu et al (2009) discuss how power dynamics can significantly affect the process of informed consent. Producing information sheets in a range of languages may have helped address this, however, women in the study area communicate in such a wide variety of dialects this would have been an insurmountable task. Translating into a few may have discouraged participation from women who read other languages. Additionally, it is not possible to translate some spoken languages into written format at all. Furthermore, some women may be able to communicate verbally in a language, but may not be able to read it. For example, some African women were able to communicate verbally in French, however, most of the women would have been unable to read or write in French. Providing written research information would not have overcome these difficulties.

The views expressed by these women provided unique and invaluable insight into the communication problems they face. Excluding these women from participating in the research was considered unethical. In order to facilitate inclusion, the study information was provided to all women in written English and translated into their spoken language by interpreters. This was an effective way of ensuring informed consent, but made the process very time-consuming.

The need to obtain written consent to participate in a ‘discussion’ was also something that was not familiar to a number of women who wanted to participate. Women were cautious about signing documentation that they could not read. In order to overcome this, a significant amount of time was taken to explain the need to obtain written consent prior to undertaking research and why this is necessary. Murphy et al (2004) suggest that it is imperative for researchers to adapt and translate research information to meet individuals’ language and understanding capabilities and allow informed consent. The researchers ensured that every woman clearly understood the purpose of the project and what participation involved, before the consent form was signed. This often meant reiterating the information a number of times, translating the text on the consent form verbally into their own language with interpreters, and asking each woman individually if she had any specific questions or anxieties regarding the focus group or about signing the research consent form.
There is an abundance of guidance available on the principles of obtaining informed consent during research and clear advice available for researchers when obtaining consent from adults without sufficient mental capacity or from children (National Research Ethics Service, 2009). There is however no advice available on how to translate these principles when engaging with non-English speaking research participants. The research governance framework (Department of Health, 2005) simply states that consent should be sought in the way agreed during ethical review. Murphy et al (2004) concur with this, stating that the elements of informed consent are widely acknowledged, but their translation into practice is not easily achievable. Further guidance is required in this area and researchers should develop innovative ways of ensuring consent is truly informed. These could include exploring the possibility of audio-recording verbal consent to avoid asking participants to sign consent forms they are not able to read.

The obstacles to participation in this project were successfully overcome. A wide variety of women’s views were obtained by accessing a range of community groups and although the process of consent was more time-consuming than originally envisaged, ultimately all women were able to comprehend the research and gave consent to participate. No women had to be excluded for this reason. However, in view of the current standards for obtaining written consent from research participants, a permanent solution to the anxieties this process created will be difficult to find.

Conclusion
This paper has presented the difficulties and challenges encountered while undertaking qualitative research with previous maternity service users. The research aimed to explore views of maternity information and ways of improving it. In order to obtain the views of women from a wide variety of social and ethnic backgrounds, the research was conducted in a number of community venues. A proactive approach was used to address the difficulties faced when accessing a wide range of women’s views as recommended by Smith (2008). Conducting the research alongside existing community groups, collaborating with community workers and health professionals and involving interpreters proved to be effective. Overcoming language barriers and acknowledging the impact of potential power differences between researchers and participants prevented women who do not speak English from being excluded from the research.

Overcoming the barriers in accessing the views of women from a variety of social and cultural backgrounds requires a proactive and determined approach. Researchers wanting to target specific groups should be prepared to go out into the wider community to identify potential participants, acknowledging that this may be more convenient and acceptable. Using a person already known to a particular group to act as a mediator is recommended and consideration should be given to the development of innovative ways of working, including the use of novel methods of ensuring truly informed consent is achieved.

References
Researching with hard-to-reach groups: working with Burmese migrant women in Thailand

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Abstract

Background. This reflective paper describes the experiences of a novice qualitative researcher collecting data into the experiences of Burmese migrant women in the Thailand-Burma border areas.

Aim. It demonstrates the research process journey and aims to inform researchers intending to do research with participants who are classified as voluntary people.

Method. The paper reflects on the experience and lessons learned conducting qualitative interviews in the field.

Issues arising and conclusions. Sensitive issues such as being labelled a migrant were recognised, along with limitations in language and communication and time restrictions when doing research with vulnerable women. To help access and interview hard-to-reach groups effectively, consideration should be given to sensitivities surrounding social status and language used in the research field and ways to enhance their sense of empowerment and value.

Key words: Hard-to-reach groups, Burmese migrant, vulnerable participant, research reflection, accessing, interviewing, evidence-based midwifery

Background

This paper is a reflective account of the experiences and lessons learned during the first author’s PhD study of Burmese migrant women’s access to antenatal HIV screening services in a northern part of Thailand. A qualitative study aimed at exploring the healthcare experiences of these women while pregnant, in relation to a programme for the prevention of mother-to-child transmission of HIV and their reasons to either accept or refuse testing and/or anti-retroviral prophylaxis.

The study was conducted among 38 Burmese migrant pregnant women in the Thai-Burmese border provinces during 2008 and 2009. With its high rate of HIV infection and high numbers of Burmese migrants, this area was selected in order to access the desired group of participants.

The aim in sharing these experiences is to enable other researchers planning on accessing vulnerable migrant groups, whether in the UK or in other countries, to consider some of the issues that I encountered and enable them to learn from my experiences.

Research supervisors’ comment

Before entering into the research field, Pleumjit had not really considered how complicated it would be to conduct her research among these participants. She was very optimistic and considered that as a woman who had worked with the migrant women in the past as a healthcare worker, she could overcome most problems with comparative ease. Finch (1993: 167) states that ‘women are almost always enthusiastic about talking to a women researcher’ and Hofman (2004) similarly supports the view that women are most comfortable when being interviewed by another woman. Moreover, Pleumjit was used to working with women, both as a healthcare worker and as a college lecturer in midwifery and nursing. Finally, she had been aware from discussions with local healthcare workers that there were large numbers of Burmese migrant women in her chosen settings and thought that it would be easy to involve them in her study.

Identifying research participants

I want to begin by describing the confusion I faced in identifying the potential research participants. I sought to identify and interview migrant women on the Thai-Burma border areas. But once in the field, it became clear that they did not form a homogeneous group. I concluded that there were four groups of Burmese migrants that I came into contact with. These were:

- Legal migrants – they comprised a large proportion of the study participant group. They or their husbands held permits allowing them to work in Thailand. It also included migrant women holding registration documents stating their legal status to be in Thailand
- Illegal migrants who came to and stayed in Thailand without any registration documents
- Burmese people who came and stayed in Thailand solely in order to use the Thai health service. They wanted the better health care on offer for pregnant women in the antenatal period and the hospital facilities for birth, and preferred to pay for the full cost to access this care. I named this group as ‘visiting migrants’
- Women staying in refugee camps (refugees).

With these groups of women, I experienced various responses when I asked them to become involved in the study. The ‘illegal’ women were uncertain about whether they should talk to me. They feared that if their presence and identity was revealed, they could be deported back to their home country. The political situation in Burma is difficult and discussing it is beyond the scope of this paper. Repeatedly making reassurances about confidentiality was therefore central to ensuring the cooperation of participants coming from this group.

While the other migrants had decided for themselves to be given the information about my study, the refugee women were prevented from doing that. They were accompanied to the antenatal clinic where recruitment took place through their refugee camp ‘guardian’, and I was told that I had to ask for permission
to recruit and interview these women from the refugee camp director. I attempted to make contact with the camp director, both directly and by email to ask for permission. Unfortunately, the permission to interview these women was refused without stating a reason. In addition, according to the political and legal situation, refugees have very little rights to take part in research or outside activities by themselves (Jacobsen and Landau, 2003) and their individual rights to be a research participant were not clearly defined (Leaning, 2001).

Research supervisors' comment
The issues mentioned above highlighted the need for any researcher to be very clear about their sample population, in this case ‘Burmese migrants’ and to seek out the secondary unexpected permissions required before they enter into the research field. In Pleumjit’s case, a good understanding of the concerns about deportation of undocumented migrants was also required.

Accessing potential participants
The community healthcare workers in each setting gave permission to access women and staff in the antenatal clinics. Accessing potential participants was a challenge as I was an outsider and had few clues to help me identify these women. The healthcare staff helped to identify those women who were eligible to take part. They also informed the women about the study before I approached each to explain the study and seek their consent. Although none refused, there was a range of reactions.

I still remember the sight when I entered the antenatal clinic waiting area, there were no smiles from the women and I felt like a Thai migrant woman among Burmese women. They were watching me attentively and, after the healthcare worker introduced me to them and explained what I was planning to do, they immediately avoided looking at me.

There was no readily available database that I, as a researcher, could access to identify their Burmese nationality and their ability to communicate in Thai. Most potential participants were identified as being Burmese on the outpatient database, as their Burmese names differ from Thai names. On other occasions their nationality could be determined from their dress and face make-up as these Burmese women had their own specific characteristics. While Thai women in these areas wore the modern dress with trousers or skirts, the Burmese women usually wore sarongs and they still used the traditional cosmetic made from sandalwood known as Thanaka. If I saw a woman who had the big circles of smeared (yellow) Thanaka on her cheeks, I could predict that she was Burmese. And to classify Kareni, one of the Burmese minority ethnic groups, they usually wore many necklaces, a practice known in Thailand as ‘Burmese neck elongation’. I have learnt about these women’s characteristics mainly from my own observations when I lived and worked in the Thai-Burma border provinces.

Moreover, I had no idea of how many potential participants could speak Thai fluently. In the first research setting when I contacted each potential participant by asking the question ‘Can you speak Thai?’, many of them immediately shook their head to indicate that they could not. But nurses who cared for them usually indicated that they could speak in the language and sometimes they sent to tell these women, who had already refused to speak Thai to talk with me. They tended to trust healthcare workers who cared for them and who were familiar to them. At that time, I felt uncomfortable and thought that they might feel embarrassed because they already had lied to me or perhaps that the health workers were in some way coercing them to take part. I could only smile and start to talk with them carefully. Fortunately, after I explained the objectives and details of my study, most of them appeared more comfortable and some of them were clearly interested in talking to me. However, not all women showed reluctance and some were keen to speak to me at the first meeting. I drew on my previous experiences as a midwife in order to put the women at ease so that they realised I was not a threat to them. This is an important aspect of qualitative research that should not be underestimated. Importantly, gaining trust from participants is needed when doing research with a vulnerable and hard-to-reach population (Lampertong, 2007).

Research supervisors’ comment
The problems mentioned above indicate that when doing research with ethnic migrant groups, consideration needs to be given about how to identify and contact them as potential participants. Researchers should spend enough time in the research field to become a familiar sight, in order to gain the trust of those they are planning to invite to participate. Assistance from local care workers was essential for Pleumjit, but their role in recruiting had to be clearly defined to prevent coercion and to ensure that participants understood the voluntary nature of taking part.

Before beginning interviews
Nearly half of the women had not been educated in formal school, although some had been educated in refugee camps. Most of the rest of the respondents who had been educated, graduated only at primary school level and only some had studied or learned to speak the Thai language. Therefore, most of the women were illiterate in both Thai and their own language. For ten participants who stated that they were literate in Thai or could read Thai, only half of them were literate in their own languages.

Informed consent must be written in clear and simple language that may be readily understood by potential participants (Marshall, 2007). Therefore, I prepared the consent form and information sheet in Thai and Burmese and wrote them in the simple language suggested by the Faculty of Health Research Ethics Committee at University of East Anglia (reference number: 200727). I also arranged a version for potential participants who could not read, so that it could be read to them.

During this stage, I found that most of them were illiterate in both Thai and their own language. Only seven women could accurately read the Thai consent form and information sheet and there was only one of the 38 women who recognised some written words in the Burmese version. This was because most of them were Tai Yai, a Burmese subgroup, and not Bamar-Burmese which is the largest single ethnic group in Burma. There are more than 100 different ethnic groups and sub-groups in Burma (Ekeh and Smith, 2007). As a result, I needed to read the Thai information sheet and consent form to most women. They could understand spoken Thai more readily.

After reading out the information sheet and asking for
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Chotiga P, Crozier K, Pfeil M. (2010) Researching with hard-to-reach groups: during the study. It is important to consider that interviewing thinking about the response was something I came to learn whether at all and then how to answer it. Understanding whether a pause meant a lack of understanding or whether they were thinking about the response was something I came to learn during the study. It is important to consider that interviewing women in a language that is not their first language can take more time.

Although these migrant women could speak Thai, some of them could not understand some words related to the study. As Fontana and Frey (2005) point out, researchers need to clarify questions and adjust to communicate with participants even if they are fluent in language used in the interview. Consequently, for these women for whom Thai is not their first language, I had to spend time clarifying the definition of many words, such as ‘voluntary’, ‘experience’ or ‘development’. Hence, different approaches to asking the questions were required by using simple words or extended sentences to define and clarify. For example, I used ‘make it better’ instead of ‘development’.

Many participants also asked how they could answer the questions. They were always uncertain about whether they gave the ‘right’ answers. The pauses could affect the time set aside to conduct the interview and decrease participants’ confidence to reveal their thoughts. This would influence the quantity and quality of the data collected. Nevertheless, giving them more time and hospitality to explain and waiting for the answers helped to gain more significant data in greater depth and allowed experiences to be revealed by the women who had communication limitations.

Unfortunately, most of these migrant women, especially those who had been in Thailand for a few years, feared to give many comments or suggestions about being in Thailand and the healthcare services.

Having finished each interview, I always summarised what I had been told by them. None of them made any comments or raised any questions about these brief summaries. I did therefore wonder whether they had fully understood what I had said or whether they just wanted to finish the interview as quickly as possible. Perhaps they did not know the benefits of hearing what they had said once again.

