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CONTENTS

Research ethics: issues for midwives

Key words: Technology, childbirth, doctoral midwifery research society, evidence-based midwifery

The four main principles of research ethics for midwives are the same as for any researcher who has contact with human beings; respect for autonomy, beneficence, non-maleficence and justice. These ethical principles therefore challenge all researchers to consider the risk of harm to the person(s) involved in their research endeavour and to do all in their power to reduce or minimise that risk. However, from a realist perspective, when carrying out research that involves human beings, achieving 'zero risk' is recognised as impossible; human subjects research by its very nature can be 'sensitive' and leave individuals prone to variation in their perception of the benefits, threats and all that lies in between in this continuum of participation. The key principles of ethical research must therefore always be imposed on the researcher that is the students, supervisors and sponsors must be accountable for ensuring that all logical and auditable steps have been taken to demonstrate that their research is ethical, rigorous and commensurate with good clinical practice. In relation to midwifery research, the midwife researcher must act appropriately and within the sphere of her role as a registrant practitioner, to protect the rights of the individual woman, do her no harm, obtain informed consent, respect her individual autonomy and be an agent of professional, legal and moral justice.

While research ethics is today an accepted part of the research process, historically, it is important to note that it was the inhumane experimentation on Jewish prisoners in Nazi concentration camps that led to the need for a recognised ethical code. Development and universality of the ten key principles of ethics is therefore underpinned by the Nuremberg Code (1948); stating that all subsequent research involving human beings must have their voluntary consent and the benefits of the research must outweigh any potential for harm. It was almost 20 years before the World Medical Association (1964) produced a declaration guidance statement that focused on the appropriate conduct of clinical research; known as the *Declaration of Helsinki*, the statement has now been revised four times, with the most recent revision occurring in 1996. The key messages of the statement are presented under three broad categories: basic principles (12 statements), medical research combined with professional care: clinical research (six statements) and non-therapeutic biomedical research involving human subjects: non-clinical biomedical research (four statements). These core elements have consistently reiterated to researchers, the good ethical and clinical practice of autonomy, informed consent, beneficence, non-maleficence, justice and more recently, appropriate independent critical appraisal of the research by appointed committee members.

It is therefore not surprising that the main principles of ethics should be at the heart of every researcher's work and every research ethics committee whose role it is to appraise the submissions before them. As the challenges of research meets the required ethical principles autonomy, beneficence, non-maleficence and justice, the papers selected for this special themed edition of *Evidence Based Midwifery* , clearly demonstrate the importance of careful and guided application by midwifery researchers.

The first paper, by Ryan et al (2011), is a very subtle presentation of the ethical issues and conflicts experienced by five different researchers consciously considering whether or not they were wearing their professional code of conduct hat or their clinical researcher hat; the associated consequences, dilemmas and issues surrounding this challenge is debated and discussed.

The paper by Herron et al (2011) is extremely relevant to researchers' conducting online research and challenges them to explore their professional and academic beliefs about whether or not informed consent is required for this type of research.

The third paper, by Rees (2011), provides an illustration of the problems associated with an 'outsider' to the profession (social worker) conducting sensitive research. Discussing issues such as methodology, professionalism, anonymity, confidentiality and legal issues. Ledward (2011) focuses on the deeper philosophical issues associated with seeking informed maternal consent, respect for maternal autonomy and the role and rights of the fetus.

The final paper, by Anderson (2011), offers educators conducting student research, advice on how to tip the balance from being one of potential vulnerability for the students, to becoming one in which there is a balance of power between the researcher and participants.

In concluding this special edition it is important to remind ourselves that our knowledge of healthcare ethics must be established on research evidence. As a profession we need to collate this evidence for future syntheses so that we can collectively, rationally and sensitively guide our midwifery research strategists and ethicists of the future.

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Which hat am I wearing today? Practising midwives doing research

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Abstract

Doing research and practising as a midwife at the same time can lead to ethical conflicts as the ethical codes for midwifery practice and those for conducting research are subtly different. We use five narrative case studies of midwife-researchers, who have struggled with ethical considerations doing research as a practising midwife, to distil some of the key conflict areas. The key issue was around multiple and conflicting roles including the ethical issues of confidentiality and trust. Potential ethical dilemmas seemed to be related to the amount of control the midwife-researcher had over the research process, especially data collection. We conclude that it is time to discuss the issues and consider how best to support midwife-researchers; we must trust the researcher to make the best possible ethical decisions as we trust the health professional to in practice; and ultimately ethics governing practice must be given priority.

Key words: Research ethics, code of conduct, principles of research, evidence-based midwifery

Introduction

Practising midwives are governed by a professional code of ethics (NMC, 2008) and midwife-researchers like all health researchers are governed by the Helsinki Declaration (see: www.wma.net/en/30publications/10policies/b3/index.html). Midwife-researchers, however, often find themselves positioned between these two behavioural guides with the need to be very clear themselves and to make explicit to others the purpose of their activity at any particular time (Rogers, 2008; Soteriou et al, 2005). Hence the question, which hat am I wearing today? In this paper we ask how midwifery practitioners engaged in research deal with the ethical dilemmas that arise. As midwifery practitioners and educators who are also involved in research we draw upon our collective experience and doctoral work.

Background

All health professionals' codes of practice are based on the four principles of biomedical ethics: respect for autonomy (the right to choose); beneficence (do good); non-maleficence (do no harm); and justice (fairness and equality) (Beauchamp and Childress, 2001). When applied to research with human participants in health and social care settings, these basic principles are translated into many tenets, including but not limited to informed consent, mutual respect, confidentiality, anonymity, trust, truthfulness, sensitivity, protection of vulnerable research participants, debriefing and the safety of researchers. When the roles of research scientist and clinical practitioner are integrated conflict and ethical dilemmas that challenge traditional roles, core tasks, goals, values and professional identities become an issue for all professions (Taylor, 1992; Greenberg, 1997; Morin et al, 2002). In general, these issues revolve around 1) the nature of the relationship between the researcher-practitioner and the participant where boundaries may become blurred and false perceptions and expectations develop 2) confidentiality where anonymity cannot be maintained and 3) the dual roles of the researcher-practitioner where a duty of care and maintenance of the integrity of the research may conflict (Houghton et al, 2010). Recognition of these issues has resulted in suggestions for an ethical protocol for researcher-practitioners providing guidance for when a researcher will intervene in the care of a patient (Houghton et al, 2010) and the development of guidelines for research-practitioners (Soteriou, 2005).

For UK midwives the principles of ethical practice are articulated in *The code: standards of conduct, performance and ethics for nurses and midwives*, so people within the care of a midwife can trust her with their health and wellbeing (NMC, 2008). Midwives often find themselves in multiple roles, for example, clinical practice, midwifery education and research. Ethical dilemmas can arise for midwife-researchers when their code of practice conflicts with the principles of research ethics. Such dilemmas often come to the fore when formulating one's research protocol or application for scrutiny to a research

ethics committee. Preparing such documents requires prior consideration of possible ethical dilemmas and is aimed at raising awareness of situations as well as helping to avoid or pre-empt problems. Conflict arises in these multiple roles when a participant does not distinguish a midwife-practitioner from a midwife-researcher or when a midwife is placed in a position of needing to breach confidentially. We present five case studies of midwifery research to highlight ethical conflicts between 'doing midwifery' and 'doing midwifery research' and how these conflicts were dealt with. These cases also touch upon other ethical dilemmas not specifically confined to midwifery research, including working with vulnerable people (for example, babies and young children), possible identification of participants when anonymity cannot be offered and working in other countries and cultures (for example, Parker et al, 2010; van Teijlingen et al, 2010).

Methods

We use a case study approach (analysing five personal reflective narratives) to give an impression of the range and scope of the work of midwife-researchers, thus providing insight into the similarities and differences that they face around ethical decision-making. Mitchell (1979: 24) defines the case study method as 'a holistic treatment of a subject whereby through the detailed examination of one instance information about a class of entities... may be obtained'. In general, we recognise that the case study 'allows an investigation to retain the holistic and meaningful characteristics of real-life events' (Yin 1989: 14) at the expense of generalisability while possibly demonstrating overriding principles that can be extrapolated to other similar situations. Each of the contributing midwife-researchers wrote approximately two pages in which they reflected on their study particularly on ethical issues they faced and how they dealt with them. These writings were then analysed by all authors to identify overriding issues.

The cases

1. Interviewing lactation consultants by Sarah Brown

As a midwife and an International Board Certified Lactation Consultant (IBCLC) I was always aware of the rewards and stressors of the joint roles. In 2007 I discovered that other IBCLCs working in the National Health Service (NHS) were describing similar experiences and some considered themselves 'burnt out'. Therefore I started a qualitative study to understand the experiences of IBCLCs in England, which included two in-depth interviews set six months apart with 12 practitioners, six of whom were midwives.