With over 100 ethnic groups, there were not only the problems with languages, but also with conflicts among the different ethnic groups. Because of an ongoing conflict between the rebel Shan State army and the Burmese government army (Ekeh and Smith, 2007), most participants who were Tai Yai from Shan state, the largest minority ethnic groups of Burma, did not like to call them Burmese [Bamar]. They said that they were not Burmese, they were Tai Yai as the conflict between their group and the Bamar-Burmese forced them to immigrate. Being aware of this conflict was important. To secure the cooperation of these Tai Yai migrants, I carefully used the word ‘migrant’ instead of ‘Burmese migrant’. However, the word ‘migrant’ also made some Burmese women feel like strangers or outsiders. Moreover, I needed to avoid using words such as ‘alien’ or ‘refugee’ and I adopted the phase ‘being Tai Yai’ or ‘foreigner’ when talking with them, because they found this more acceptable. This raises my concerns about labelling people.

Time limitations were an issue when interviewing these women due to many of them or their husbands needing to go back to work as soon as possible. The journey to hospital usually took them a long time and some of them had to take time off work. The faster they were able to go back to work, the less earnings they were to lose from their wages. Thus, I needed to carefully and accurately manage the queue and interview time.

Research supervisors’ comment

Polit and Beck (2007: 176) state that informed consent means that ‘participants have adequate information regarding the research, are capable of comprehending the information and have the power of free choice’. But Pleumjit had to question the potential participants’ ability or capacity to make the decision to participate in the study. She could not always be fully certain of their understanding and perception of their right to withdraw from the study. It appeared that the decision of many women to become involved was not dependent on their understanding or their willingness to join, but on the trust they developed towards the healthcare workers or the researcher herself. Others also relied on their husbands to whom they wanted the information about the research to be repeated.

The difficulties with the refugee camp heightened her awareness of political issues influencing the research setting and the people within it.

Pleumjit learned that when recruiting or talking with potential participants as a researcher, she must examine their ability to communicate, to speak and to understand.

During the interviewing

Some difficulties arose during the interviews due to language difficulties and limitations in some participants’ ability to communicate, a lack of confidence on the part of large numbers of women and hidden issues that they were reluctant to discuss. Most of all, I was faced with difficulties in gaining access to the private lives of these women. Although Finch (1993) states that women participants are more willing to talk to a woman researcher and most women are more likely than men to talk about their private life, asking these women about their family or spouse was very complicated. They always appeared uncomfortable talking about their family lives and marriage.

In some women, especially those who were illegally staying in Thailand, there were difficulties and it took more time to get the details of their private lives in relation to HIV/AIDS issues. Unexpectedly, the women who were HIV positive disclosed their experiences openly. On reflection, this may have been because they assumed that since I was working with the healthcare professionals, I would be aware of their HIV status.

I also faced periods of silence during interviews. These silences were related either to not understanding the question or because the women were considering whether they should answer at all and then how to answer it. Understanding whether a pause meant a lack of understanding or whether they were thinking about the response was something I came to learn during the study. It is important to consider that interviewing
Considering interviewing them at their accommodation or in their ‘after-work time’ could be more convenient for them, but safety issues as a lone researcher prevented this.

Finally, the nature and expectations of this group of women meant that interviewing them was generally easy, because they did not argue and they did not refuse to answer any questions. However, in order to be successful I needed them to tell me about their opinions, feelings and experiences. I therefore had to constantly reassure and encourage the women to explain what they thought, and not what they assumed I might like to hear. This was a new concept for many women, whose opinions had been all too often ignored.

Research supervisors’ comment

Assumptions during the planning phase of a research project are always problematic. Pleunmit learned quickly that what was meant to be easy, that is speaking with women as a female researcher, did not turn out to be the case. At least not as much as she had expected. On the other hand, the assumed problematic issue of the participants’ HIV status posed few problems during the interviews.

‘Pliable’ interviewees do initially seem easy to interview, but the data they deliver will frequently be of poor quality, not reflecting their own thoughts. Pleunmit had to invest considerable time to build up confidence, explain why their opinions, even their feelings were of value. This extra effort required considerable time, but resulted in a rewarding harvest of revealing data.

The problems in recruiting and interviewing resulted in delays in the data collection phase. In our experience, novice researchers frequently underestimate the time data collection will take and, in this aspect, their research schedules often need revising.

Conclusion

Three significant issues related to doing research with or caring for migrant women became most apparent. These issues apply equally to clinical practice as they do to research.

First, limitations in communication are a major source of difficulties. This problem could occur during the provision of research information, when asking for consent, and during the interviews. The participants’ inability to communicate can be expected to be most prominent when a variety of languages are spoken or when the potential participants are illiterate. As a result, any researcher should be aware that migrants from countries composed of various ethnicities do not necessarily share a common language. The communication challenges also lengthen the time spent in sharing information and allowances should always be made for this.

Secondly, most of the migrant women (especially those who were only briefly in Thailand) appeared to be rather passive, enduring the adversities of their lives. They had never asked questions or raised any issues or concerns during the interviews. Their decision-making also depended on other outside factors. The reasons that they became involved in the study might have been due to the healthcare workers’ direction, their husbands’ agreement or following the lead of the other participants. This demonstrates that these women could hardly be called empowered. Therefore, the needs of participants who lack empowerment and mechanisms to support them should be considered in any research project.

Finally and significantly, the sensitivities with being a migrant in a foreign country are an important factor throughout the research. Being labelled as ‘migrant’ or other similar names can make participants uncomfortable or even feel threatened. Taking this into account and asking them about it, could reduce the frustrated atmosphere during the interviews and enable them to trust the interviewer enough to reveal information. Moreover, enabling them to feel as hosts in their world into which the researcher enters, could encourage them to reveal more insights and information as well as increase their sense of value. This is of course difficult when the interviews take place outside the participants’ own home environment.

However, enabling them to be comfortable enough to express their views and opinions is about gaining trust and this relates to specific skills of qualitative researchers. Our own lack of understanding of certain groups is usually the starting point for a research study and it is only through taking slow, painful steps through the difficult stages of gaining trust, learning something about the research participants, and gathering data followed by careful analysis that lessons can be learned. The way in which situations arise in the field and are dealt with by individual researchers must be shared to enable others to start from a more advanced point when carrying out research.

References


Lessons learnt from undertaking maternity care research in developing countries

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The authors would like to thank all local researchers and research participants who have helped to improve their studies in countries of the South. Special thanks to Dr Emma Pitchforth from the London School of Economics and Political Science for allowing us to share her Bangladesh experience.

Abstract

Background. Doing research in developing countries (so called Third World countries, the South or the developing world) brings with it its own challenges. There are a number of lessons to be learnt from conducting maternity studies in developing countries, encompassing issues around the best ways to plan, organise and conduct such research. Some of these lessons are related to the infrastructure and culture in developing countries, some to the research process itself and others to research outcomes.

Aim. The authors of this paper have all conducted research in developing countries in Asia and Africa, and reflect critically on their various experiences.

Findings and conclusions. They highlight the problems and potential solutions around translations and translators, difference in expectations between researchers from the North (developed countries) and the South (developing countries), and the need to be sensitive to local cultural and social needs. The paper concludes with some advice and key principles to pave the way for better and fairer maternity care research in the developing world.

Key words: Third World, developing countries, cultural sensitivity, research ethics, exploitation, reflections, evidence-based midwifery

Background

Globalisation impacts on many aspects of our lives, including that of midwifery and maternity care research. Globalisation is a set of global processes that are changing the nature of interaction between people across many social, economic, political, cultural and environmental spheres (Lee and Collin, 2005). In short, the world has become a smaller place. One can travel with greater ease and speed to many parts of the world than ever before. Information travels faster too, thus events that happen far away in a developing country are now on our television screens in London, Amsterdam or New York within hours, minutes and often live!

At the same time as this globalisation process is taking place, there is a stark gap in research capacity between the developed countries, known collectively as ‘the North’, and developing countries ‘the South’ (Nationmaster, 2010). Some people try to reduce this knowledge and research gap and support the growing interest in North-South research partnerships for carrying out research in developing countries (Edejer, 1999). A growing number of people are engaged in governmental and non-governmental organisations (NGOs), all working to improve the health and wellbeing of pregnant women and their offspring. The readers of Evidence Based Midwifery will be familiar with initiatives and organisations such as Safe Motherhood, United Nations Children’s Fund (UNICEF), the White Ribbon Alliance for Safe Motherhood, Oxfam, Voluntary Service Overseas (VSO) and the UK counterpart The Peace Corps. Many of these initiatives originate from or are (partially) run by organisations from the developed world. Such alliances between the North and South can easily lead to cultural misunderstanding due to having different expectations or simply because of different ways of seeing the world.

The three authors have all been involved in community-based studies in different countries in Africa and Asia (Bangladesh, India, Ethiopia, Zimbabwe, and Nepal) over the past 15 years. Although we like to think of ourselves as open-minded in our roles as applied and qualitative maternity-care researchers, as researchers who are sensitive about the people and communities we study, we do not always get it right. However, we have found a number of common issues relating to conducting maternity-care research in a developing country that need to be considered, or of which we have at least to be aware. These issues need continual attention to ensure we conduct the best research that is most appropriate for the local situation and that helps to improve the lives of the poorest women and their families worldwide. Some of these issues are part and parcel of the problems that hinder healthcare research in developing countries, which are complex, interrelated and often poorly understood (Abu-Zidan and Rizk, 2005).

In this paper, we reflect on a number of common issues that arose during our research. Some of these issues are more or less unique to most kinds of work (that is, not just research) in a developing country, or to one specific developing country. Others could easily have arisen during research
projects conducted in countries in the developed world, but because of the specific situation in a developing country, the impact or outcome is much greater or simply differs. Another way of distinguishing between the various issues is that some occur at the micro level, that is they relate to the individual researcher or research team, while other issues relate to the macro level of relationships between the developed and developing world – globalisation and exploitation.

Being sensitive to different cultures
Readers can accuse us of stating the obvious when we highlight that one key lesson from our international research is that researchers must be sensitive to the local culture of the study population. Most people doing research in developing countries believe they are aware of this, but it is not until you start working in a developing country and make mistakes that you realise that perhaps you are not as culturally sensitive as you thought. Three examples of cultural misunderstanding that occurred in Nepal highlight this point.

The first example relates to money, something that always has the potential to cause problems. The UK research team was funded by a London-based Buddhist charity, Green Tara Trust, to help design, implement and evaluate an intervention aimed at improving the uptake of antenatal care in a number of rural villages in Kathmandu Valley. This charity requires an account of how its money is spent, for reasons of transparency to its donors as well as under British charity legislation, which requires accountability for funds used. Our Nepalese collaborators became upset when the UK research team asked for a detailed account of their spending on the research project. A system of financial checks and balances is part of everyday life in the developed world, in some developed countries asking people to justify their expenditure and produce receipts gives out the message that you do not trust someone, and in a society where personal contacts and trust are interwoven, this can damage research collaborations.

The second example is more general around timekeeping and notions of punctuality. The relative importance of these issues varies between countries. The researchers learnt to ask whether a meeting in Kathmandu at 9:30 was to be held at Nepalese time (perhaps 30 minutes late) or British time (maximum five minutes late). Even knowing this, the UK researchers occasionally found it frustrating that they ended up doing nothing for long periods of time, waiting for collaborators and participants to turn up.

Thirdly, the way in which participants have completed research questionnaires in Nepal is interesting. In Nepali the symbols X (a cross) and ✓ (a tick) have different connotations (Simkhada et al, 2006). A cross is associated with a negative answer and a tick with a positive one. A usual questionnaire instruction in English is ‘Please tick one of the boxes’, or ‘Please put a cross in the box’. Because of the associated connotations with the symbols, we had to change the instructions to make it clearer to the respondents what we expected. Table 1 shows how several respondents gave both ‘yes’ and ‘no’ answers to a single question. This is a typical example from the pilot questionnaire.

Difference in expectations
The second key issue centres on expectations. Research colleagues from the North and South often differ in their expectations, those from the developed world sometimes expect unrealistic targets and those from the developing world expect that their ‘richer’ counterparts have instant access to pots of money to set up interventions and carry out research. At the same time, we are often not sensitive enough to culturally-sensitive issues, partly because no one can change culturally-ingrained notions overnight, such as the caste system, patriarchy, or the status of women in society. Cultural notions of right and wrong are deeply embedded, as the following two cases highlight.

The first case relates to researchers from the developed world being pressurised in Nepal to employ relatives of local collaborators. Traditionally, being able to help family and friends to get jobs is part of showing (claiming) one’s social status, and local researchers did not perceive that they were doing anything ‘wrong’ when they tried to discuss this issue with them.

Table 1. Examples of symbols used and their meaning by respondents in Nepal. Adapted from Simkhada et al, 2006

<table>
<thead>
<tr>
<th>Statements</th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
<th>Authors’ comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Condoms are available in every trekking area</td>
<td>✓</td>
<td></td>
<td></td>
<td>Respondent agrees. A positive answer gets a tick.</td>
</tr>
<tr>
<td>Condoms are available in every trekking area</td>
<td></td>
<td>X</td>
<td></td>
<td>Negative answer, hence a cross</td>
</tr>
<tr>
<td>Condoms are available in every trekking area</td>
<td>✓</td>
<td>X</td>
<td>X</td>
<td>This respondent agrees with statement, but answers all three options provided: ‘tick’ for yes and negative cross for no and don’t know.</td>
</tr>
<tr>
<td>If used properly, condoms can protect against HIV</td>
<td></td>
<td>X</td>
<td></td>
<td>Respondent does not know, but ‘Don’t know’ is seen as negative, hence cross</td>
</tr>
</tbody>
</table>
The second case relates the need for many first world country researchers to feel that they are doing ‘good’. On several occasions in different countries, we have been asked to help (usually by giving money) solve a health or social problem. For example, at a village meeting we found a mother exclusively breastfeeding a small child, who turned out to be five. The mother had no food for the child and the researcher from the UK could so easily have alleviated the problem immediately by offering to buy food for the day (or the week). However, such a gift would not be a long-term solution, as it would not solve the underlying structural problem of poverty and chronic malnutrition in this particular family; and would have made the research in the village much more difficult as it would open a floodgate of demands from other poor people on future occasions. Although giving some money to the woman would have given the researcher a sense of satisfaction and being charitable, it would not necessarily be the right course of action.

Thirdly, meeting people socially is even more important in many countries in the South than in the North. Developing a social bond is regarded as a key element of research collaboration. Keeping people informed at all levels is also important. In Nepal, we considered that having applied to the national health research council’s ethics committee and having spoken to the local and regional public health officials before we started a small-scale health promotion intervention was sufficient for the lifespan of our maternity-care research project. However, two years later we ran into some problems when regional officials, who had been appointed since we informed their predecessor, did not know anything about us. It was clear to us that there was no institutional memory, since the information about our research project was not passed on from the previous regional director to the new one. Thus, although we felt that the project had been well-established, we found ourselves being required to re-introduce ourselves and the project again in order to be accepted.

Gate-keepers
The third issue is that researchers are being dependent on ‘gate-keepers’ to get access to research participants. These can be government officials, local chiefs in the village, or maternity care providers. They can act as a barrier or facilitator between the researcher and the target study population. The first example here is from rural Zimbabwe.

One of us invited traditional birth attendants (TBAs) who had recently completed a four-month training course, to participate in a focus group in Mashonaland Province, Zimbabwe. Following the permission process, key people were identified and contacted by civil servants from the Zimbabwe Ministry of Health. The researcher had no idea what these health personnel had been told or how the TBAs had been selected, contacted and briefed.

She knew that it was likely that many of the TBAs had travelled some distance to attend the session and had assumed that the midwife who had kindly contacted them would have arranged a learning activity to make the most of the time. However, such was the respect afforded to the overseas researcher, that the Zimbabwean midwife had assumed that the visitor would be ‘in charge’ (too much mutual respect!). The focus group session turned into a good sharing and learning experience for all parties: local registered midwife, researcher and TBAs.

This was a self-funded student project of the third author as part of her MSc in advanced midwifery practice. There was no specific budget for refreshments. As the focus group progressed, the researcher realised just how far many of the women had travelled (up to ten miles on unsurfaced roads by a combination of walking and donkey cart and perhaps more on surfaced roads by public transport). As there were very few amenities around, she was only able to buy a crate of fizzy drinks at a road-side shack. To have provided nothing would have been inhospitable, which taught the researcher to plan for hospitality, something which we take for granted in most venues in richer nations. Furthermore, although there was an electric socket in the hall where they met to plug in the tape-recorder, the tin-roofed structure was uncomfortably hot and everyone preferred to sit outside under a large tree. Luckily the researcher had batteries for her tape recorder, but had not expected to use them. She was surprised and delighted to be included in a song and dance session at the end of the day. Researchers planning to travel overseas need to prepare for a range of conditions to prevent loss of potential data and a range of possible social activities, as refusing to take part may offend.

Research culture
There is sometimes a limited view as to what constitutes research in many developing countries. Often there is a more limited definition of good research being large-scale and quantitative. For example, a recent bibliometric review of Nepalese health research found that most papers (78%) reported using quantitative methods (Simkhada et al, 2010). Many poorer countries lack training in research methods, and there is a particularly limited qualitative research capacity.

A considerable amount of research in developing countries is conducted by NGOs, with some university staff also being involved in research activities. In Nepal, these academics often conduct research privately or through their own NGOs. The university is mainly seen as having a teaching role, which has implications for finding local research partners. In addition, our experience in Nepal is that local academics prefer writing books over writing for peer-reviewed journals. For these Nepalese academics, there seem to be few incentives to publish academic papers. This contrasts with their counterparts in the developed world.

Research process
There are several factors that can make the process of doing research more difficult in developing countries. The first example relates to the key issue of having to rely on translators. The second, third and fourth example relate to obstacles to doing research, which we do not really consider in the developed world.

It is widely recognised that translating from one language to another brings with it linguistic as well as cultural issues (van de Vijver and Leung, 1997). What is perhaps less well recognised...
is that there can be a range of issues related to the status, role and expectations and beliefs of the translator (Pitchforth and van Teijlingen, 2005; Kirkpatrick and van Teijlingen, 2009). In Bangladesh, one of us supervised a Scottish PhD student who used a local translator to help her interview women in the largest public obstetric hospital in the capital Dhaka. The study was based on the common translation model whereby the translator is in a traditional passive role. In other words, he or she would translate the researcher’s question and then wait for the interviewee to reply and translate this reply to the researcher. This introduced tensions into the research interviews and was burdensome for all involved. Hence an alternative ‘active interpreter’ model was adopted, whereby the translator asked the question in Bangla, got a response from the interviewee and then asked the next question. This created a more natural flowing research interview. The UK researcher would then occasionally get a short summary of what had been said between topics. This approach overcame the problem of the artificiality of the constant translating after each sentence, but effectively it meant excluding the researcher for part of the interview (Pitchforth and van Teijlingen, 2005).

In any prospective cohort study (more commonly known as a ‘before-and-after’ study), it is important to follow-up as high as possible a proportion of the population initially studied. There can be unexpected difficulties tracing people for follow-up research in developing countries. For instance in Bangladesh, in a study of women who had been admitted to the main government hospital in the capital Dhaka for obstetric emergency care (Pitchforth et al, 2006), the UK researcher and the local driver she had hired had great difficulty tracing some of the women some weeks after the birth at their home, because their house was not on a named street with a postcode. The instructions were often vague, ‘our house is in the xxx bazaar, in the alley next to the butcher, near the bicycle repair shop’. When the researcher came to the area to do the follow-up interview, there were several butchers. Asking around she also found out that that several women in the neighbourhood had recently given birth, and knocking on several doors did not prove effective.

Nepalese healthcare workers have a culture of attending training when given a ‘per diem’, or to turn the issue round, they expect a payment for attending training sessions. If they get paid, they will come for anything (regardless of need), also government staff need to be invited in writing (however low level) on official paper even if official verbal agreement has been received over the telephone.

In the developed world, there is occasional trouble with delayed trains, traffic jams, and weather bad enough to affect travel. However, this is usually not as bad as the situation in the South, where fieldwork or travel to meetings may have to be repeatedly rescheduled because of political strikes or bad weather (for example, the monsoon season in Asian countries), which makes local travel to and from research sites more difficult.

Research ethics

There is growing academic literature on the ethics of doing research in developing countries (Lorenzo et al, 2010; Nyika et al, 2009; Wendler et al, 2004) and the bioethics of medical research in very poor countries (Tausig et al, 2007). Some scholars have argued that using the universal four concepts of research ethics (non-malfeasance, beneficence, justice and respect for autonomy) as a starting point is sufficient because ethical standards should not depend on where the research is conducted (Angell, 1997). In principle, we would agree to this, but if your local research collaborators have views that are more informed by local customs, religion and perhaps myths, their ethical principles may also differ. Take for instance the very individualistic notion of consent used in the North. In countries of the South, other ways of gaining consent to research, which are locally appropriate, include gaining ‘community-based consent’ from local leaders. In rural Nepal, where mothers-in-law make many daily decisions for young pregnant women, it is accepted locally that she will make the decision about whether or not the pregnant woman will participate in a research project.

The way forward

Ten years ago, the need for research driven by developing countries in partnership with the developed world was summarised (see Table 2) by the Swiss Commission for Research Partnership with Developing Countries (1998).

To date, various strategies to increase the research resources for developing countries by international health organisations have not managed to reduce the ‘10/90’ gap – only 10% of all health research funding addresses 90% of the world’s burden of disease (Global Forum for Health Research, 2008). Edger (1999) said that scientific advances are not the only way of measuring research success, for example, the choice of identified priorities, the sustainability of the studies’ intervention outside the research setting and the investment in local research capacity can be equally important outcomes. However, we have tried very hard not to romanticise research in developing countries (the anthropologist’s equivalent of ‘going native’). We reflect on lessons learnt through our examples to help researchers conduct research in developing countries to improve their studies. Having meals and sharing cups of tea helps achieve such common understanding, while at the same time it helps to ‘grease the wheels’ of research. If possible, a researcher from the developed world also needs to be invited in writing (however low level) on official paper even if official agreement has been received over the telephone.

Table 2. Principles of research partnership

| Decide on the objectives together |
| Build up mutual trust |
| Share information, develop networks |
| Share responsibility |
| Create transparency |
| Monitor and evaluate the collaboration |
| Disseminate the results |
| Apply the results |
| Share the profits equitably |
| Increase research capacity |
| Build on achievements |
world should seek local collaborators who know the local customs and traditions as well as barriers and ways to overcome these. Working with researchers from poorer countries should be mutually beneficial as both parties can learn from each other. We also found that offering to conduct research seminars or running workshops for local collaborators, universities and research institutes helped towards creating a common understanding. These activities also help to build the local research capacity.

As researchers, we know that there are different ways of carrying out research, for example, in developing countries, and especially in the field of maternity care research, we often use participatory methods (Jentsch and Hussein, 2007). We agree with Goldemberg (1998) that developing countries should not necessarily follow the research models that led to the scientific enterprise in developed countries. Instead, they should develop their own models that stem from their understanding of their own needs, goals and surrounding environment. People from the South know what their problems are and know some of the possible solutions, although these solutions are bound by time and place. But the key to conducting good maternity-care research in the developing world is not just trying to understand and consult the people and communities involved locally. This process of understanding is a two-way process – joint ventures should start from trying to understand each other’s cultures. Researchers must also facilitate people locally in their attempts to try to get to know the researchers and the research process. It is therefore fair to say that conducting research in developing countries requires a level of flexible working and thinking, patience and open-mindedness about other people’s ways of doing things (Wall, 2000). A good dose of humor has also proved useful to the authors (although humor itself is, of course culture bound).

Conclusion

Lessons learnt from carrying out maternity care research in developing countries can only be appreciated through collaboration between researchers whereby researchers from the developed world take account of local customs, practice and culture. It is important that researchers carry out research in developing countries, that they gain experience locally in the field and not just direct the research from their university office. As Wall (2000: 9) highlighted: ‘It takes time to establish a common language, to share values and norms; one side has the cultural competence, the other may have access to the tools and the technology and have the ‘ears’ of the scientific community’. When planning a research project in a country, it is worthwhile to check the Principles of Good Practice as set out by the Global Forum for Health Research (2008). Last, but not least, it is tremendously important to reflect on your experience of doing research and learn from your own mistakes and those of others.

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Multidisciplinary research in midwifery: reflecting on a collaborative working relationship

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Abstract

In this paper, we reflect on a multidisciplinary collaborative working relationship with particular emphasis on the discussion and debate that took place between a midwife and a sociologist (the authors of this paper) surrounding women’s choices and experiences of infant-feeding. Scientific research has long highlighted the health benefits of breastfeeding for mothers and their infants, whereas sociological research points to more complex social, material and emotional concerns and issues surrounding infant-feeding choices and experiences. In a project focusing on mother/daughter relationships during pregnancy for women with pre-existing diabetes, respondents spoke about their views, intentions and experience of infant-feeding, including the influence of midwives and other health professionals. This led to discussion among the research team about the value of breast- and formula-feeding and associated pressures for both midwives and mothers. Here the authors reflect on their discussions and the issue more generally.

Key words: Midwife, sociologist, collaborative working, infant-feeding, pregnancy complicated by diabetes, evidence-based midwifery

Introduction, background and context

In this paper, we reflect on a collaborative working relationship with particular emphasis on the discussion and debate that took place between a midwife and a sociologist (the authors of this paper) surrounding women’s choices and experiences of infant-feeding.

The health benefits of breastfeeding have long been established with research providing evidence of short- and long-term advantages to the health of both mother and infant (Hoddinott et al, 2008; Gartner et al, 2005; Butte et al, 2002). For women whose pregnancy is complicated by pre-existing diabetes, research further suggests that women who breastfeed have better glycaemic control (Saez-de-Ibarra et al, 2003; O’Sullivan, 1995); although there is conflicting evidence that they may experience fluctuating blood glucose levels and symptomatic hypoglycaemia (Ferris et al, 1988; Ferris and Reece, 1994; Davies et al, 1989). Researchers argue that breastfeeding protects the infant against the development of obesity and type 1 and 2 diabetes highlighting the importance of encouraging breastfeeding in this specific cohort (Kimpimaki et al, 2001; Ziegler et al, 2003; Villegas et al, 2008; Paronen et al, 2000). Additionally, some feminists have taken on breastfeeding as a feminist cause ‘arguing that breastfeeding is part of women’s natural reproductive capacities and the efforts by doctors between the 1950s and 1970s to discourage women from breastfeeding were evidence of a patriarchal medical model that aimed to take control of women’s bodies’ (Rippeyoung, 2009: 42).