The participants changed my ethical practice from being woman-centred to practitioner-centred as my role changed. The collection of personal narratives, through in-depth interviews, encouraged practitioners to experience a similar exploration, which provided a powerful moral idea of authenticity within such accounts (Frank, 2002). The study reflected practical experience in the broad Aristotelian sense as wisdom not only concerning the technical knowledge of practice but as a holistic development of self (MacIntyre, 2007).

The collection of personal narratives was bound up with the participant's identity as a practitioner. Viewed in this way, a narrative could have the potential to become a transformational experience for the practitioner or provide a risk that the process may open participants to issues that could make them vulnerable (for example, Patton, 2002; Holloway and Freshwater, 2007). Elliott (2005) suggested that a researcher entered a personal and moral relationship with participants during the research process. The aspect of hearing practitioner's accounts contained an 'emotional heat' (Holloway and Freshwater, 2007, p.45) that sometimes closely reflected my experiences in practice. Such accounts were traumatic to listen to as well as for the practitioner to narrate (Brown, 2009). Sikes (2010) reflected a similar stance when she considered that ethical review procedures and codes do not always address what may occur during the research process when the researcher may have to return to the essence of personal practice. Maintaining a reflective research log throughout the study enabled me to navigate an ethical pathway within the study.

2. Emotional processing in childbirth (EPIC) study by Carol Wilkins

My research explores the relationship between the way women process their emotions during the major life-changing events of pregnancy and birth and the emergence of perinatal psychological problems. A cohort of 973 women completed three questionnaires between early pregnancy and six weeks postpartum. Participants were assured of anonymity and confidentiality and a structured feedback system was established to ensure that no participants who subsequently suffered pregnancy loss or neonatal death were emotionally disturbed by the receipt of further questionnaires. A number of specific ethical issues arose, however, from completion of the questionnaires, which sought information about women's emotions, mental health, self-esteem and general health. Certain questions might cause distress by raising personal awareness of emotional or psychological vulnerability. However, such probing questions were deemed ethically admissible as they are recommended in normal midwifery care (NICE, 2007). To assist any participants identifying difficulties the information sheet contained advice to contact a midwife or other health professional if they felt anxious. In addition a list of national and local support groups and advice lines was included. This action ensured that the researcher used professional guidance in managing potential risk contemporaneously whilst respecting the confidentiality required of the research study (NMC, 2008).

The questionnaires each included the Edinburgh Postnatal Depression Scale (EPDS) (Cox et al. 1987). Completion of question ten on that scale ('The thought of harming myself has occurred to me') raised a number of ethical issues in relation to confidentiality and duty of care. A response revealing thoughts of self-harm might raise an ethical dilemma for me, a registered midwife bound by professional regulation. Failure to exercise my professional duty of care as a midwife and seek appropriate professional support for women at risk might be deemed negligent and in breach of my professional code of conduct (NMC, 2008). Yet as a researcher I promised confidentiality to participants.

It was decided that in the case of a positive answer to this question research ethics are overruled and the midwife's clinical

judgment must prevail. *The code* (NMC, 2008) expects a midwife to work (which includes 'research') to protect the health and wellbeing of those in her care. Thus responses identified contemporaneously in antenatal clinic would be managed, with the woman's permission, in the same way as other vulnerable women, or else the issue would be addressed in the same way as postal questionnaires, which was to provide advice about contacting their midwife or GP if there were concerns. In this way I managed potential risk, while respecting the confidentiality required of the research study.

3. Midwifery research in Afghanistan by Rachel Arnold

This ethnographic study of Kabul public maternity hospitals explores the culture of care predominantly from the perspective of the healthcare providers. An initial glance at my Afghan ethics application form shows that anonymity, confidentiality, informed consent, risks and benefits have all been duly discussed. Behind the application however lies the complex, multifaceted world of culture. To represent another culture with its underlying meanings, values, perspectives and beliefs, and to delve beyond what is seen will depend not on ethical approval but on my ongoing commitment to perpetual learning, questioning and reflection on this world of 'others,' and equally on my own internal world of values, prejudices, assumptions and the requirements of conduct in professional practice. Challenges include cultural understandings of 'confidentiality' and the translation of information sheets and consent forms. Simply translating words from English to Dari or Pashto does not equate to communicating the same meaning. 'Confidentiality' in Afghanistan appears to mean that you do not tell the patient 'bad' news, but can discuss it with everyone else. Explaining the principle of confidentiality did not involve the Farsi/Pashto word for confidentiality but required words and concepts that can be understood by illiterate and literate alike. As a qualified midwife who has worked in the Afghan health system for some years, my new role as a participant observer with its promise of confidentiality could pose a dilemma. It is possible that during the course of observation I might witness care that is sub-optimal or potentially dangerous. Despite my desire not to jeopardise the study or the trust and acceptance I hope to achieve as an outsider, my most likely course of action would be to inform the ward supervisor immediately. Regardless of the consequences, it is clear that in accordance with the code of practice (NMC, 2008) my first duty of care would be to 'act without delay if a colleague was putting the safety of a mother or child at risk.'

4. Midwifery research with children by Catherine Angell

A PhD study of 56 schoolchildren aged between nine and 11 in Southern England explored children's infant-feeding awareness (Angell, 2010). Children were shown a series of drawings, and a story was read to them about a hungry newborn infant. They were asked to finish the story, showing how they thought the baby was fed using 'Draw, write and tell', a creative method developed for this study. The children produced pictures, often with text, and were offered the opportunity to talk about their own work. This child-led approach to the research was complemented by a range of measures put in place to support and protect children, parents and teaching staff. Parental permission (Koocher and Keith-Spiegel, 1990) was a prerequisite to seeking children's consent to participate. Parents were provided with information about the research as well as contact details of the researchers, and the option to withdraw their child from the research. Careful classroom organisation ensured that the children's contributions to the research were anonymous, especially to the teacher.

Ethical issues related to the perceived vulnerability of the participants (Thomas and O'Kane, 1998), permission and consent (Wiles et al, 2006), gate-keeping (Murray 2005), and research around a 'sensitive' subject in a non-health-related setting. A well-recognised concern when involving children in research is the risk of exposing them to ideas or situations, which they have not previously encountered, which potentially may be harmful or distressing (Freedman et al, 1993).The use of a storytelling technique meant that the children could only respond from their existing knowledge and were not introduced to new ideas. Equally, when the children discussed their creative work with the researcher (a midwife engaged in breastfeeding education) no comment was made about the choices they had suggested. While this was ethically sound it clearly did not provide an opportunity for individual participants to expand their knowledge around infant feeding. As a midwife it was regrettable to lose this opportunity for health education that may have benefitted individual participants in the future, and this epitomized the dichotomy between the role of the midwife and that of the researcher.

5. Exploring women's breastfeeding experiences using video diaries by Alison Taylor

My prospective qualitative study will ask eight women to keep personal daily video diaries for the first two to eight weeks of their baby's life until their feeding method is established. Participants will film anything and everything that reveals their breastfeeding experiences, including interactions with the baby, friends and family and may involve others using the camera.

Informed consent using participant information sheets and a pre-birth meeting with participants will ensure that both the woman and her family have the opportunity to raise questions and have them answered. Since video recording may involve infants, 'parental consent' will also cover the baby or any toddlers (Allmark, 2002). Thereafter, the responsibility and decision rests with the parents as to what images they record.

Further inherent complexity appears initially to contravene the ethical principles of both researcher and midwife alike. Unlike most other research, confidentially and anonymity cannot be maintained when collecting visual data. Obscuring images using computer software to blur facial or other identifiable features was considered but was viewed as 'objectifying people' and a mark of disrespect that might provoke criticism about the integrity of the data or cause offence to participants (Wiles et al, 2008). To explain the loss of anonymity, participation was compared to appearing on television. Evidence suggests that participants who engage in this type of research often want to be identified and have a voice (Tenney and MacCubbin, 2008). To increase safety and security, participants will be advised not to record identifiable features such as road names and

house numbers. Also, they may choose to use a pseudonym. Furthermore, participants will be encouraged to edit their own tapes before releasing them to me, to ensure that only video footage that they are comfortable about sharing is used (Tenney and MacCubbin, 2008). It is argued that recording and editing research material in this way can empower participants to create videos that represent their views, voices and experiences in a meaningful way (Banks, 2001).