The promotion of breastfeeding has been a key priority for many with policies and initiatives such as the Baby Friendly Initiative (BFI) (UNICEF, 1994); Our healthier nation: a contract for health (Department of Health, 1998); National breastfeeding awareness week (NHS, 2009) and the National Institute for Health and Clinical Excellence postnatal guidelines (NICE, 2006) outlining best practice standards for breastfeeding. Professional bodies such as the RCM (2004) have developed policy statements related to the promotion of breastfeeding with the NMC (2007) standards required for pre-registration programmes in midwifery including essential skills clusters related to the initiation and continuance of breastfeeding, making breastfeeding and its promotion a central element of the role of the midwife. Therefore, midwives have a crucial and pivotal role in promoting breastfeeding as a positive choice for all pregnant women and for women with pre-existing diabetes.

A consideration of infant-feeding from a wider sociological perspective and an exploration of empirical research on infant-feeding suggests that a more complex analysis is needed of both the lived experience of breastfeeding and the state promotion of it (for example – Lee, 2007). With reference to the breastfeeding experience of women with pre-existing diabetes, there have been studies that demonstrate that these women may experience particular difficulties in initiating and establishing breastfeeding. It is thought that fluctuating maternal glucose levels experienced by mothers following birth delays lactogenesis, as lactose levels are lower with the consequence of a reduction in milk volume (Stage et al, 2006; Neubauer et al, 1993). Other studies suggest that this cohort tend to feed for shorter duration than the general population, which may be due to the increase maternal and infant morbidity – known barriers to breastfeeding (Ahlwalia et al, 2005; DiGirolamo et al, 2005; Sikorski et al, 2003).

Furthermore, the ‘breast is best’ message has ideological overtones (Murphy, 1999; Lee, 2007; Knaak, 2008). In addition, although women who breastfeed are seen to be ‘doing what is best’ for their baby, at the same time, they need to be careful not to transgress other norms and expectations.
For example, they must maintain ‘their modesty’ and must stop feeding their child at the (often externally) defined appropriate time (Murphy, 1999). All of this has implications for women’s choices and experiences of breast- and formula-feeding and women’s feelings of self-worth with reference to motherhood. If ‘breast is best’, formula is second best, and by association mothers who successfully breastfeed are better mothers than those who do not. Breastfeeding then is symbolic of both womanliness and ‘good motherhood’, which is often externally defined, an unreachable ideal for many and representative of an era that ‘demands’ intensive mothering (Lee, 2007; Knaak, 2008). Furthermore, social networks and societal influences affect all women’s infant-feeding choices and for various reasons including the desire for parental involvement in feeding, the belief that bottle-feeding is more convenient, the ability to quantify formula feeds, difficulty of managing paid work and breastfeeding and dislike of breastfeeding in public all mitigate against breastfeeding as a positive choice (Earle, 2000; Shaker et al, 2004; McCann and Baydar, 2007; Soltani et al, 2008).

Our research
Some of the complexity surrounding infant-feeding choices and experiences became evident to us during work on a qualitative research project focusing on ‘mother/daughter relationships during pregnancy for women with pre-existing diabetes’, funded by Diabetes UK. The study was exploratory in nature and our aims were to consider what support pregnant women felt they needed and what support they received from their mothers and significant others, to discover policy and practice needs and to identify further research concerns. In-depth qualitative interviews took place with 12 pregnant women with pre-existing diabetes and five of their mothers, two (male) partners and one father.

The research team comprised of a midwife with specialist interest in diabetes, a sociologist with expertise in non/motherhood and qualitative methods, a social worker with a professional interest in maternal mental health, a diabetologist and obstetrician with clinical responsibility for caring for women with pre-existing diabetes. Each brought to the project their own professional ideology, knowledge, expertise and attitudes towards breastfeeding.

Within the study, respondents talked about their own infant-feeding choices and experiences saying that they had not received sufficient antenatal information regarding infant-feeding, nor sufficient support to enable them to breastfeed and felt anxious and defensive about their choices. This suggests that although over a decade ago, research highlighted a lack of information for women with diabetes who intend to breastfeed (O’Sullivan, 1995), lack of appropriate knowledge and support is still a problem, at least for some. Indeed, some of our respondents felt both anxious and guilty not only about their choices, but also the perceived pressure they would be put under by others. For example as one respondent said: “Well I might be wrong, but I heard that um, my, well, I’ve heard a few friends of mine who started breastfeeding and then wanted to stop were put under tremendous amounts of pressure by their midwife, they had like bleeding nipples and in absolute agony, but they were told to carry on, keep doing it, you know, these poor women crying their eyes out in pain and stuff, and not being able to leave the baby for even an hour because they’d have to breastfeed it. And I know that when I speak to [her midwife] I’m gonna have to tell her at some point... I’m gonna have to tell her eventually, but I’m absolutely dreading it because I know everywhere you read it says – that is the right thing for the baby... It’s a decision I’ve made and I wanna be able to say to the midwife – ‘I’ve made a decision, I don’t want to breastfeed’ – and I don’t want to have an argument with her about it or debate.”

This narrative and others like it led to discussion and debate among us, particularly the midwife (ES) and the sociologist (GL).

The midwife’s view (ES)
As a midwife and an advocate for breastfeeding, exploring why women with pre-existing diabetes did not breastfeed was of great interest. Anecdotal evidence, clinical experience and a recent clinical audit showed that very few women with pre-existing diabetes exclusively breastfed their infants, with only a small number breastfeeding beyond the recommended six months. Following informal discussion with midwives and healthcare professionals related to the promotion of breastfeeding and supported by the findings of our previous study, the need to explore this topic was evident to me. Midwives and healthcare professionals have told me that they offer infants formula milk more readily to infants born to women with diabetes. In part, this may be explained as being driven by clinical guidelines on neonatal hypoglycaemia that stipulate the need for ‘supplementary feeds’ if neonatal blood glucose levels fell below a designated level. Thus, in supporting breastfeeding as a choice and experience for women with pre-existing diabetes within our mother/daughter study, midwives were clearly using their previous knowledge, not least from the literature suggesting supplementary feeds with formula milk can affect short- and long- term health of the infant and the mother/infant’s success in breastfeeding (Baird et al, 2005; Ong and Loos, 2006; Ong et al, 2006).

Having the professional knowledge of the benefits of breastfeeding for women with pre-existing diabetes means the clinical diabetes team; consisting of a diabetologist, obstetrician, diabetes nurse specialist, dietician and midwife (ES) passionately promote breastfeeding and feel disappointment when women decide in pregnancy to formula feed their infant. Therefore, reflecting professional knowledge/experience and ideological stance, we wanted to undertake research designed to explore women’s choices surrounding breastfeeding and the significance of pre-existing diabetes to these choices. However, this caused a great deal of professional discussion within the research team as the sociologist (GL) within the group challenged our assumptions that the study should emphasise only breastfeeding.

The sociologist’s view (GL)
Having undertaken a significant amount of research over...
the last 20 years in the area of reproduction and non/motherhood – including research on pregnancy loss, infertility, involuntary childlessness, voluntary childlessness and young motherhood – I am very aware of how the experiences of these issues and identities can add to women’s anxiety and negative sense of self. Despite much evidence to the contrary, the external, and often internalised expectations are that all women will become mothers and do so easily and that motherhood is an instinctual experience, something that comes ‘naturally’. The fact that individual reproductive experience and the experience of mothering is often more complex, more difficult and more frightening than the ideal suggests leads to feelings of anxiety, guilt and failure for many.

Committed to a research agenda that attempts to make a difference to people’s lives, I have always tried to approach research with an ‘open mind’, although I appreciate that I, like all other researchers do not enter the field ‘empty-headed’. Thus, in my research on infertility and involuntary childlessness, I aimed to highlight the misunderstandings of experience that to me appeared to characterise these issues and in my studies of young motherhood (and fatherhood), I wanted to challenge the stereotypical view of ‘teenage mums’ (and ‘reckless dads’). For me then when respondents in our mother/daughter study spoke of their anxiety surrounding their infant-feeding choices, I felt angry on their behalf. So when the midwife member of the team (ES) spoke of the medical importance of breastfeeding and the possibility of a project specifically on breastfeeding issues, I could only see problems. For me, this focus would only add to the negative sense of self-worth those who choose not to breastfeed feel and support, rather than challenge, an un-thought through political agenda: surely those who chose to formula feed feel and support, rather than challenge, an un-thought through political agenda: surely those who chose to formula feed need support too, maybe even more if their infants are already ‘at risk’? So, I too felt strongly about our future research possibilities in a way that could have threatened our future working relationship.

The experience of collaboration

Our differences of opinion challenged us both to examine and evaluate our opinions and approach and led to an exploration of the literature related to midwives’ attitudes to bottle/formula and breastfeeding. A study undertaken by Battersby (2009) explores the issue of ‘midwives, infant-feeding, and emotional turmoil’. This work investigated the personal experience of midwives who are mothers who had breastfed and the influence this may have on care. As a midwife and a mother, ES could identify with many of the findings of this study; how breastfeeding had helped her professional practice and the experience had given her a greater understanding of women’s concerns and fears related to breastfeeding. However, it also led to her acknowledgement of feeling disappointed when women chose not to breastfeed or stopped breastfeeding at an early stage. This was a theme identified in the study undertaken by Battersby (2009), which supported the findings of Furber and Thomson (2008), who identified that midwives felt saddened and despondent when they could not convince a woman of the benefits of breastfeeding. In ES’s experience, these emotions are frequently felt by the clinical diabetes team, when women decide during the antenatal period that following birth they intend to feed their infants formula and these emotions can be unconsciously relayed to the women and/or women may perceive negative judgements where they do not exist. This accords with previous research conducted by GL (Letherby et al, 2002), which highlighted that sometimes midwives’ attempt to support pregnant women/new mothers is perceived as interference and pressure; research that highlighted to GL the importance of focusing on all the perspectives of an issue.

Working within a multiprofessional team led us all to reflect further to a wider perspective of infant-feeding not only of the infant of women with pre-existing diabetes, but also for all women. The discussion related to this topic was at times challenging and generated many powerful emotions related to our identities as women and as professionals, and in some cases as mothers. It caused us to question our previously held views and reflect on our professional knowledge.

Concluding reflections

In the presentations we give and the reports and papers we write, the ‘we’ we present is in some ways false, as it hides the levels of negotiation, compromise and accommodation we have experienced (Malina and Maslin-Prothero, 1998). As women who respect and hope to learn from each other, we are keen to conduct research and to present and write about our work in ways that we both feel comfortable with, while at the same time attempting ‘not to subsume each of our individual identities and thoughts into an undifferentiated we’ (Karach and Roach, 1992). Thus, our experience of working within a collaborative team has led us to trying to develop a truly collaborative project. As a group, we have challenged others’ views, debated our personal positions and come to compromise. As our working relationship continues, there will likely be more discussion. This we see as a positive strength of the multidisciplinary work that we do.

The reasons why women choose to feed their infant with formula milk has received limited attention, however, a recent systematic review of mothers’ experiences of bottle-feeding (Lakshman et al, 2009) concluded that women who chose to formula feed their infant do not receive support in many settings and that some healthcare professionals have the mistaken belief that initiatives like BFI prohibit this. Yet, as BFI recently stated: ‘The role of the Baby Friendly Initiative and of health professionals is to give pregnant women and new parents the full facts about infant-feeding based on the best available evidence in an objective and non-judgemental manner in order to allow informed decision-making. We then need to help mothers to make decisions appropriate to their circumstances and to support them in their decision whatever that may be’ (UNICEF UK Baby Friendly Initiative, 2009).

With this in mind we hope in our future research to explore all aspects of infant-feeding choices and experiences for women with pre-existing diabetes.
on a collaborative working relationship. Evidence Based Midwifery 8(1): 17-20

References


Reflexivity: the experience of undertaking an ethnographic study to explore issues of consent to intrapartum procedures


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The principal author is grateful to the Hospitals Savings Association in conjunction with the RCM for awarding a bursary towards the financing of this PhD study.

Abstract

Background. Reflexivity is a popular, yet complex process, which attempts to analyse personal, intersubjective and social processes that influence research projects, particularly those using a qualitative approach. With the rising popularity of qualitative methods being used to examine health care and midwifery practice, as well as the increased public and professional scrutiny of research, reflexivity provides a means of strengthening greater transparency and quality in this type of research.

Aim. This paper examines the concept of reflexivity and highlights specific issues that researchers need to consider when undertaking ethnographic studies involving participant observation. Reference will be made to personal experience of undertaking an observational study examining informed consent to intrapartum procedures.

Methods. Application to undertake the study was approved by the local research ethics committee. Data were collected by field-notes, which were made through participant observation, followed by semi-structured interviews with each woman observed and the corresponding midwives within 24 hours of the baby’s birth. In addition, notes pertaining to personal thoughts and experiences before, during and after the data collection and analysis were recorded in a research diary to add to the reflexive account.

Findings and conclusion. Each way of approaching reflexivity has strengths and limitations and will be dependent on the research methods used in respect of fulfilling the aims of the study. Each researcher is responsible in deciding how best to exploit the reflexive potential of the research to ensure their final account is authentic, trustworthy and of good quality.

Key words: Reflexivity, introspection, inter-subjective reflection, collaborative reflection, social critique, conscientious reflection, ethnography, participant observation, informed consent, evidence-based midwifery

Introduction and overview

All qualitative researchers are part of the social world in which they study, regardless of the approach they use, which in turn raises issues of subjectivity and bias when attempting to demonstrate the trustworthiness of their findings. It is therefore important that as the study is being carried out, the researcher has the ability to reflect back and forth on the research process and challenge their own perceptions and influence on it. This is known as reflexivity.

For the purpose of this paper, a number of variants of reflexivity will be examined within the context of the personal experience of undertaking an ethnographic study, which set out to examine informed consent to intrapartum procedures through the interactions between health professionals and women in labour. The ethnographic study using participant observation aimed at determining to what extent health professionals obtain informed consent during labour within the labour ward environment of a large teaching hospital in an East Midlands city in the UK. A total of 100 healthy women who went into labour spontaneously at term took part in the study and were observed throughout their labour, until they were transferred to the post-natal area with their baby. Follow-up interviews were conducted with the women and the attending midwives within 24 hours of the baby’s birth, using a semi-structured format based on the earlier observations. In addition to the observation field-notes and interview transcripts, notes pertaining to personal thoughts and experiences before, during and after the data collection and analysis were recorded in a research diary to add to the reflexive account. To be in-keeping with the focus of this paper, personal reflections will be written in the first person.

The concept of reflexivity

Being reflexive is more complex than being reflective. The latter term can be defined as thinking about something after the event, whereas the etymological origin of the former concept means to bend back upon oneself. Finlay and Gough (2003) indicate that this can be applied in research terms as thoughtful, self-aware analysis of the inter-subjective dynamics between researcher and the researched. Lipp (2007) relates this to how the researcher examines the way in which their research acts on the world and how the world acts on their research. Lipson (1991) affirms that reflexivity requires critical self-reflection of the ways in which the researcher’s social background, personality, personal assumptions, position and behaviour can impact on the research process, particularly the collection and analysis of the data.

Numerous typologies/variants of reflexivity have been published (Lipp, 2007; Taylor, 2006; Davis and Klaes, 2003; Freshwater and Rolfe, 2001; Finlay, 2002; Lynch, 2000; Marcus,
Reflexivity as introspection

It could be argued that much research that is undertaken originates with data from the researcher’s personal experience and interest, as in my own case. In clinical practice, it had not only been personally observed, but also documented in studies that during intrapartum care, women accept what is done to them without challenging midwives and doctors, and in turn, health professionals accept this as consent to proceed (Henderson, 1984; 1991; National Childbirth Trust (NCT), 1989; Bergstrom et al, 1992; Menage, 1993; Coldicott et al, 2003). As a consequence, such introspection had yielded a personal insight that would then set out to form the basis of a more generalised understanding and interpretation of intrapartum informed consent.

As an experienced midwife and university lecturer, I was fully conversant with the legal and ethical concepts of informed consent, the local labour ward environment where the study was conducted and my own clinical practice. Consequently, I needed to be aware of the extent personal experience was integrated into my personality and the effect this would have on data collection. The phenomenologist Husserl (1970) asserts that it is important to identify, examine and bracket out [reduce] presuppositions and pre-understandings, in order to enter the lived experience of the participants and appreciate their perspectives. However, in comparison, Heidegger (1962) argues that it is not possible or even desirable to bracket personal beliefs during the philosophical process. Conceptual understanding of bracketing is therefore complex and can be problematic when we already know too much about the issue being studied (LeVasseur, 2003; van Manen, 1990). Merleau-Ponty (1962) acknowledges that the most important lesson that the bracketing process educates us about is that a complete reduction is impossible. On the other hand, it could be argued that the researcher should at least attempt to make their position explicit to better contextualise any understandings. Applying these principles to my study, I aimed to be reflexive on my experience of being a midwife-researcher studying other midwives and health professionals as they attended women in labour, and thus made additional notes in a diary as to any personal thoughts and feelings of what I was observing. This was to attempt to reduce the effect of my own experiences of obtaining consent in labour on what I was studying. The challenge, as Finlay (2003) purports, is for researchers using introspection to draw on personal revelation not as an end in itself, but as a springboard for interpretations and more general insight. As a result, links between knowledge claims, personal experiences of both participant and researcher and the social context become more explicit.

Reflexivity as inter-subjective reflection

This type of reflexivity can be found across a range of research approaches such as ethnographic, feminist, phenomenological and psychoanalytical research. The focus is on the situated, emergent and negotiated nature of the research encounter and how unconscious processes structure relations between the researcher and the participant. Sartre (1969) states that the self and its relation to others becomes the aim and object of the focus, requiring a radical self-reflective consciousness on the part of the researcher in relation to those being researched (Lipp, 2007).

Researchers who utilise this variant of reflexivity are generally critical of the emotional investment they have in the research relationships concerned. Goffman (1959) recognised that during the course of fieldwork, participants who associate with the ethnographer will cast him or her into certain identities on the basis of described characteristics as well as aspects of appearance and manner. This must be monitored for its effect on the types of data collected. At the same time, the ethnographer will generally try and shape the nature of their role, through adaptation of dress and behaviour in order to facilitate obtaining data.

Hammersley and Atkinson (2007) considered that age and its associated features will have a bearing on the way people react to the researcher and what they are permitted to do. This ultimately will determine the kinds of relationships established between researcher and participants and the extent of data collected. The personal characteristics of the researcher and how these relate to participants in the study can be controlled to a degree by the researcher’s presentation of self. Measor (1985) found that taking care to dress appropriately according to the age of the teacher she was interviewing and drawing on shared interests and biographical experiences, helped to facilitate the interview process. More recently, Johnson et al (2008) discovered that where helping behaviours were apparent in social interactions, dress, status and attractiveness between the participants played a considerable role.

As in Kirkham’s (1987) study, I had decided not to wear a uniform when undertaking participant observation to avoid being identified as a member of the midwifery staff and being expected to contribute to the activities of the workforce. In contrast, Holdaway (1982) wore the uniform of a police officer in his covert study, and proceeded to participate as such a professional, which caused him difficulty in making contemporaneous field-notes of his observations. To become part of the scene in her ethnographic study that explored the lives of childbearing women and their families living in material poverty within the West Midlands in the UK, Hunt (2004) had adopted a less formal dress code of leggings, T-shirt and trainers. Bearing these studies in mind along with the findings from Johnson et al’s (2008) critique, I carefully considered the style of dress I should wear for the follow-up interviews to ensure my presentation of self was facilitative to the interaction. This was not only influenced to some extent by the age and background of the individuals being interviewed, but also the range of other responsibilities I had scheduled for the same day in my capacity as a university lecturer. The dress code was less formal when interviewing the younger participant with trousers/jumpers/blouses being worn in comparison to the older/professional participant, when I chose to wear a dress/skirt and blouse/suit.

Despite all efforts to ensure my dress code was compatible to
the individual being interviewed, the women in the study generally appeared willing to converse and articulate their birth experiences regardless of their age and social class. This was probably due in part to my continued presence throughout their labour and the degree to which the relationship had developed during the observational stage of the study, prior to the interviews.

Reflexivity as collaborative reflection

Lipp (2007) states that the intent of collaborative and action research studies is to reduce the power differentials between researcher and researched by facilitating participant reflexivity in order to establish a team of equal co-researchers. Undertaking an ethnographic study regarding informed consent in labour as a sole researcher rather than a member of a team, this level of collaborative reflection did not exist. However, I did engage in reflexive discussion on a regular basis with my research supervisors (using entries from my research diary) and with members of the local inter-professional research seminar meetings. I was often faced with challenging questions at these meetings, particularly in the early stages of the study and as Barry (2003) warns, team members may offer differing, even conflicting perspectives on a specific issue that might overwhelm the inexperienced researcher. Nevertheless, the experiences that I encountered helped to facilitate enhanced reflexivity by challenging the research methodology I had chosen alongside my personal motivations and prejudices. This in turn led to a greater understanding of the area under investigation and a final reflexive account where the degree of bias towards a particular group of participants would be minimal.

As research participants also have the ability to be reflexive, Finlay (2003) and Lipp (2007) acknowledge that they can be co-opted into the research as co-researchers, involving collaborative reflexive dialogue during data analysis and evaluation. This practice extends beyond the usual strategy of offering the data to the individual participants for their commentary in order to validate the researcher’s interpretations, which was the level of collaboration I adopted in my study.

While collaborative reflexivity enables members to move beyond their preconceived beliefs and prejudices towards representing multiple voices and conflicting opinions, critics of this type of reflexivity reject the element of compromise and negotiation, believing that it has the potential for diluting the insights of the individual researcher. The following section attempts to further address the unequal relationship between researcher and participant in respect of power and authority within the context of reflexivity as social critique.

Reflexivity as social critique

This type of reflexivity seeks to manage the power imbalance in the research setting, the organisation or society between researcher and participant (Lipp, 2007). Johnson and Scott (1997) affirms that reflexivity as a social critique attempts to provide a voice for the unheard, while acknowledging tensions that may arise from different social positions, such as gender, class, status and race. In this context, Finlay (2003) states that the researcher’s imperative is to unravel the rhetoric of being a voice of authority and enable multiple voices to be heard instead. Because of the nature of ethnographic studies, it is expected for there to be a degree of bias, but rather than champion the underdog as Dingwall (1980) warns, the findings from the study should reflect a ‘reasonable’ level of objectivity by discussing the perspectives of all participants in the study regardless of their position (Spencer et al., 2003).

Hammersley and Atkinson (2007) acknowledge that the researcher cannot escape the implications of gender as no position of genderlessness neutrality can ever be achieved, though the implications of gender vary according to setting and are intertwined with sexual orientation. When undertaking the study into intrapartum informed consent, being female enabled me easy access to the labour ward and its participants in order to undertake the study using both observational and interviewing techniques, as childbirth is essentially women’s work. It was also important to be reflexive and constantly assess the impact of one’s gender and familiarity with the setting to ensure the account accurately reflected the experiences of all the participants and was not biased to one particular sex or group. In addition, some women later revealed during the interviews that they had only given their consent to take part in the study having been informed by the attending midwife that the researcher (myself) was both a woman and a midwife, as they “did not want just anyone seeing them in labour”.

As a professional, middle-class woman, considering Johnson et al’s (2008) findings, I needed also to be mindful of how my social class and status could affect my relationships with the participants and the collection of data, especially as far as the childbirthing woman was concerned. Both Kirkham (1987) in her study of interaction between health professionals and women during labour, and Holdaway (1982) in his study into police practice, particularly among the lower ranks, used participant observation as their data collection means, in settings they were professionally qualified and well experienced in. Although being a professional in the setting enabled me access with relative ease, it also highlighted similar areas of concern to consider when undertaking the study into intrapartum informed consent. Similar to Kirkham (1987) and Holdaway (1982), I would never be a complete stranger in the way that most researchers are, giving rise to issues of familiarity potentially being overlooked in my observations. However, Hunt (2004) found in her ethnographic study, that being an outsider on the inside was uncomfortable and demanding as she had little in common with those women she was interviewing. Her social status, Welsh accent and vocabulary were barriers she had to deal with alongside facing challenges within the community, such as reverting to use public transport to travel to the area after finding the wheels had been stolen from her car. Kirkham (1987) states that she felt very uncomfortable at first attempting mere observation, as it was difficult to refrain from thinking as a midwife, rather than viewing the situation from the woman’s perspective. In some instances, when the number of staff on duty was limited, she had a tendency to intervene. Although Henderson (1984) considered that observation was the most appropriate method of enquiry to study consent to intrapartum amniotomy, she realised that such a research approach could not only influence the behaviour of those observed, but also the data collection may be further complicated by her being known to the midwives in the area under study. Nevertheless, she claimed that as the study progressed and she became accepted as part of the scene, the influence of her presence became minimal. As Pellat (2002) highlights, researching one’s own culture can cause tension between strangeness and over-identification of professional role. It is therefore important
in settings that are familiar to be reflexive, adopting a more marginal role and being intellectually poised between familiarity and strangeness, in order to minimise subjectivity and bias and aim towards a more objective, critical and analytical perspective. Assisting with simple tasks on the labour ward while waiting to recruit suitable women to the study rather than being a hindrance to the midwives and sharing their coffee room, enabled me to become part of the labour ward scene such that the influence of my presence during the observational stage became less obtrusive as the study progressed (Stoddard, 1986; Posner, 1980). However these activities, as well as making the decision to always accompany the last midwife out of the labour room and undertake the follow-up interviews in the hospital environment, could be considered to be a limitation of the study as they clearly identified my position with the labour ward midwives, rather than the childbearing woman and the medical staff.

Furthermore, my professional status of being not only a midwife, but also an experienced midwifery lecturer known to many of the midwives and student midwives in the study, may have accounted for them never refusing to participate in the study: an effect that Taylor (2001) previously reported. While this may be perceived by some as a limitation of the study in terms of researcher influence, others may see it as a strength, as some midwives readily sought to recruit women to the study on my behalf. However, Pearsall (1965) and Hunt (2004) recognise that there may also be problems with being accepted by those in the field, because they are on home territory and make the ground rules about collaboration. This was apparent to a degree in my study as there were three midwives who appeared reluctant to recruit women to the study, possibly perceiving the presence of a midwifery lecturer to be a personal threat to them, assuming I would be scrutinising their clinical practice. As a midwife and a teacher, Adams (1989) also experienced difficulty collecting data in her ethnographic study into communication during the second stage of labour. While some midwives readily gave her access to the women, believing that by participating in the study it would not only help to improve their communication skills, but also benefit their teaching such skills to student midwives, others failed to inform her when women were nearing the second stage of labour as they felt their practice would be under scrutiny.

Where student midwives had provided the majority of intrapartum care with indirect supervision from their midwife mentor, I had observed that they attempted to fully inform women of the benefits and risks of procedures as far as their knowledge allowed. It was recognised that my existing relationship with the student midwives in the study as a midwifery lecturer could have affected the data that were gathered to the extent that women were more likely to be given non-biased information, enabling them to make their own intrapartum decisions. In this context, my presence as the researcher therefore could be seen as a further strength of the study design in terms of benefiting the participants, namely the women.