According to UK law, copyright of moving images such as video footage belongs to the person actually recording the images (Wiles et al, 2008). In this study that means the copyright of the video diaries will rest with the participants. Before the video data can be used for research purposes, copyright will need to be signed over to the organisation hosting the research. This provides added protection to the participant. Arguably, recording the challenges of breastfeeding on a daily basis could be emotionally draining. When visiting the family to collect the tapes (as a midwife-researcher), I will look carefully for any signs of psychological stress (as a midwife-practitioner) caused by recording and/or editing the video diary and, if necessary, I will suggest stopping data collection and offer referral for specialist support. Reporting the findings without causing any psychological harm will be essential. Participants will be reassured that all data will be sensitively reported and that particular care will be taken not to make any judgements or assertions about their actions or decisions. A reflexive approach will thus be adopted in all stages of the research.

Multiple and conflicting roles

Our five cases raise several ethical issues common to all health and social care research, such as informed consent, confidentiality, anonymity, and cultural and personal sensitivity (Parker et al, 2010; van Teijlingen et al, 2008). The one unique theme that links all is that of the 'multiple and potentially conflicting roles' of the midwife-researcher, especially around confidentiality and trust. The latter is central in the woman-centred philosophy underpinning midwifery, which promotes a close bond between a woman and her midwife during pregnancy and childbirth. In contrast, research ethics guidelines are very clear about the need for a researcher to maintain a role discrete from their professional role. In reality, it might be difficult for a midwife (or a mother) to make this distinction. For example, what does a midwife-researcher do if she suspects or becomes aware that her participant is in a life-threatening situation, such as experiencing domestic abuse or receiving substandard care from a professional colleague? Her code of practice says that she has a duty of care to give assistance or to report the situation to the appropriate authority, while standard research ethics call for maintenance of confidentiality and participant anonymity within the role of researcher. Many ethics committees recognise this dilemma, recommending pre-emptive transparency and information for staff that observed malpractice may be referred to supervisors/managers. In some of the cases above it seemed easier to anticipate ethical dilemmas and attempt to avoid them, for example in the cases of the schoolchildren and that of emotional processing. In others, though, such as the cases of video diaries and conducting research in Afghanistan the potential dilemmas seemed less predictable, largely because the midwife-researcher had less control over the actual research process and data collection environment.

Discussion

From the cases above, we would argue that the midwife's role, governed by her professional code of conduct (NMC, 2008), must override her role as a researcher and her duty of care must come to the fore (Rogers, 2008; Hegney and Chan, 2010). Pragmatics say that when life is threatened a midwife-researcher is morally obliged to exchange her research hat for her professional one and act accordingly. Research-practice dilemmas may possibly be rationalised by ensuring a thorough understanding and adherence to professional codes but this does not stop the midwife from feeling conflicted at times. Thompson (2002), however, looked critically at professional codes of practice and ethics in general and the then current midwifery codes of practice (UK and Australia) in particular and concluded that codes offer very little guidance to enable practitioners to transform principles into the practice of ethical engagement with others. She argued that they were inadequate 'to address context, historical changes, culture, character and relationship' (2002: p531) and called for ethical behaviour based on the sincerity and veracity of human engagement in relationships. Ethical protocols and open discussion may help to reduce the tension between the research and practice roles (Houghton, 2010). Research ethics guidance for nurses was recently updated by the Royal College of Nursing (Haigh, 2009) and by An Bord Altranais (2007) for Irish nurses and midwives but both of these documents are principles-based and very prescriptive. Perhaps it is time to look at NMC guidance for midwife-researchers that is constructed from the experiences of the researcher's themselves. These researchers may be defining a new clinical research discipline (Taylor, 1992).

Along similar lines to Thompson, Holloway and Wheeler (1995) encouraged midwives and nurses to ask questions about the utility of their research, their obligations to the participants and to construct a complex ethical framework for their research. They argued that the researcher-practitioner must be clear about their own identity and their duty to their 'patient' first, responding to distress and need and involving colleagues when appropriate. Our cases show that there is no substitute for good research design, including reflexive practice and the keeping of a research journal and accurate records, design that clearly outlines role boundaries and includes consideration of the possible ethical dilemmas and a means of dealing with them. Moreover, these cases also highlight that 'the researcher is central to ethical research practice' (van Teijlingen et al, 2008). In the same way that the midwife is responsible for their own decisions surrounding the care they provide they are also responsible for the way they conduct their research. In a similar conclusion, regarding doctors doing research, Holmes (2004: 309) suggested: 'We must trust researchers – as we do physicians and surgeons 'to do the right thing'.' We trust the midwife to make the right ethical decisions in their practice; similarly we must trust the midwife-researcher to conduct their research to the highest ethical standard.

Conclusion

However much detail we cram into research proposals, research ethics applications, ethical protocols and codes of practice we

must remember that it is always the midwife-researcher in the field who has to decide what is the best action to take when there is tension between their professional ethics and their research ethics. Moreover we must trust the midwife-researcher to do what is ethically sound, in the same way that we trust them to make the best ethical decisions in practice and education.

Finally, we conclude that ethical considerations governing practice must come first and that there needs to be discussion about the best way to support midwife-researchers. It is very important to conduct research ethically, but it is ultimately more important to save the life of a mother or baby than to study its passing!

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Ethical issues in undertaking internet research of user-generated content: a review of the literature

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Abstract

Background. The internet enables innovative and cost-effective research with an increasingly global population. There are numerous approaches to internet research including virtual ethnography, thematic analysis, discursive analysis and network analysis using data collection techniques such as observation, interviews, surveys and experiments. The point of contact for the researcher includes e-mail, discussion boards, chatrooms, multi-user domains, social virtual worlds, blogs, video sharing sites and social networks. Although some guidance is available, there is no consensus or standardised approach to internet research ethics. While this situation enables freedom to consider a variety of approaches, it can be difficult for researchers (as well as research ethics committees) to ascertain minimum standards and good practice.

Aim. To identify key ethical issues in relation to undertaking web-based research of user-generated content.

Methods. A structured literature search was undertaken using seven databases; PsycInfo, Cochrane Library, Computer and Information Systems Database, CINAHL, Web of Science, Social Services Abstracts, ERIC, IEEExplore and OVID SP Collection. References and citations were also trawled to identify relevant papers, books and web based sources.

Results. A total of 438 papers were retrieved of which 22 were deemed relevant based on the inclusion and exclusion criteria. Thematic content analysis revealed three over-arching themes related to internet research ethics: person-, researcher- and systems-orientated.

Conclusion. Online researchers should consider the ethical issues pertaining to themselves as researchers, the perception of individuals and the unique features of the network environment.

Key words: Ethics, internet research, online ethics, guidelines for internet research, user-generated content, evidence-based midwifery

Background

The internet is now accessed by over a quarter of the world's population (Internet World Statistics, 2010), rising to just over 77% of the population in both the US and the UK (internet World Statistics, 2010; Office for National Statistics, 2010). An increasing number of people, particularly young people, are also accessing the internet through their mobile phones (Nielsen, 2010). The development of Web 2.0 technology has led to what has been described as the 'Participative Web' – an evolution from mainly information seeking behaviour to more interactive behaviour including user-generated content (UGC) (OECD, 2007).

UGC has been defined as 'i) content made publicly available over the internet, ii) which reflects a certain amount of creative effort, and iii) which is created outside of professional routines and practices.' (OECD, 2007: 4). UGC can include postings to chatrooms, newsgroups or forums as well as blogs and multi-media uploads (OECD, 2007: 10). Online activity and UGC provides a rich arena for both interactive research as well as unobtrusive research (Kennedy, 2008) which is easy to access and gives unique insights into everyday life in contemporary society (Garcia et al, 2009). Compared to other disciplines, there is a view that health professions have not fully embraced the research opportunities presented by the internet (Sinclair, 2010; Kennedy, 2008; Stockdale et al, 2007; Haigh and Jones, 2007). However there is limited ethical guidance for researchers and ethics committees about undertaking internet research (Hewson and Laurent, 2008; Keller and Lee, 2003).

Inadequacy of applying conventional ethical guidelines to internet research

The 'Research Ethics Timeline' provides a visual map of the evolution of research ethics from 500 BC to the present day (National Patient Safety Agency, 2008). The literature highlights the Nuremberg Code (1947) which established ethical standards in response to Nazi war crimes as being a particularly pivotal moment for human subjects' research. This code subsequently provided the basis for the internationally recognised Declaration of Helsinki which is used widely by ethics committees to ensure that research proposals respect and protect research subjects.

Many countries have developed their own approaches to human subject research and ethics, with variations in interpretation between countries and even within countries (McKee and Porter, 2009). For example, in the United States, The Belmont Report (Harms, 1978) is the key ethical guidance in human subjects research – identifying respect, beneficence and justice – alongside the most recent (2005) regulations regarding human subject research contained in the code of federal regulations also known as *the common rule* (Chiasson et al, 2006); however, researchers have experienced both exemption and scrutiny when presenting similar proposals to different institutions (McKee and Porter, 2009) reflecting the variation in interpretation and levels of consensus in research ethical approaches. In the UK, the approach to research ethics and governance is becoming more streamlined, mainly in response to European Union (EU) directives and UK legislation, but also due to the need for health trusts and educational institutions to co-ordinate their research processes and activities.