Taylor (2005) and Richards and Emslie (2000) recognise that the status of the researcher can influence the type of answer from the respondent, where the researcher is seen as a powerful figure. As a result, socially desirable answers may be given in which the respondents say what they feel will show them in a positive light or what they think the researcher wants to hear. These issues were particularly important to consider as to their effect in my study as I conducted the interviews myself and was known to many of the midwives and staff, of whom some had been former, or were current, students. The midwives’ responses were therefore compared with the earlier observational data to assess whether their perceptions were an authentic and trustworthy reflection of how they communicated and behaved in the natural setting of the labour ward.

**Reflexivity as conscientious reflection**

Being privy to unacceptable and unethical/illegal conduct by staff or getting caught between clients and staff has been claimed by Munhall (2007) to be two of the most problematic situations for the researcher in the clinical setting, especially when they are familiar with the accepted standard of practice. Refusing to intervene in a situation that is in conflict with the conscience of the researcher, would place the value of the research above the quality of the life of the woman and fetus. Furthermore, as a midwife I am also bound by the NMC’s (2008) *The code: standards of conduct, performance and ethics for nurses and midwives* to ensure that the standard of care women and babies receive is appropriate and that there is no breach in the duty of care resulting in harm to the recipient. However, as Hewitt (2007) purports, ethical codes, biomedical principles and care philosophies provide little contextual guidance on the moral dilemmas encountered in the practice of healthcare research. If researchers are to navigate the moral complexities of research relationships within this context, then sensitivity to risk to participants must be of continual concern: from the outset of the study to the reporting of findings. Examination of the self through conscientious reflection and supervision are therefore necessary components of ethical research.

In the informed consent study, unethical practice was observed on only one occasion. When a male obstetrician attempted to undertake a ventouse birth without the woman having any analgesia, I became fully aware of my conscience and moral obligations to the woman, such that no harm should befall her and her baby, as well as to her husband. As the midwife involved in the case intervened and prevented the doctor from proceeding with the birth, I did not personally have to act and consequently step out of the role of researcher. However, the supervisor of midwives (NMC, 2004) was informed of the incident should there have been any redress sought by the woman and her family.

**Conclusions and implications for researchers**

While this paper has highlighted some of the variants of reflexivity that were pertinent to my ethnographic study into the practice of intrapartum informed consent, there was not scope to examine all variants. Each way of approaching reflexivity has strengths and limitations and will be dependent on the research methods used in respect of fulfilling the aims of the study. As Lynch (2000: 273) purports: ‘What reflexivity does, what it threatens to expose, what it reveals and who it empowers depends upon who does it and how they go about it.’ It is up to each researcher how best to exploit the reflexive potential of the research, based on their research aims. To avoid reflexive analysis altogether is likely to compromise the research, which should ensure the research’s final account is authentic, trustworthy and of good quality.
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Internet-mediated research: a reflection on challenges encountered and lessons learnt

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I would like to thank my supervisors Professors Marlene Sinclair and George Kernohan for their support and encouragement during my PhD journey and the University of Ulster’s James Corle for his assistance in the setting up of the web-based questionnaires and the Department for Employment and Learning, Northern Ireland for supporting and funding the research.

Abstract

Background. The internet is an exciting and relatively new medium for conducting midwifery research that, to date, only a few midwifery researchers have embraced. The different methodologies used in internet-mediated research (IMR) gives rise to additional challenges for researchers.

Aim. This paper aims to provide a personal reflection on some of the challenges encountered and lessons learnt by one researcher who utilised a multi-method IMR research strategy for a doctoral research project.

Method. The researcher’s experience is presented as a case study from data that were collected from a reflective journal. Using a first-person writing style, alongside confessional and creative non-fiction vignettes, the author will reflect and discuss challenges encountered and lessons learnt, while using web-based questionnaires and asynchronous online focus groups to conduct a mixed-methods IMR research study.

Results. Challenges to using the internet to facilitate health research include ethical, technical, and methodological issues. The researcher’s sustained passion for the topic and the novel methodology provided encouragement to explore ways to manage, resolve, and learn from such challenges.

Conclusion. Advances in technology, such as the internet, have extended opportunities for research. Many of the issues reported in this paper are transitional in nature due to the rapid pace of technological development. Significant lessons were learnt that will enhance the researcher’s future research efforts and may help other researchers who decide to use a similar approach for their own research project.

Key words: Internet-mediated research, reflection, challenges, lessons learnt, evidence-based midwifery

Introduction

The internet has become an important form of communication in modern society, with the latest figures showing almost 1.7 billion people in the world have internet access (Internet World Stats, 2010). Not only has the internet become an everyday communication tool for countless people, but it also offers many new ways of conducting quantitative and qualitative research (Pittenger, 2003; Rhodes et al, 2003). One-to-one interviews can be conducted via email or chat rooms, virtual focus groups can be conducted by email, chat rooms or discussion groups/forums and questionnaires can be administered by email, discussion forums or on the worldwide web.

Although data collected by online methods can be rich and valuable, to date, only a few midwifery researchers have embraced this medium for conducting research. The challenge for researchers is to learn to use this medium to their best advantage. However, this can be difficult as internet technology is changing rapidly and ‘present’ literature (books in particular) on internet-mediated research (IMR) date quickly.

This paper aims to provide a personal reflection based on one researcher’s experience who utilised a multi-method IMR strategy for a doctoral research project. The researcher’s experience is presented as a case study from data that were collected from a reflective journal. Finlay (2002) suggests that personal and methodological reflexivity should be included as a general element of integrity in the research process and without it, the validity of the research could be undermined. It is not the intention of this paper to focus on the advantages and disadvantages of IMR. Using a first-person writing style alongside confessional and creative non-fiction vignettes, the author will reflect and discuss some of the challenges encountered and lessons learnt, while undertaking a research project that employed this methodology. The author makes no apologies for utilising the first-person narrative, as authors such as Fulbrook (2003) recommend it when giving a personal ‘reflection’. To preserve confidentiality, pseudonyms have been used throughout the text.

Background

The rationale for undertaking any research is to extend knowledge and understanding (Rees, 2003; Polit, 2006). This study was advertised by the University of Ulster’s, Institute of Nursing Research and built on previous research conducted by Professor Marlene Sinclair and Professor George Kernohan. They advertised the study as a Department for Employment and Learning funded, full-time, three-year PhD. I was personally motivated to apply for the study as I had clinical experience of women coming to antenatal consultations with internet printouts and this research matched my personal, professional, and academic interests. I too wanted to know and understand why women were seeking information online, what kind of information was being sourced, and what type of websites women actually selected. As Louis Pasteur stated, ‘to know how to wonder
and question is the first step of the mind towards discovery’ (cited by Yang, 2006).

The aim of the overall study was to investigate women’s use of the internet in pregnancy and the effect it had on their decision-making and midwifery care. The study involved developing and conducting a three-phase sequential exploratory investigation using a multi-method IMR strategy to provide a coherent and rich picture of pregnant women’s use of the internet in pregnancy. A sequential approach is ideal when one phase can contribute to the next phase and enhance the entire study (Creswell et al., 2004).

In phase one, a convenience sample of 303 international midwives completed a web-based questionnaire designed to explore midwives’ attitudes, experiences and perceptions of women using the internet and whether or not they perceived the internet affected pregnant women’s decision-making. Theoretical principles underpinning information-seeking behaviour and outcomes from phase one were synthesised to formulate a second web-based questionnaire designed to explore pregnant women’s use of the internet. A convenience sample of 613 international women who were pregnant or had had a baby in the previous year participated in a web-based survey. In phase three exploratory, confirmatory online focus groups (n=13) enabled the researcher to confirm the theoretical structure of the decision-making processes of pregnant women who sought information from the internet.

This doctoral study was guided by my enthusiasm for the subject and self-motivation. I treated it as a job. Like any job, one has a role to play and goods to deliver. The goods were to fulfil the aims and objectives of the project and the roles included:

- Planning the project
- Determining the research plan
- Conducting the research
- Reporting and disseminating the results.

The following paragraphs will demonstrate how other attributes came into play such as the ability to make decisions, design, negotiate, moderate, facilitate and problem solve when I was faced with ethical, methodological and technological challenges when utilizing a multi-method IMR strategy for a doctoral research project.

**Challenges encountered**

**Challenge 1: ethical approval**

Researchers frequently encounter ethical challenges when planning and undertaking research. My first main challenge was obtaining ethical approval. After months of planning, the study was first processed and approved through the University of Ulster Research Governance Filter Committee. The proposal was then presented to the Office for Research Ethics Committees Northern Ireland (ORECNI). ORECNI asked for the protocol to be strengthened with the justification for the non-inclusion of non-English speaking participants, and to reflect that this had been considered. In response to this request, the following statement was added to the protocol and was received favourably by ORECNI: ‘…according to Buncombe and MacArthur (1999) within London alone, 300 different languages are spoken regularly. The choice to not have the online questionnaire translated into different languages was in part determined by the resources available to the researcher, the time period and funding available for the research and also it would not be feasible or practical to administer the questionnaire online in 300 languages and it was envisaged that only women who can read and understand English would actually access the questionnaire.’

Following ORECNI approval, I was able to proceed to the third part of the ethical review process. As I had decided to conduct the first part of the pilot studies for both phases one and two within two local Trusts, the proposal then had to be reviewed by each of these Trusts’ research and governance committees. This is when my first real challenge began. I wrote to both Trusts’ research governance committees. For one Trust, once they received a copy of the letter from ORECNI, I was granted permission to proceed with the pilot study. However, the second Trust’s research governance procedures proved to be more of a challenge. The process took four months and involved completing seven different forms for each phase and an application form for an honorary contract. Completion of the forms was relatively easy, but the problem was the timeframe between when each form was forwarded, to it being approved by the Trust’s research and development committee and the next form being sent. The process took so long that when it came to undertaking the pilot for the women’s survey (phase two), I had less than 72 hours to conduct the pilot as my honorary contract would then expire. This meant I would not have been allowed to start recruitment without putting in an application for an extension, which I was very much reluctant to do, because of the time taken to get through the process initially. Following negotiating and explaining my circumstances to the midwifery sister in the antenatal clinic, she kindly arranged for me to attend the antenatal clinic sessions the following two days where I was able to pilot the questionnaire.

**Challenge 2: instrumentation**

During the pilot of phase one, when the questionnaire was sent out as an email attachment, some of the questionnaires were returned incomplete and some midwives identified that they did not receive the instrument in its original format, for example, tick boxes were missing. I then learned email questionnaires could only be accurately reproduced on every email system, regardless of the program, if ‘simple text’ was used. However, using ‘simple text’ allows recipients the possibility to reformat the questionnaire, which can result in reliability and validity issues. Once this problem was highlighted, I was no longer in favour of using the email mode and decided after further reading about online survey research to opt for using web-based questionnaires for the first two phases of the study. Although there are many advantages to web-based questionnaires compared to email-based questionnaires, with the web-based mode came further challenges.

IMR was relatively new to the midwifery/nursing department within the university. As I did not possess the skills to design and develop an IMR-based study, I had to seek assistance. First, I attended a short course on designing web-
surveys and read numerous papers in the literature providing guidance to researchers on the ‘dos’ and ‘don’ts’ derived from the experience of other researchers who have designed online questionnaires, such as Peytchev et al (2006), Dillman (2007), Tourangeau et al (2007), Toepoel et al (2009). However, as Madge et al (2006) point out the massive range of purposes of questionnaires and diversity of the populations to be studied mean that there is no single design approach that is appropriate for all online surveys.

In the first instance, I had to choose software for online questionnaire production before a web-based prototype of the questionnaires could be designed. Once the questionnaires were designed, I then required a website to host the survey that would be accessible to potential participants nationally and internationally. Next, I had to consider survey sampling and recruiting methods and, finally, when I would activate and how I would manage the surveys.

Much of the literature advised seeking technical help to gain practical advice and support. Following numerous emails, telephone calls and with perseverance, I obtained technical support from a web design technician. The assistance of the technician was invaluable. He explained the interface of the chosen software, and procedures for creating and managing the questionnaire. He also taught me how to design the web questionnaires using new software that had just been purchased by the university faculty. Once I had designed the questionnaires, the technician assisted me at each phase with hosting the questionnaire onto a webpage specifically designed for the study, with its own unique uniform resource locator (URL) address. He showed me how to activate the study and how to download the data in a format that could be easily imported into the statistical analysis package I planned to use.

**Challenge 3: cross-cultural differences**

As this was a global study, cross-cultural differences had to be considered. I had to bear in mind individual countries had different healthcare systems and maternity care/delivery models. Practical issues, such as using terminology and spellings that would be understood by all participants also had to be considered. Despite piloting the questionnaires internationally prior to undertaking the main study, I was still met occasionally with the challenge of having to consult international colleagues working within maternity services to clarify statements or terminology participants had used when answering the open-ended questions within the questionnaires.

A further cross-cultural difference was time zones. Although using online asynchronous communication to conduct online focus groups, where communication can take place at different times or over a certain period of time gave the study participants more flexibility, compared to synchronous communication where communication takes place at the same time, this placed a greater responsibility on the researcher. In order to successfully participate in online focus groups, the researcher must be well organised, self-motivated, and possess a high degree of time management and moderating skills to keep up with the pace of the discussion and to ensure that the focus of the discussion remains on target. This was especially challenging when the focus groups were in geographic regions where there was a vast time difference between the UK, for example, Australia.