The two main ethical frameworks which are used to guide research ethics are deontological (also known as Kantian) and utilitarian or consequentialist. The deontological approach which is summarised as: 'no human should ever be treated as a means to an end' (Johnson, 2007: 38); is rule based and regards human subjects as autonomous beings with rights such as privacy, anonymity, confidentiality and autonomy (Buchanan and Ess, 2008). In contrast, the utilitarian approach includes focus on the consequences of actions and thus may allow the treatment of human subjects as a means to another end, if the benefits outweigh the risks (Buchanan and Ess, 2008). European Ethics tends to be more deontological in approach while the UK and USA take a more utilitarian or pragmatic approach (Cappuro and Pingel 2002, Ess and the AoIR, 2002).

These principles are applied to individual proposals by researchers and members of ethics committees; however there is uncertainty about their application to the World Wide Web. This raises difficulty in the relative freedom of undertaking internet-based research. While it seems that many of the ethical issues raised by internet research are similar to those in conventional research (Pittenger, 2003; Elgesem, 2002), internet research raises some unique ethical questions (McKee and Porter, 2009, Wood and Griffiths, 2007; Chiasson et al 2006; Pittenger, 2003; Elgesem, 2002). In the past ten years many researchers have debated the adequacy of applying traditional ethics to internet research without reaching consensus (Buchanan, 2010; Berry, 2004; Cappurro and Pingel, 2002; Bassett and O'Riordan, 2002; Ess and the AoIR, 2002; White, 2002; Bakardjieva and Feenberg, 2000). Therefore the aim of this paper is to identify key ethical issues in undertaking web-based research of UGC in online forums.

Method

With the assistance of a subject librarian, a structured literature search was undertaken in order to identify recent guidelines or models for ethical decision making in online research. A modified four step searching and retrieval process described by Taylor et al (2007) was used to guide the literature search.

Step one – *choose the search question:* what are the ethical considerations or guidelines that should be considered prior to undertaking web-based research of UGC?

Step two – *selection of databases:* in order to obtain a wide view of how internet research ethics are approached by a range of disciplines the following databases were selected – PsycInfo, Cochrane Library, Computer and Information Systems Database, CINAHL, Web of Science, Social Services Abstracts, ERIC, IEEExplore and OVID SP Collection.

Step three – *develop search formula:* in order to ensure that the search is both sensitive enough to retrieve all relevant articles and precise enough to ensure that irrelevant articles are not included, Taylor (2007) suggests the following 3 approaches: create concept groups – in this case the research question can be broken down into the following concepts – internet, research and ethics; search terms – internet OR online OR web AND research OR analysis OR observation* AND ethic* OR guideline* OR model*; use of search filters: searches were limited to articles that met the following criteria: published during 2000-2010; written in English; and peer reviewed to ensure quality papers.

Selection of articles: a) Identify and select possible articles: The search identified 438 papers. In order to determine if the paper had a focus on internet research ethics relating to unsolicited UGC, the title and in some cases the abstract were read especially if the title was somewhat obscure (O'Brien and Clark, 2010; Hawker et al, 2002). This process reduced the number of papers to 67 which was further reduced to 52 potential papers by eliminating 15 duplicates. b) Apply inclusion/exclusion criteria. The next stage involved reading the abstract and in some cases the paper where the abstract was obscure (O'Brien and Clark, 2010; Hawker et al, 2002) and applying the following inclusion criteria: If the paper outlined ethical considerations in undertaking research of unsolicited UGC in publicly accessible online venues for example discussion forums and online chat. Reviews or discussion papers were considered to be particularly useful in order to get an overview rather than single studies, however in some cases single studies also included a good overview of the issues. Exclusion criteria were applied to other forms of online research such as researcher-generated online communities, focus groups, interviews, or surveys With the focus on UGC in online forums, player-generated content such as online games and immersion in virtual social

worlds were also excluded. This process, outlined in Table 1, identified 22 relevant papers.

Extending the search, we looked at 'references cited in studies found in electronic searches, including unpublished work or work that has been published outside the academic arena' (Newell and Burnard, 2006: 34). In this regard, a trawl of references and citations from the retrieved papers, identified further articles, books and recommendations about online internet ethics. The inclusion/exclusion criteria identified above was also applied to this material.

Thematic content analysis was undertaken using an approach suggested by Newell and Burnard (2006). The selected papers and supplementary material were read a number of times with the aim of identifying the main ethical issues related to researching online UGC. The ethical issues highlighted in each paper were then synthesised into themes.

Findings

The review of the literature identified three overarching themes concerned with the ethics of internet research of UGC: person, researcher and systems orientated considerations. Each of these themes contains three sub-themes (see Table 2).

Person orientated considerations relate to the human subject research debate, the need for informed consent and considerations about the vulnerability of the participant. Human subjects research is defined as 'that in which there is any intervention or interaction with another person for the purpose of gathering information, or in which information is recorded by the researcher in such a way that a person can be identified directly or indirectly with it' (Walther, 2002: 207). A main focus of discussion in the literature is about whether to classify internet research as human subjects research or text-based analysis. There appear to be at least three distinct perspectives in this debate: general agreement on a human subjects approach with some variations in application, an alternate perspective that regards UGC including online discussions as a type of published work or art and a third perspective which seeks the middle ground. Firstly, internet research is regarded as human subjects research which requires informed consent and the option to withdraw from the research (Kennedy, 2008; Kleinman, 2002; Elgesem, 2002). Some authors advocate that where possible the internet study should include the active participation of subjects (Berry, 2004; Brownlow and O'Dell, 2002; Bakardjieva and Feenberg, 2000). An opposing view is that analysis of publicly available material online should not be treated as human subjects research but instead may be regarded as textual representation (White, 2002; Walther, 2002; Bassett and O'Riordan, 2002) or as non-reactive data collection which can be gathered without the knowledge or consent of the subjects through non-disruptive observation (Janetzko, 2008) or through analysis of archival records (Walther, 2002). A variation on this view is that while acknowledging that some user-generated material may not be human subjects research, care should still be taken to ensure that no harm comes to the people involved or to the group (Kennedy, 2008). Similarly the internet could be regarded 'as a playground for amateur artists creating semi-published work' (Bruckman, 2002: 217) with an onus on the researcher to balance the right of the internet user to be acknowledged for their contribution with their right to be protected from harm through a level of disguise. White (2002: 249) laments the apparent dominance of the human subjects approach in internet research ethics and expresses concern that 'researchers who use human subjects models have not fully acknowledged computer mediation, the constructed aspects of internet representations, and the screen.' She also regards online material as representational writing, art or performance that can be subjected to critical analysis using a humanities model of ethics without the need to consider human subjects

Table 1. Showing the locations trawled for evidence on internet research ethics

Database	Identified papers	Possible paper indicated by title or abstract	Relevant paper
PsycInfo	94	22	11
Cochrane	4	0	0
Computer and Information Systems Database	88	7 (inc 1 duplicate)	1
CINAHL	19	6 (inc 3 duplicates)	1
Web of Science	91	16 (inc 7 duplicates)	3
Social Services Abstracts	26	2	0
ERIC	88	3	0
IEEExplore	4	0	0
OVID Sp	18	10	6
Total	**438**	**67 (inc 15 duplicates)**	**22**

Table 2. Key ethical considerations in conducting internet research grouped according to theme