**Challenge 4: data transmission**

In the first survey (the midwives’ phase), the data were downloaded into Excel and then the Statistical Package for Social Sciences version 14 (SPSS, 2005) without any ‘hitches’. However, when it came to the women’s survey, there were twice as many questionnaires and this caused a major problem. The system only allowed 30 seconds for download, my data were taking much longer and I kept getting the message: ‘Fatal error: maximum execution time of 30 seconds exceeded…’. I was naturally concerned I had all these data sitting in a system that I could not access. I could visually see the data, it was not lost, but if I did not get the data to download I would have to manually enter it from the 613 questionnaires one-by-one into SPSS. Time was running out and I knew I would not have the time to do this and I needed to analyse the data from the survey before I could proceed with the focus groups. The team that managed the software were reluctant to reset the maximum execution time beyond the 30 seconds, because they had concerns that computer hackers could get into the system. After several negotiations, it was agreed they would extend the download time at 02:00 one morning (when they envisaged there would be less users on the system) to allow the data enough time to be exported from the survey package to a Microsoft Excel/CSV files spreadsheet from where I could then download into SPSS for data analysis.

**Challenge 5: disclosures**

Researchers have no control over what information participants disclose. In phase two, one woman mentioned in her web questionnaire searching the internet for information on cannabis use in pregnancy. I had to hope the woman would avail of information that I had supplied within the questionnaire homepage, which provided links to validated websites, one of which provided information on illicit drug use in pregnancy.

During the pilot study of the online focus groups (phase three), one of the participants ‘Sarah’, in her welcoming message mentioned that she had a stillbirth eight days previously, “but would like to participate in this research if everyone is comfortable with that. I don’t believe in burying my head in the sand and am trying to be as ‘normal as possible’. One of the six principles of research ethics is harm to research participants must be avoided (National Research Ethics Service, 2009). I was faced with the ethical dilemma: should Sarah be excluded from the group in which case there was a possibility that this could add to her distress at a difficult time, or let her participate, which could have implications for the other participants. As Sarah had already voiced her willingness to participate and as long as the remaining participants were happy, the decision was made in consultation with the chair of the university’s ethics committee and a member of ORECNI to let Sarah remain in the group and let the other group members opt out if they
felt uncomfortable. In addition, and similar to phase two of the study, I also developed a link within each focus group homepage to a webpage that contained information on support groups that vulnerable women could avail of.

**Lessons learnt**

There were a few lessons learnt during the project. The first one being, with hindsight due to the length of time it took to get through the research governance procedures for one of the Trusts and the methodology being utilised. I should have focused on obtaining a sample for the pilot of the web-based questionnaires online, as I still had to conduct a second pilot for both phases one and two to test the feasibility of accessing the questionnaire via a URL address using different computer types and international sites/settings. However, there was an advantage of conducting the pilots within the two local Trusts as it provided the opportunity to gain a local perspective on women’s use of the internet in pregnancy.

One key success factor in web-based research is choosing the right software package to program the survey. Releasing an online survey is not as simple as creating a questionnaire in Microsoft Word, copying it to a website and then sending around the URL address. Any data entered into the questionnaire has to be passed to a database somewhere. I was fortunate to have had access to a simple-to-use software package that fulfilled all my requirements. However, I was the first person to use the software in the university so in essence I was piloting a new system and therefore problems like the download perhaps I should have anticipated.

When choosing a software package, ensure it allows a copy of the completed web questionnaires and online focus group responses to be sent to an email account, so there is a back-up copy of each submission in the event of there being problems accessing the data collected via the databases. I was fortunate that I did not lose any data; however, previous researchers using IMR have not been so lucky, such as Braithwaite et al (2003) who suffered a technical error with the server they were using, resulting in the loss of some data. By having a back-up copy of the completed web questionnaire sent to an email account, it also allows the researcher to check that the data received are exactly what were submitted to the database. This is another check to ensure the reliability of the system being used.

Current online survey products and services can vary considerably in terms of available features, consumer costs, and limitations. At the time when the study was undertaken, I was not familiar with any web survey software that permitted online surveys to be published in different languages. However, with the advancement of emerging language technology, there are now software packages available that allow the automatic translation of web-based questionnaires into different languages and are able to create one report that includes all responses. I envisaged if I was to give the explanation that I gave to ORECNI for not including non-English speaking participants today, it would be challenged. However, as Day (2009) points out, conducting a global multi-language survey brings with it its own challenges that need to be addressed, especially in relation to ambiguity. With the possibility of having potential respondents from many different countries accessing and completing a web survey, the researcher must ensure the questionnaire undergoes linguistic and cultural validation to ensure it is valid for extensive use in different cultures, for example, occasionally the same words can have different connotations for different cultures.

I took for granted that all websites had a website counter that would have provided a ‘count’ of the number of ‘hits’ the two individual websites had when the web surveys went live. It was only when I asked for the number of hits to the sites that I realised that the individual sites I had used could not record the number of visitors. This is something I will consider when I undertake any future online surveys especially when I now realise there are services that provide a free website counter and have free built-in statistics facilities.

Many of the issues and problems of conventional research methods still apply in the virtual field (Madge et al, 2004). As Duffy (2002: 87) points out: ‘Experimenting with this new methodology requires understanding how to use the strengths of web-based research and to compensate for its limitations.’ Conducting a pilot study is a crucial element of a good study design, as it may provide an insight into where the main research project could fail, where research protocols may not be followed, or whether proposed methods or instruments are inappropriate (Oppenheim, 2000; Hundley and van Teijlingen, 2002). Piloting is of increased significance in IMR because if the researcher acts too quickly, the result can be disastrous, as a poorly designed study can be sent around the globe at the click of a button. However, as identified in this paper even with pilot studies and the best planning, the unexpected can still happen. Like any researcher, midwifery researchers have a responsibility to anticipate problems and, insofar as is possible, to resolve them without harming the research participants. We should endeavour to protect the physical, social and psychological wellbeing of those whom we study.

Having had the experience of using both traditional methods of data collection and online data collection tools, I would concur with Gunn (2002) that there is no other method of collecting survey data that offers so much potential for so little cost as IMR. Using an online medium to conduct research enabled the researcher to obtain a global and diverse group of participants and present a cross-cultural dimension. As there is so little up-to-date information on conducting IMR, a lot of the learning was self-taught as I went along. Research is about problem-solving and there will always be problems to be solved.

**Motivational feedback**

This research project was filled with highs and lows, tears and laughter, late nights and early mornings. However, my commitment to learn and personal vision to produce a quality research project that was innovative and exciting and would add to knowledge, all contributed to my determination to accomplish my goals. I was and continue to be passionate about my research topic and methodology. It was also reassuring when others felt the same. Feedback from research participants, research and midwifery colleagues, conferences and seminar presentations provided me with the...
reassurance that others also felt that this was a topic and methodology worth exploring. For some midwives it made them reflect. For example, a community midwife from Scotland wrote:

“Congratulations for coming up with such a good topic... I may have to rethink my practice and broaden my outlooks. No one is ever too old to learn new things.”

And a midwife from New Zealand wrote:

“This survey has made me aware of the power of the internet. I have not previously followed up information that clients have talked about. I shall in future make a point of asking clients their information source and follow it up.”

Even some of the women who participated in the focus groups wrote positively of their experience in participating:

“Thank you for allowing us to answer these questions at our pace and read the responses of the others in our group. I am a mother of five-month-old fraternal twins, so if you have any focus groups for twins I would love to take part!” (Becca, US)

Staying focused and motivated was never a problem as the topic was stimulating and IMR not only provided me with a whole range of new technical and research skills, but also brought with it unique experiences. For example, during the online focus groups one of the participants moved house, but still made a huge effort to contribute to the focus group discussion and two of my antenatal participants became mothers and also continued to participate in the online focus group discussion. I cannot visualise that being possible within the traditional face-to-face focus group setting!

Conclusion

This paper has provided a personal reflection and discussed challenges encountered and lessons learnt while using web-based questionnaires and asynchronous online focus groups to conduct a mixed methods IMR study. My doctoral journey was a journey of discovery both professionally, personally and academically. There is no doubt that research is demanding and brings with it highs and lows. As a novice researcher, I learnt how important it is to be passionate about your research topic. My passion for the topic and the novel methodology maintained my enthusiasm about the project and gave me encouragement to explore ways to manage and resolve challenges. Researchers must not become disillusioned when problems become frustrating. Problems are part of the research process. Be persistent and resilient. Do not be afraid to ask and seek support from others with skills and expertise where and when necessary. A final word of advice, focus on the highs, the lows will pass.

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Challenges of undertaking a retrospective cohort study

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This paper was presented at the Doctoral Midwifery Research Society on 29 January 2010. The author would like to thank her supervisors Dr Fiona Alderdice, Dr Maura Stewart, Professor Henry Halliday and Professor Garth McClure.

Abstract

**Aim.** To highlight challenges and lessons learnt from using a retrospective cohort design and historical birth records to determine whether infants born growth restricted achieve the same health-related quality of life in adulthood as infants born at normal birthweights for gestation.

**Study design.** The cohort consisted of 50-year-old adults who were born between 1954 and 1956 in the Royal Maternity Hospital, Belfast. The exposure in this defined population group was intrauterine growth restriction (IUGR). The study group were born at term (≥37 weeks of gestation) with IUGR (birthweight <10th centile) and the comparison group were born at term without IUGR (≥10th centile). A very personal journey is presented, addressing issues such as identifying appropriate resources to use, access and retrieval of historical birth records, sample selection, tracing the sample 50 years on, with discussion around the decision-making process involved.

**Conclusion.** The key message from these lessons learnt is the irreplaceable contribution of data from good quality historical birth records, which give a privileged insight and detailed picture of maternity care provision over half a century ago.

Key words: Challenges, historical birth records, intrauterine growth restriction, reflections, retrospective cohort study, term infants, evidence-based midwifery

Background

Intrauterine growth restriction

The title of my research was ‘Infancy to adulthood: a 50-year follow-up of those born growth restricted’. Intrauterine growth restriction (IUGR) is defined as a failure of the fetus to achieve the expected weight for a given gestational age (Arulkumaran et al, 2004). The fact that some fetuses will not reach their optimal growth potential thus presents a challenge for midwives and obstetricians involved in antenatal care provision. Issues around identifying those at risk and planning appropriate surveillance thereafter, add to this challenge. Antenatal care in developed countries such as the UK, place great emphasis on prediction, detection and treatment of mothers and babies potentially at risk of adverse outcome in pregnancy. IUGR is one of the two major conditions that account for most cases of adverse perinatal outcome, yet unfortunately there has been no substantial progress globally in its prevention, detection and treatment (Sankaran and Kyle, 2009). IUGR is associated with increased perinatal mortality and morbidity, with significant mortality caused by ‘unexplained’ stillbirths, many of whom are small for gestational age. These often present in what may be classified as ‘low-risk pregnancies’, with most deaths involving IUGR occurring after 36 weeks’ gestation (Bricker et al, 2009). This places huge responsibility on midwives, as the key professionals providing antenatal care for the majority of this group of women.

Recent decades have seen the introduction of some of the most innovative therapies in the history of fetal medicine and neonatal intensive care, resulting in an increased survival rate of a heterogeneous group of babies, including those with IUGR (Saigal and Rosenbaum, 1996). It is therefore important to assess if the associated problems with these babies who do survive, impact on health-related quality of life long term. The primary question addressed in my study was: do infants born growth restricted achieve the same quality of life in adulthood as infants born with normal birthweights for gestation? Study objectives were to compare health-related quality of life, general health, health service use, socio-economic status, blood pressure and anthropometric measures in adulthood in a group born with IUGR and a group born with normal birthweight for gestation, using a retrospective cohort design.

This paper focuses on the challenges of a retrospective cohort study and the use of historical birth records, which I encountered throughout the course of my research.

Retrospective cohort design

This was a retrospective cohort study, which received ethical approval from the local research ethics committee, Queen’s University Belfast (QUB) reference number S6/00. Research indemnification was also obtained from the Royal Group of Hospitals Trust Research and Governance Office. The cohort consisted of babies born in the Royal Maternity Hospital (RMH), Belfast between 1954 and 1956, who were traced and assessed in adulthood, after a period of almost 50 years. The cohort was assembled from historical birth records on exposure status. The exposure in this defined population group was IUGR. In all retrospective cohort studies, the investigation begins at a point in time when both the exposure and disease have already occurred (Hennekens et al, 1987). The study group comprised babies born at term (≥37 weeks’ gestation), who were growth restricted (<10th centile) (Arulkumaran et al, 2004; Kliegman, 1997). The comparison group was babies born at term (≥37 weeks’ gestation) and not growth restricted (≥10th centile).

Description of experience

This section of the paper outlines some of the challenges and lessons learnt throughout my research journey. It discusses some of the issues faced and the subsequent decision-making process.

Doctoral fellowship
I was privileged to be awarded a doctoral fellowship by the Research and Development Office for the Health and Personal Social Services in Northern Ireland. It also provided funding for equipment used in the study, under the Small Equipment Scheme. The preparation required for this application was one of the initial challenges I encountered. However, having been successful in this selection process, I would unreservedly recommend the route of a full-time funded PhD, as it certainly reaps rewards on numerous fronts for a postgraduate research student.

Identifying appropriate resources
To undertake this type of study, I required access to a wide range of resources to enable a wider understanding of the Belfast this cohort were born in, and childbirth as experienced at that time over half a century ago. Resources such as such as historians, libraries including the History of Medicine Library (Wellcome Trust) in London, past and present staff of RMH (medical records staff, midwives, neonatologists, obstetricians, physicians) were invaluable. Informal interviews with such staff, in particular, the retired obstetrician Professor Harley who provided historical background information on RMH and secondly, gaining access to hospital reports and health reports for Belfast at that time, made it possible to build a very accurate picture of life, health and childbirth in Belfast for the study period. Support from current staff was crucial in terms of access and retrieval of the actual historical birth records required to carry out such a challenging, but very rewarding study.