Person	Researcher	Systems
Human subjects research	Disclosure of research	Public or private space
Informed consent	Dealing with distressing information	Archived material
Vulnerability of participant	Anonymity and confidentiality	Data protection and copyright

concerns (White, 2002). A third view put forward by McKee and Porter (2009) is that defining internet research as either human subjects or published text/representation is inaccurate and that it is more correct to regard this as a continuum along the lines of 'author-person versus person-author' (McKee and Porter, 2009: 81). This continuum reflects the earlier work of Ess and the AoIR (2002) who identified the need for 'ethical pluralism' – an interdisciplinary approach recognising the wide range of ethical traditions including the human subjects model applied by the social sciences, medical and legal disciplines, as well as the non human subjects approach adopted by humanities with emphasis on creative works and publication (Ess and the AoIR 2002). *Informed consent*: is a key requirement in human subjects research. With regard to internet research and the lack of consensus about whether it is human subjects research or not, there is also lack of agreement about the need for informed consent – even when the authors agree that it is human subjects research. Some authors suggest that it is good practice to secure informed consent unless there is good reason not to (Bakardjieva and Feenberg, 2000). Hoser and Nitschke (2010: 183) argue for the right of people 'to be let alone' and suggest that online postings should only be used for the 'intended audience' unless informed consent has been secured. Reasons for not seeking informed consent on publicly accessible sites include not wanting to disrupt the online community especially if the data collection is to be anonymised (Hudson and Bruckman, 2004; Eysenbach and Wyatt, 2002). The practical difficulties involved in securing consent from the entire population of an online forum (Kleinman, 2002) may warrant a waiver of informed consent (Hudson and Bruckman 2004). If a study is not regarded as a human subjects study, then informed consent is not required (Ess and the AoIR, 2002; Walther, 2002). From a copyright perspective, if the material is for research and 'fair use' then it is exempt from requiring informed consent (Hookway, 2008). Alternative approaches to seeking informed consent from the whole community, include contacting the site moderator for 'negotiated consent' to study the site (Kennedy, 2008) and/or contacting individual participants for their permission if quotes are to be used in the study (Eysenbach and Wyatt, 2002. *Vulnerability of the participant and the community*: Many online posters seem unaware that their communication may be subject to covert research, perhaps due to the relative anonymity that the internet appears to offer (Kennedy, 2008; Brownlow and O'Dell, 2002). When considering whether to refer or quote directly from online material that is publicly available, it is important to consider the impact of this on the subject now and in the future. It has been shown that many people post personal information online, without apparent concern or awareness about their privacy or security or the 'informational traces' they leave behind. (Hoser and Nitschke , 2010: 181). The need to ensure that no harm comes to the individual or fellow researchers is identified: 'it is worth thinking about 'the whole picture' and the implications of the research before it is undertaken' (Wood and Griffiths, 2007: 159). It is also important to consider the impact of the study on the community, for example if informed consent is not sought: 'Indeed, the climate of trust in a self-defined community ... can be threatened if information is disseminated without the consent of those concerned. Not only can this be harmful to the people whose words are quoted, but it can also potentially be a threat to the social dynamics that made the group an interesting object of study in the first place.' (Elgesem, 2002: 202).

Researcher orientated considerations include disclosure of the researcher, dealing with distressing information online and anonymity and confidentiality. *Disclosure of Researcher*: The online researcher, like the off-line researcher can choose an approach that is unobtrusive, passive observant or active participant (Garcia et al, 2009). It has been established that it is ethical and legal to carry out web-based research using covert observation or 'lurking' (Ess and the AoIR, 2002, Walther, 2002). Some online researchers decide not to announce their presence online for a range of reasons – they may wish to have a better understanding of the group by lurking before they make initial contact (Garcia et al, 2009; Kleinman, 2002) or they may wish to preserve the group dynamics (Janetzko, 2008). The literature identifies that some researchers are averse to 'lurking' and prefer to engage with the subjects from the beginning of the study (Berry, 2004; Brownlow and O'Dell, 2002; Bakardjieva and Feenberg, 2000). Concerns include the reaction of the subjects and the impact on the group if they become aware that they are being, or have been, secretly studied (Eysenbach and Wyatt, 2002) and this consideration seems to be borne out by a study which found that over two thirds of people in online communities did not react well to the idea of being researched (Hudson and Bruckman, 2004).*Dealing with distressing information online*: this may raise particular questions for researchers who have ethical approval to research public places but are now faced with decisions about what to do with any private or potentially distressing material they might find there (Bowker and Tuffin, 2004; Stern, 2003). If a researcher finds distressing information in online research which is exempt from human subjects protocols, is there any onus on them to do anything? It is suggested that in these cases, the researcher should regard this not just as data, but acknowledge that it has been communicated by 'very real people', and as such it is more than a representation (Stern, 2003: 256). This contrasts sharply with the view that online postings are textual representations and 'not people because this conception makes highly constructed words and images seem natural and stereotyped representations appear to be real.' (White, 2002: 249).Stern's reflections on her own initially unobtrusive research, lead her to question the ethics of undertaking such research from a non human subjects model (McKee and Porter, 2009). *Anonymity and confidentiality*: whether an online study is regarded as human subjects research or representational text, the anonymity and confidentiality of the subject needs to be considered: Anonymity implies that there should be no connection between the data and the subject; and if the data are collected in confidence, the researcher may know the subject's identity but undertakes not to disclose this. A unique concern in online research is the

difficulty of assuring anonymity and confidentiality because if the name of the group, direct quotations or even online pseudonyms are presented in the findings, anybody can enter these into a search engine, and may retrieve the source of the quote, and thereby undermine any confidentiality that may be promised to the individual or the online group (Snee, 2008; Chiasson et al, 2006; Eysenbach and Wyatt, 2002). Another unique aspect to online research is the need to consider that some individuals may want their postings or online work to be acknowledged: 'If the study is low risk, it seems appropriate to give amateurs credit for their work if they desire it. Researchers need to ask: "do you want me to list your real name, your pseudonym, both, or neither?" If the study is higher risk, then listing either names or pseudonyms is probably not appropriate. As always, the degree of risk and potential for harm must be balanced against the benefits of the study.' (Bruckman, 2002: 228).

Systems orientated considerations include public or private space, archival material and copyright and data protection issues. *Public or private space*: this issue has been long debated in the quest for clarity about whether informed consent is required in internet research. The internet could be regarded as a spatial setting for human interaction which could be private or public as well as a place of 'textual production' which is public. (Bassett and O'Riordan, 2002). Membership of a private website or password protected access gives individuals 'a reasonable expectation of privacy' (Chiasson et al, 2006: 80) compared to the publicly accessible online spaces that require no subscription or membership to access data (Ess and the AoIR, 2002; Walther, 2002). However, many people perceive themselves to be in a private space online even when it is publicly accessible (Hudson and Bruckman, 2004; Bassett and O'Riordan, 2002). Furthermore, just because a space is publicly accessible does not automatically mean that it does not require informed consent (Bowker and Tuffin, 2004). It is important to take into consideration the perception of privacy held by the individuals using the site (Hudson and Bruckman 2004, Bowker and Tuffin, 2004; Elgesem, 2002) and their 'intended audience' (Brownlow and O'Dell, 2002: 7) which is unlikely to include researchers (Hoser and Nitschke, 2010; Brownlow and O'Dell, 2002). Assessment of the sensitivity of the topic may give some indication about whether a site should be regarded as public or private (McKee and Porter, 2009). In a global internet study it is also important to consider that the understanding of privacy varies across cultures and this can also influence how the online space or place is interpreted (Ess, 2009). While some online communities may welcome research and publicity, there is a need to check the forum policy about privacy and research – some sites discourage research. If research is perceived to be intrusive, this can irritate online communities (Hudson and Bruckman, 2004) and may also disrupt the dynamics of the community (Eysenbach and Wyatt, 2002). Some researchers regard the issue of alienation to be more fundamental than the public/private debate and advocate that whatever the apparent public/private status of the online arena, participants should not be alienated from the research process: this entails involving participants in the research design as well as the process thereby enhancing the outcomes of the study (Berry 2004, Bakardjieva and Feenberg 2000). *Archived material*: the internet enables easy access to archived materials including datasets, email and discussion board archived material that, if publicly accessible, can be researched without permission (Code of Federal Regulations, 2005; Walther, 2002) and is allowable under copyright law (Hookway, 2008). However, there is a strong view that, 'It is still incumbent on the researcher to protect the confidentiality and privacy of those who wrote the e-mail messages if the study deals with a controversial topic or if reports about the research could negatively affect those who were studied' (Kleinman, 2002: 56). *Copyright/intellectual property and data protection*: Bowker and Tuffin (2004) highlight an ethical quandary that arises when online research is legally carried out without consent and includes direct quotations (which require acknowledgment for copyright purposes): if the research includes the source, this may compromise the subject's anonymity and if the research does not include a direct quotation but conveys the information, the researcher may be infringing intellectual copyright law. All material published online is copyright under US, UK and Australian copyright laws (McKee and Porter, 2009; Hookway, 2008) and although this might appear to inhibit anyone from doing anything with online material, an 'implied license is assumed by society to access information on the web' (Kennedy, 2008: 4). Furthermore the concept of 'fair use' or 'fair dealing' entitles researchers and academics to access and quote such material if it is for non commercial or academic purposes (Kleinman, 2002).With regard to data protection, the usual ethical considerations should apply, however 'the greatest risk associated with online research involves the potential for breaches in subject confidentiality' (Chiasson et al, 2006: 80). Data that is captured online and stored on a computer, may be vulnerable to inadvertent disclosure (Chiasson et al, 2006) or by hackers gaining access 'thus compromising its integrity and confidentiality' (Pittenger, 2003: 47).

Discussion

Ethical issues and dilemmas

The diverse range of viewpoints found in the literature highlights the predicament faced by new researchers and ethics boards with regard to internet research in general and UGC in particular. Within the findings, the key concerns relating to internet research ethics appear to be the blurring of the notion of private and public space on the internet and the subsequent need to focus on the perception of the individual and their understanding of privacy and intended audience; the difficulty of ensuring confidentiality and anonymity in online research coupled with the need to take care with data handling and publication of results; and finally the underlying decision that needs to be made by the researcher about whether the research is based on human subjects or an analysis of text and the subsequent impact that the research and reporting of this may have on the researched individual and their online community. If the research is deemed to be about human subjects, the choice appears to come down to whether a deontological or utilitarian approach is taken; if the internet research is not perceived as human subjects research,

but is rather identified as textual representation, ethical considerations such as anonymity and copyright still persist.

Current guidelines

It is apparent that there are distinct ethical issues that arise when conducting internet research which are not easily answered using the main ethical frameworks (McKee and Porter, 2009; Brownlow and O'Dell, 2002). The dominance of the human subjects approach to internet research clearly challenges those who engage a humanities and non human subjects approach to internet research (Bruckman, 2002; Bassett and O'Riordan, 2002; White, 2002). A number of authors highlight the growing interest in applying a more contemporary ethical framework to internet research using an 'ethics of care' or 'ethos of care' approach (McKee and Porter, 2009; Berry, 2004; Capurro and Pingel, 2002). The Ethics of Care has evolved from feminist methodology with a focus on the researcher-subject relationship and challenges the researcher to consider the impact of their research from a more subjective experiential perspective: in other words 'how would I feel if this was happening to me?' (McKee and Porter, 2009; Buchanan and Ess, 2008).

In recent years, there have been a number of key texts, reflections and developments regarding online internet ethics, some of which have been listed by McKee and Porter (2009): *Ethical and legal aspects of human subjects research on the internet: a report of a workshop* (Frankel and Siang, 1999), the *National committee for research ethics in the social sciences and the humanities (NESH) guidelines* (2003) which have been translated from Norwegian (Lundh and Ess, 2003), an EU code of ethics for socio-economic research (Dench et al, 2004), *Psychological research online: opportunities and challenges* (Kraut et al, 2004) and the ethical decision-making and internet research recommendations produced by Ess and the AoIR (2002). Frankel and Siang (1999) produced what is considered to be the 'pioneering report of internet research' (McKee and Porter, 2009: 157), however while the report is praised for providing an overview of the main issues, it has also been criticised for adopting a rigid ethical approach that hindered approval of internet research by ethics committees (Bassett and O'Riordan, 2002; Walther, 2002). The EU code of ethics (2004) contains broad ethical considerations which can be applied generally, however there is very little specific reference to internet research, and while the NESH guidelines (2003) do provide a specific and user friendly approach to internet research ethics, they have been criticised for being too simplistic (McKee and Porter, 2009).

Kraut et al (2004: 108) identify that internet research 'changes the nature of the risks and investigators' ability to assess it' and provide a list of recommendations for researchers and ethical committees. However according to McKee and Porter (2009: 159) 'these ethical concerns do seem to be a secondary consideration to the emphasis on research integrity and data quality.' While the AoIR guidelines are generally well regarded, they are also perceived to be 'slightly out of date and a little too general' (Snee, 2008: 19) and despite the plethora of guidelines, it seems that many established internet researchers are 'still not certain how to proceed' (McKee and Porter, 2009: 161). The need for more explicit guidelines concerning online research ethics is highlighted with a provision that such guidance should accommodate rather than restrict the innovative practice of online research (McKee and Porter, 2009; Buchanan and Ess, 2008; Berry, 2004; White, 2002).

Conclusion

While there are internationally recognised research ethics, it is clear that there is an ongoing debate about whether traditional ethics encompasses internet research. It is apparent that internet research poses distinctive ethical challenges that many researchers have been grappling with. This review of literature has identified some of the key themes relating to individual-, researcher- and systems-orientated considerations in internet research: most notably the need to focus on the individual's perception of private and public space, the need to consider anonymity or authorship in a digital environment and the need to define the ethical framework for undertaking internet research. All of these considerations underline the responsibility and integrity of the researcher to do no harm. We need specific internet research ethical guidelines that will provide both practical direction and freedom to engage with the opportunities presented by evolving technologies.

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A consideration of ethical issues fundamental to researching sensitive topics: substance use during pregnancy

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Abstract

Background. Pregnant, substance-abusing women remain an unseen group and stigma continues to act as a barrier preventing access to and engagement with care.

Aim. This paper examines the ethical dilemmas experienced when undertaking sensitive research. It reflects upon the particular experiences of a social work educator currently undertaking qualitative research to explore the antenatal support experiences of women who used substances (drugs or alcohol) problematically during pregnancy. The ethical dilemmas examined are universal and relevant to any individual undertaking sensitive research.

Objective. To consider the ethical dilemmas that are fundamental to the process of gathering data on the experiences from women already facing multiple discrimination and inequality.

Method. This paper applies a conceptual framework to the ethical issues experienced when undertaking research following a qualitative, participatory knowledge approach. The research methodology was selected to encourage the empowerment of participants through claiming rightful ownership of their own experiences.

Findings/results. The use of methodological safeguards is fundamental to the protection of vulnerable participants. This process is not straightforward, but a number of strategies exist to safeguard the individual and protect their rights. These strategies are considered in some detail in this paper.

Implications. This framework may assist the qualitative researcher's obligation to take methodological precautions to ensure due care and respect is given to protecting the privacy and identity of those participants willing to share their stories with others. This is particularly important when researching sensitive or illegal issues such as substance use where identification could have a significant impact upon the participant or others close to them.

Key words: Substance use, pregnancy, research, qualitative, ethics, service-user participation, social work, evidence-based midwifery

Introduction

'Research is an activity that, in itself, is fraught with ethical and moral decisions at every stage of the process' (Sherlock and Thynne, 2010).

While the role of ethics within research aims to avoid or minimise harm to participants (Israel and Hay, 2006), there is a growing body of evidence that suggests bias may stem from individual differences in the assessment of the ethical acceptability of research (Kimmell, 1988; Sherlock and Thynne, 2010). This may particularly affect research within the fields of health and social sciences, which are characterised by sets of governing professional codes and standards. As midwives must conform to standards of conduct and ethics, so must social workers: practitioners must be accepted onto the Register of Social Care Workers for their particular country – in Wales, The Care Council for Wales (CCW).

One condition of acceptance is the act of signing to abide by the applicable codes of practice; in Wales these are The Codes of Practice for Social Care Workers (CCW, 2002). The codes identify the professional standards of conduct that the public can expect from social workers, and failure to adhere to these codes may engender one of a range of strict penalties such as admonishment, suspension or removal from the Register preventing any future career in the social care field (CCW, 2010). The existence of professional codes suggests that while guidance can be and is provided, the daily reality faced by practitioners is that each individual case/intervention/action must be decided upon in consideration of and in relation to its own exclusive and distinct set of circumstances.

In the context of midwifery research, this subjectivity ensures that during the 'rigorous process of inquiry' (Sinclair, 2008: 3) the researcher is inevitably required to grapple with a host of ethical and moral dilemmas. Furthermore, research that follows a multi-disciplinary approach with both participants and other professions has the potential to create and develop synergies of mutual understanding (Sherlock and Thynne, 2010), a key requirement of both the National Health Service and Community Care Act 1990 and the Children Act 2004.

The challenge

This paper examines the ethical dilemmas faced by a social work educator undertaking qualitative research to explore the antenatal support experiences of women who used substances (drugs or alcohol) problematically during pregnancy. This is a topical issue, as the attention of policy makers is currently focused on the physical and emotional harm caused to up to 350,000 children (Advisory Council on the Misuse of Drugs, 2003) as a result of problematic parental substance (Copello et al, 2009). The key messages of the *Hidden harm* report (Advisory Council on the Misuse of Drugs, 2003) include the call for effective treatment for parents supported by services that work collaboratively. However, pregnant substance-using

women remain an unseen and marginalised group (Mkandawire-Valhmu et al, 2009; Kerrigan and Houghton, 2010), and stigma continues to act as a barrier preventing access to and engagement with care (Gaudion, 2009; Lloyd, 2010).

Qualitative research

It has been suggested (Rogers, 2008) that while qualitative research was traditionally perceived as a 'female' concept due to its descriptive nature (as opposed to the traditionally more 'masculine' focus on prediction and control) a measured change in values now affords more weight to the understanding of experience. This shift in thinking both recognises and acknowledges the pivotal contribution made by qualitative research to the investigation of complex issues (Hunter, 2007). However, with this propriety comes responsibility, and the qualitative researcher must grapple with a range of ethical considerations in order to produce research that is both ethical and sensitive (Sherlock and Thynne, 2010). The researcher is ethically obliged to take appropriate steps to ensure the wellbeing and safety of the research participants, both during and after the research process (Baker, 2006; Kaplan and Bryan, 2009).