Study in context
Study setting
The first maternity unit in Belfast was established in 1793 by ‘benevolent ladies’ who created a charity entitled ‘The Humane Female Society’, which was for the relief of ‘lying-in’ women. Their ‘hospital’ was opened with six beds in January 1794 at Donegall Street to serve poor women of Belfast. A larger replacement hospital was constructed at Lancaster Street in 1830 and, in 1904, a new hospital was opened at Townsend Street. It was replaced by the present RMH in 1933, the setting for this study.

Belfast in the 1950s
This cohort was born into Belfast, which in the 1950s had become a city with a population of 440,000 by 1951. Of the total number of persons employed in manufacturing in Northern Ireland (NI), 58% worked in factories in Belfast. The main occupations at that time were in shipbuilding, tobacco products, linen and specialised engineering of various kinds. The total number of women employed in 1951 (last census available relevant to the study period) was 76,473, which was 42.4% of females in the city aged 14 years and upward (Northern Ireland General Register Office, 1953). It was post World War II and the effects of the blitz were still very evident with overcrowding, lack of amenities and poverty. There were huge public health concerns with tuberculosis rife and maternal mortality rates higher than anywhere else in Great Britain or Ireland. Although the NHS had been introduced in 1948, there were clearly major problems detrimental to the health of those living in the city of Belfast throughout this study period of 1954 to 1956. By 1955, the estimated population was 453,900 and the continuing emigration to seek employment from rural areas to Belfast, combined with low incomes and periodic high unemployment, had created extensive areas of sub-standard back-to-back housing, a substantial percentage of which were slums.

The 1950s may not seem so long ago, yet, these data available, which provide a microscopic and detailed sense of the health in Belfast then, is undoubtedly very different to the Belfast of today, over half a century later (Swann, 1954; 1955; 1956).

Historical birth records
Having established that historical birth records were stored on the hospital’s site, the challenge was then to access and retrieve them. On the surface this may seem a relatively simple task, however, the experience was somewhat testing.

Consecutive obstetric records exist for every birth occurring at the RMH Belfast in the 1950s and have been kept in bound volumes. A three-year period was selected, with the years 1954 to 1956 chosen because records were mostly complete. There were only two missing volumes, one from 1955 the other from 1956, which equated to 200 births. The records were stored in a building separate to RMH, which required a risk assessment, resulting in a delay in obtaining access while a health and safety report was compiled. Medical records staff were not allowed into this building and permission had to be sought from the directorate and medical records managers for the researcher to be granted access. Having overcome that hurdle, negotiating a six-foot high overgrown yard to unlock a door secured by five varieties of locks, seemed relatively simple! When inside there were more surprises, the ‘filing system’ lacked organisation and numerous boxes piled high and in no particular order, had to be negotiated. With a lot of effort and assistance from colleagues, the numerous volumes of birth records were eventually retrieved and transferred to RMH. It was certainly worth all the hard work and was most satisfying to see all these volumes eventually on shelves in RMH ready for use.

It was with great excitement and awe that the first volume was opened. The records were of extremely good quality, handwritten and legible. They were fascinating to read and many long hours were spent going through page-by-page each individual birth record, initially abstracting all relevant details and transferring these on to a hard copy and finally entering the details onto an electronic database. For the three-year study period, there were a total of 6366 birth records.

Sample selection
The next challenge was to begin the search for IUGR babies. Birthweight was converted to grams, and gestational age was calculated based on the first day of the last menstrual period (Hypponen et al, 2003; Strauss, 2000; Kiserud and Marsål, 2000), as ultrasonography was not used in the 1950s. All modes of delivery and onset of labour (spontaneous or induced) were included. Inclusion criteria were singleton, live births at term. Exclusion criteria were multiple pregnancies, those with major congenital abnormalities, and those...
individual potential participants whom their GP deemed inappropriate to include in the study.

The issue then arose as to what growth reference chart was appropriate for use in this cohort who were born in the 1950s. Advice was sought from a variety of organisations and experts in this field. Researchers involved in the Thousand Families Study, which is a prospective cohort study of babies born in May and June 1947 in Newcastle upon Tyne, compared birthweight standard deviation scores by gestation among Tanner et al (1966), Gairdner and Pearson (1971) and the UK 1990 reference standards (Freeman et al, 1995). It was concluded that the UK 1990 reference standard was superior and could be used in the 1947 cohort (Wright and Parker, 2004). In view of this, the same was used for the RMH cohort born in the 1950s. Software provided by the Child Growth Foundation, London – which summarises the UK 1990 growth reference from infancy to adulthood, and is already in evidence and readily available – was thus used in sample selection for this study.

Use of this software made it possible to adjust birthweight for gestation and gender and to convert these to a standard deviation score. The study and comparison groups were selected from n=4667 who met the inclusion criteria. Using Statistical Package for Social Sciences version 11 (SPSS, 2001), a syntax was run to identify the study group (n=491). A random selection of the non-study group was then chosen (n=491). A one-to-one ratio for study group and comparison group was used. A check was done using the Tanner and Whitehouse and Gairdner and Pearson programmes to ensure the study and comparison groups identified were similar to those selected using the UK 1990.

The total sample including study and comparison groups was 982. The overall groups (each n=491) were similar in terms of available birth characteristics. Actual study participants were also similar in terms of birth characteristics and, in addition, social class at time of study. Sociodemographic and lifestyle characteristics such as education, employment, marital status, diet, smoking and alcohol intake, recorded at the time of study did not differ significantly between groups. Losses to follow-up, drop-outs and non-participation were recorded at the various stages to enable the researcher to examine potential sample bias.

Tracing the sample selected
Tracing potential participants proved to be a huge challenge and involved three main phases, namely the Central Services Agency (CSA), GPs and participants. The success of the entire study hinged on this aspect of the research process and as a researcher, I had little control over the outcome. The most I could do was to provide as accurate information as possible and continually follow progress. At this stage I was solely relying on others, particularly GPs, therefore the ability to pass on my enthusiasm and highlight the value of such a study was crucial.

Central Services Agency
The Family Practitioner Services Information and Research Branch of the CSA for NI provide a range of support functions to health and personal social services organisations. When the study and comparison groups were selected, maternal and birth details were forwarded to the branch for tracing. CSA was able to use these details recorded in the birth records of infants born in the 1950s to trace this cohort 50 years on, and identify the GP CSA records indicating who they were registered with. Electronic matching was done for the majority of records and for those traced, CSA provided the GP reference code (n=591) they had linked to individual potential participants, now aged 50 years. The researcher then used a current GP practice reference code list from the four health boards in NI to identify the name and address of these GPs.

Although this service is charged per trace, regardless of whether it is successful, lack of personnel and continuity at CSA compounded the difficulties surrounding the tracking process. One example of the problems encountered is that the first batch returned from CSA did not provide forenames for any individuals or current surnames, which are needed to contact females who are married. It would not have been feasible to send a letter to a GP with no first name for either gender or only a maiden name for married females, as patients with duplicate names and dates of birth can be and were registered in the same practice.

General practitioner
The information returned from CSA was then sorted by health board, GP code and practice. Individual GPs, or where appropriate practice managers were posted a pack consisting of a cover letter, study information leaflet, structured sheet for the GP to complete and a stamped addressed envelope (SAE). Assistance from GPs was essential and this phase required a lot of personal input by the researcher. Some GPs had no record of individual patients, which suggests that CSA records are incomplete or not updated if patients change GP practice. A minority of GPs were not happy to assist with the study and this may be related to data protection issues, or volume of work. Overall however, response from GPs was good.

Participants
When participant information was returned from GPs (n=515), a pack containing a cover letter, information leaflet, consent form and an SAE was posted to potential participants, inviting them to take part in the study. In total there were 235 who participated in the study, three of which completed the questionnaire only, but were unable to attend for testing. Some members of the original cohort now live abroad and completed questionnaires were returned, for example, from Australia, Germany and Hong Kong. Of those who could be contacted, 45% were followed up, which is comparable to a study by Barker et al (1990), also involving follow-up 50 years after birth. It was interesting that some individuals who were born in RMH at that time but were not selected, contacted the research office offering to take part after a friend or relative had received information about the study.

On a small number of occasions, the wrong individual may have been traced or had an incorrect address. One person contacted said she was born in the Republic of Ireland, though had lived in NI at one stage. Another person thought she was born in England and abandoned there and had no information about her early childhood until she went into...

Care in Belfast. In light of the human organs enquiry, a female participant who had experienced a stillbirth several years ago requested information regarding this. All these unforeseen discrepancies created a totally new set of challenges for the researcher that had to be investigated and resolved appropriately. It should be highlighted that no contact had been made with the cohort since they were born in RMH in the 1950s. As it transpired many of the study group were not aware they had been ‘born small’, nor indeed did they know their actual birthweight. This is quite a contrast to deliveries now in this century, where birthweight has such a focus and is one of the first details parents like to know about their newborn baby.

The importance of an efficient administrative database established at an early stage could not be stressed enough. Keeping track of each individual cohort member at each individual stage of the research process, from the original historical birth record entry to tracing through to response, certainly posed a huge challenge.

Reflection on learning

As I wrote this paper, which provides insight into my personal journey of my research experience, I recounted key challenges. These were to the fore as I considered what lessons I had learnt from the experience and how these may help other researchers embarking on such a study as this in the future. To attempt to summarise these presents a challenge in itself. However, key points include retaining your belief in the immense value of your research and the substantial benefits of using data from historical birth records to share with others. Access to such records unlocks the door to give a privileged insight and accurate picture of maternity care over half a century ago. As time passes and midwifery and obstetric colleagues from this era also pass on, these detailed birth records are all we will have to understand what birth was like in the 1950s and also reinforce what progress has been made, particularly in terms of improving outcomes for mothers, babies and their families in the present day arena of maternity care. Yet, to undertake such a long-term follow-up study in the current research climate would continue to pose difficulties regarding data protection and confidential policy, particularly tracing individuals and accessing records. However, many additional challenges may arise, such as the impact of lack of resources. Obstetric records must be kept for 25 years and within RMH as in many healthcare Trusts, there are enormous pressures in terms of available space and associated storage costs of records prior to that period. It is incredibly difficult to contemplate destroying historical birth records and the loss of a wealth of irreplaceable data that provide such an accurate and detailed sense of birth in the previous century.

More generally, establishing goodwill with various key players, often over a series of contacts, was crucial to the overall success of this research. Having worked as a midwife in Royal Jubilee Maternity Service, Belfast also helped considerably, particularly in the early stages of my research. Many challenges were encountered, requiring me to use a diversity of skills and many lessons were learnt along the way and I hope sharing some of what are very personal experiences, will be thought-provoking and perhaps helpful in future research within the maternity care environment. My journey was by no means a solo effort and I am appreciative of all those who contributed to the completion of this ambitious, but very rewarding retrospective cohort study.

References


© 2010 The Royal College of Midwives. Evidence Based Midwifery 8(1): 31-34
Information for authors

Evidence Based Midwifery is published quarterly and aims to promote the dissemination, implementation and evaluation of midwifery evidence at local, national and international levels. Papers on qualitative research, quantitative research, philosophical research, action research, systematic reviews and meta-analyses of qualitative or quantitative data are welcome. Papers of no longer than 5000 words in length, including references, should be sent to: maura@redactive.co.uk in MS Word, and receipt will be acknowledged. Suitable papers are subject to double-blinded peer review of academic rigour, quality and relevance. Subject area and/or methodology experts provide structured critical reviews that are forwarded to authors with editorial comments. Expert opinion on matters such as statistical accuracy, professional relevance or legal ramifications may also be sought. Major changes are agreed with authors, but editors reserve the right to make modifications in accordance with house style and demands for space and layout. Authors should refer to further guidance (RCM, 2007; Sinclair and Ratnaike, 2007). Authorship must be attributed fully and fairly, along with funding sources, commercial affiliations and due acknowledgments. Papers that are not original or that have been submitted elsewhere cannot be considered. Authors transfer copyright of their paper to the RCM, effective on acceptance for publication and covering exclusive and unlimited rights to reproduce and distribute it in any form. Papers should be preceded by a structured abstract and key words. Figures and tables must be cited in the text, and authors must obtain approval for and credit reproduction or modification of others’ material. Artwork on paper is submitted at the owner’s risk and the publisher accepts no liability for loss or damage while in possession of the material. All work referred to in the manuscript should be fully cited using the Harvard system of referencing.

Reference

News and resources

ICM 2011 – call for abstracts
The deadline to submit abstracts to present at the International Confederation of Midwives (ICM) triennial conference in South Africa in June 2011 is fast approaching.

Abstract submissions should be written in English indicating which of the three official languages – English, Spanish or French – speakers would like to present in. Submissions should be based on the conference theme ‘Midwives tackling the ‘big five’ globally’, which are globalisation, listening to women and their partners, the continuum of care, strengthening midwives and midwifery, and cultures, societies and traditions.

Abstracts should be 300 words in length and should be submitted by 17 May. Further information can be found at: www.midwives2011.org/Conference/Abstracts.aspx

Training reduces stillbirth rate
In developing countries, training birth attendants in newborn care and resuscitation significantly reduces the stillbirth rate.

This is the conclusion of a new study conducted in six countries: Argentina, Democratic Republic of Congo, Guatemala, India, Pakistan, and Zambia where local birth attendants were trained in the World Health Organization’s essential newborn care course and a basic resuscitation course.

The researchers note that the rate of death seven days after birth did not decrease after training, but the rate of stillbirths reduced by 30%.

Reference

DMRS conference
The deadline to submit abstracts to the DMRS’s first international conference in September has been extended until 31 March. Further information can be found at: www.doctoralmidwiferysociety.org
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