The aim of social sciences research is to build on current knowledge to develop more of an evidence-base for policy and practice (Sherlock and Thynne, 2010). Qualitative research in particular explores feelings and this opens wide the potential for painful experiences to be probed, perhaps unintentionally. Pregnancy and childbirth is always a sensitive topic; even more so when combined with the illegal, guilt-provoking activity of substance use – women may be perceived as little more than 'lethal fetal containers' (Ettorre, 2007: 31). Society remains judgemental in its attitude towards pregnant women in general and is critical of substance use in particular (Harding and Ritchie, 2003; Kerr-Corrêa et al, 2007). The situation is exacerbated by alarming (or alarmist) press warning us 'Pregnant smoking linked to child tantrums' (Nursing Times.net, 2009). The National Institute for Health and Clinical Excellence (2010) has recommended that midwives should administer carbon monoxide tests to every pregnant woman at their first antenatal appointment. This came just after the accusation of 'child-abuse by umbilical cord' (Royal College of Midwives, 2010) by a prominent government advisor towards women who consume alcohol during pregnancy. While these actions are clearly impelled by concern, they remain cloaked in a rhetoric of blame that continues to dissuade women from disclosure of problematic substance use and subsequently acts as a barrier preventing access to support services (Mkandawire-Valhmu et al, 2009; Kerrigan and Houghton, 2010).

Another news headline 'Selling sterilisation to addicts' (BBC News, 2003) refers to Project Prevention, a non-profit making, privately-funded organisation founded in the US that attempts to remove the negative effects that substance use can have on a fetus by paying women (and to a lesser extent men) the equivalent of US$300 in exchange for sterilisation or long-term contraception. Project Prevention has now controversially emerged in the UK, spawning much moral debate including its perceived promotion of sexism, racism and class inequality. In particular, the Project has been criticised for its resemblance to the US eugenics movement of the 1930s which aimed to prevent the reproduction of people perceived to be genetically inferior, including the 'licentious' and the 'indolent' (BBC News, 2003). Therefore, ethical considerations are fundamental to the process of gathering experiences from women already facing multiple discrimination and inequality (Mkandawire-Valhmu et al, 2009; Kerrigan and Houghton, 2010).

The ethical framework

Research governance has its origins in Germany in the 1940s, following the revelation of the extent to which illegal and unethical medical experimentation procedures were abusing human rights. The agreement of The Nuremberg Code in 1946 produced ten principles by which human experimentation should be guided. These principles include the presence of a reputable scientific basis for the research, beneficence and informed consent, with the absence of coercion (Office of Human Subjects Research, 2010). With the Helsinki Protocols of 1964 came greater accountability within research involving human subjects resulting from the introduction of ethics committees (Sherlock and Thynne, 2010). The protocols were most recently revised in 2000 to reflect the development of genetics and the requirement for appropriate guidance for research in developing countries (World Medical Association, 2010).

The focus has shifted somewhat and the concerns of contemporary health and social care researchers include issues of true participation and power (Dominelli and Holloway, 2008) and the balance of governance with sensitive flexibility (Sherlock and Thynne, 2010). Kaplan and Bryan (2009) have suggested that the application of a framework based on an analytical heuristic model can provide a theoretical base which allows the researcher to address both procedural and ethical requirements of research. The framework is based on a concept that originated in bioethics and was introduced by Gerts et al (1997, in Kaplan and Bryan, 2009). The aim was to assist researchers and practitioners develop a meaningful approach that went beyond simply checking the presence of all pieces of documentation required by the relevant ethical review body. The authors believed that research can be undertaken from an ethical stance, and furthermore it can be taught and learned. The framework requires the researcher to consider possible actions and decide if something is ethical or not. This decision, they argue, is based on concepts of 'common morality', 'moral rules' and 'moral ideals' (Kaplan and Bryan, 2009). 'Common morality' refers to behaviour and actions understood by the majority to prevent or avoid harm. However, while 'moral rules' require a certain course of action to be followed, 'moral ideals' encourage but do not require compliance. To apply this framework to practice, 'moral rules' require midwives and social workers to adhere to their respective codes of practice, conduct and ethics and violation of these codes can have a punitive result. 'Moral ideals' require researchers to consider the possible outcomes and balance the risks and benefits when deciding what actually constitutes informed consent for that particular individual in that unique situation at that precise time.

This framework resonates with the work of Barksy (2010) who suggests that traditional approaches to the study of ethical research focused on 'deontology', or 'teleology'. While

deontology comprises ethical duties, for example following a code of conduct (Gray, 2010), teleology considers the ethical consequences of behaviours – the understanding of the moral inspiration behind the code of conduct (Gray, 2010). Barksy further proposes that a contemporary approach of 'virtue ethics' encourages the further development of these positive morals and ideals (Barksy, 2010). These virtuous characteristics include inquisitiveness, concern for others and trustworthiness – all desirable characteristics in a researcher, and purported to encourage a different sort of relationship with service-users. Codes of conduct are simply not necessary because the virtue is intrinsic (although it can be further developed), and because 'it is good to be good merely because it is good to be good' (Gray, 2010).

Research design

Qualitative research relies upon the sharing of experiences; usually sensitive, often painful and sometimes illegal (Sherlock and Thynne, 2010). It is therefore crucial to ensure the methods of data collection selected are appropriate for the task. A multi-method strategy may be considered to avoid the limitations of a single method which 'obscures the breadth of issues and arguments involved in the methodology of social research.' (Hammersley, 1992: 39). However, multi-method strategies come with their own unique set of problems that can encourage 'A diversity of imperfections' (Brewer and Hunt, 1989: 17).

Within this research, a focus group approach was initially considered for phase one – the planning phase. Focus groups represent a relatively unrestricted and free approach to data collection that encourages egalitarianism and the deconstruction of the perception of the researcher's power (Mkandawire-Valhmu et al, 2009). They are an opportunity for participants to validate their personal experiences through a process of articulating their stories and listening to the narratives of others (Mkandawire-Valhmu et al, 2009). The groups can be fitted in to best suit the requirements of the participants in relation to timings and location, reflecting a flexible (Sherlock and Thynne, 2010) and proactive (Kerrigan and Houghton, 2010) approach to research that draws on a feminist approach advocating the welfare of the participants over the aims of the researcher (Mkandawire-Valhmu et al, 2009). Initial contact with potential research participants was made through a professional known to them, such as their midwife or drugs worker, as it would be unethical and a breach of confidentiality for an unknown researcher to make cold calls (Sherlock and Thynne, 2010). As well as being known to the potential participants, the professional will know their situation and will be able to ensure insensitive approaches are not made – such as contacting a woman currently going through childcare proceedings.

Following initial contact, the focus group approach was very quickly reconsidered and dropped in favour of one-to-one meetings with participants when the logistics of getting everyone together in the same place at the same time on the same day were realised. Furthermore, in hindsight a focus group approach may not have encouraged the frank disclosure that resulted from the one-to-one meetings that were instead held, due to participant's prior experiences of stigmatisation and concerns about confidentiality when discussing emotional and potentially illegal behaviours (Makandawire et al, 2009). Therefore, it could be argued that the design was influenced primarily by pragmatic rather than epistemological demands (Cain and Finch, 1982; Brannen, 1992; Punch, 2005). This highlights the requirement of a flexible methodology when researching sensitive and highly stigmatised subjects (Sherlock and Thynne, 2010).

Phase two of the research – data collection – also revealed ethical dilemmas. One-to-one semi-structured interviews were considered an appropriate method of allowing participants more control over the way in which they present their experiences and perceptions. This approach redressed the power imbalance between the participants and the researcher to an extent as it allowed the participants to take the lead as the narrators of their own stories (Sherlock and Thynne, 2010), while ensuring that the focus of the research remained within the boundaries of a pre-determined framework. Construction of the interview schedule was aided by the process of piloting them with the planning group participants prior to the data collection stage, thereby allowing the suitability and appropriateness of the questions to be assessed and amendments to be made prior to the data collection stage (Roulstone et al, 2006). I considered myself fortunate that I was able to benefit from the plain-talking advice of a small number of service users who freely gave their time and expertise to improve my naïve, stiffly worded and preconceived ideas of what I thought the main topic areas were. In retrospect, the question 'What the **** does that mean?' has become by far the single most important and beneficial piece of advice I have been given in the drafting of semi-structured survey questions.

However, semi-structured interviews rely upon the ability of the participants to 'verbalize, interact, conceptualize and remember' the research themes (Mason, 2002:64) within an artificially contrived situation. What we as researchers obtain are responses that have been 'constructed or reconstructed' (Mason, 2002: 64) as we are not able to observe the behaviour itself, and this increases the risk of error or misrepresentation. Furthermore, the researcher may be enticed to select only data that fits with their own preconceived ideas or the research hypothesis, or to select spectacular rather than mundane data. Yielding to this temptation, while being an understandable action, ultimately results in research with questionable levels of rigour and power (Glaser and Strauss, 1967; de Vaus, 1986; Hartnoll, 2004).

Interest in my topic of research began with admittedly preconceived ideas resulting from prior practice experience in a statutory drug and alcohol team and previous research experience. Admitting this lays the research open to criticism based around bias. However, the idea that any form of research can be completely free from the taint of values is itself questionable (Kimmell, 1990; Humphries, 2008). The researcher inevitably becomes locked into a dyadic relationship with the focus of their research, within which they are affected by the focus of their examination while inevitably producing an effect upon it themselves (Anderson, 1991).

Research that may be described as outsider or researcher led, disinterested or even 'neutral' (Dona, 2007: 211) may in fact hinder the compulsion to undertake work that benefits both the target group and the wider populations (Mackenzie,

2007). In essence, the ethical question should instead consider what type of research is morally required: research with, on or for participants? (Hynes, 2003). In my case, so true of the notoriously busy professions of social work and midwifery, time-limitations and a non-existent research budget came into play. The best was made of discussion, recordings, copious notes, reflection and modifications to plans where necessary. It was essential that a consistent reflexive approach (Kingdon, 2005) was used to ensure values, experience and assumptions (Eastmond 2007) were not allowed to corrupt findings, such as the representation of the views of the participants. In my experience and in light of the scarcity of time and financial resources, the assistance of a research planning group and supportive colleagues was invaluable. Nevertheless, the principle of service-user participation in designing research provoked further ethical analysis.

True participation?

The globally accepted definition of social work provided by the International Federation of Social Workers (IFSW, 2000) promotes empowerment and liberation and emphasises the fundamental principle of social justice. Within the UK, this definition is echoed by the Code of Ethics held by the British Association of Social Workers (BASW, 2010), and it is expanded to include the key principles of empowerment and partnership with service users and carers. This belief in the centrality of the service-user is reflected in the rapid development of and current spotlight on explicit service user and carer participation within all spheres of the social care field, including social service planning, delivery and research and education – we are in the era of the 'empowered service user' (Carey, 2009: 179).

In accordance with this entrenched value, I marched into my research arena armed with a passionate conviction that the service-users/participants themselves, as the experts in their own experiences, would be the main driving force of my research. My research would be focused on the emic rather than the etic perspective (Hunter, 2007). My vision balanced participants on at least the sixth rung of the ladder as conceptualised within Arnstein's (1969) model of citizen participation – true partners in the research rather than manipulated, informed, consulted or otherwise placated individuals. A 'participatory knowledge approach' (Creswell, 2003: 6) would be followed, and this would encourage the empowerment of participants through the act of claiming rightful ownership of their own experiences and revealing what they wanted to reveal on their terms. My vision was of true partnership with a planning group of empowered participants or 'collaborators' (Mead 1969: 371), and together we would design understandable, appropriate research that was meaningful to them and which would bring about some yet-to-be-discovered form of 'change'. However, as researchers learn to expect, the outcome differed from the aim and on this occasion a critical ethical dilemma was prompted by this deliberate focus on and inclusion of the rhetoric of the service-user.

While the voices of women from marginalised and stigmatised groups are underrepresented and often unheard in research (Mkandawire-Valhmu et al, 2009), inclusion required particular consideration. Analysis questions whether this method actually does represent participation and engagement at any level beyond the thinnest veneer. It has been suggested (Carey, 2009; Jones, 2005) that this model of 'participation' is in reality a clever use of hegemony (Gramsci, 1971): a shape-shifting tactic that entices unsuspecting victims in with its seductive whispers of choice and equality, while in reality ensuring that those in charge are secure in the retention of their power (Eagleton, 2007). Researchers must undertake cost/benefit analyses in order to consider whose interests are being served: those of the participants, through the inducement of the development of more effective services, or those of the researcher, through the use of social inequality to justify and possibly advance a career. For many participants social inequality is a daily reality (Mkandawire-Valhmu et al, 2009). Research suggests that up to 60% of pregnant women living in refuges are victims of relationship conflict, and they and their abusive partners are more likely than non-victims to use substances (Amero et al, 1990; Campbell et al, 1993). The embodiment of true hegemonist style is to offer disenfranchised people the opportunity of salvation and liberation at an unrevealed cost (Carey, 2009). But, a feminist approach would argue that we as researchers cannot and should not aim to liberate the participants when they have the capacity to achieve that themselves (Mkandawire-Valhmu et al, 2009). However, the researcher has a social duty to ensure that the short and long term beneficial outcomes of research are not exclusive to them or even to the research participants, but are felt by the wider population. This places researchers under a weighty obligation not only to personally undertake but also to ensure potential participants undertake stringent analyses of the potential benefits and harms that may emerge as a result of participating in the research.

Informed choice

The relationship between the researcher and the participant may be characterised as being built upon the touchstone of voluntary and fully informed consent (Kimmel, 1988). This allows the individual to make an educated decision regarding participation, in full knowledge of what will be expected of them and what they will be subjected to, free from coercion and deception (Kimmel, 1988; Sherlock and Thynne, 2010). The principle of voluntary fully informed consent is considered to be particularly important when the behaviour being researched concerns the invasion of privacy relating to sensitive or illegal activities (Mkandawire-Valhmu et al, 2009; Sherlock and Thynne, 2010). Understanding of and commitment to the principles of informed consent, the freedom to refuse to participate and the right to withdraw at any point is crucial to ensure that the subsequent invasion of privacy is undertaken in an ethical manner (Kelman, 1972; Parsons, 1969).

However, the suggestion that consent is only truly valid when totally free from coercion (Kaplan and Bryan, 2010) negates the reality of the situation experienced by most researchers. Participants maintain extremely powerful positions as the keepers of the experiences we as researchers want access to (Kelman, 1972). Despite the best efforts of the researcher, participants may still perceive power differentials between them and the 'expert' researcher (Reinhartz, 1992). In addition, the process of gaining trust is a lengthy one (Jacobson and Landau, 2003) that is beyond the scope of many research studies. Taken

together, these two points suggest that participation can never be fully voluntary, but is instead consistently (albeit unconsciously) coerced by the researcher.

The researcher is ethically obliged to consider the most appropriate strategy for reducing the likelihood of negative outcomes such as stress, shame and reduced self-esteem (Kelman, 1972; Bower and de Gasfaris, 1978; Sherlock and Bryan, 2010) that may result from asking women to revisit and disclose behaviour that is not only frowned upon by society in general but is also illegal in the eyes of the law (The Misuse of Drugs Act 1971). Insufficient consideration of issues that might pose a risk to the participant can impact upon their safety or well-being, in both the short and long term. Fully revealing the nature of the research allows potential participants to make an informed decision about proceeding. However, research indicates that the goal of fully informed consent usually remains unattainable (Kaplan and Bryan, 2009). The ethical dilemma is located in the reason behind this; whether it occurs as a result of chance or by design. It is unreasonable and impractical for the researcher to attempt to disclose and explain to each potential participant every single detail of the research, some of which may emerge during the research process and as such will be unknown at the start. Furthermore, instead of reaching for impossible ideals, the researcher must focus on ensuring potential participants have (in understandable written and verbal forms) sufficient detail to decide whether to proceed or not. This includes information about the research topic and what it will be used for, the role of the participant, systems for ensuring confidentiality and protecting anonymity, the right to withdraw at any stage without detriment to themselves (Kelman, 1972; Sherlock and Bryan, 2010) and the mechanism by which the outcomes will be disseminated to participants. An awareness and open acknowledgement of the bias that stems from the researcher's position and knowledge is crucial, as it is this element that allows the researcher to ensure their judgement remains (as far as possible) unsullied by it (Palmer and Kaufman, 2003, in Kaplan and Bryan, 2009). The key for both the researcher and the potential participant is the balance achieved between the perceived risks and benefits of participation (Sherlock and Thynne, 2010).

Reward for participation

The debate concerning the appropriateness of providing financial reward for participation in research continues. Those in favour of it campaign that payment represents reasonable and equitable acknowledgement of services provided, and represents a tangible respect for the time and emotional generosity of the participant (Mkandawire-Valhmu et al, 2009; Kerrigan, and Houghton, 2010).Opposing arguments revolve around the perception of participants being coerced or even bribed for their contribution: a tokenistic yet businesslike gesture ensuring that the participants sell-out their ownership of and interest in the research and its outcomes (Wright et al, 2006; Kerrigan and Houghton, 2010). In addition, the form and amount that any reward takes requires careful consideration: monetary reward may impact upon the status of participants in receipt of certain types of welfare benefits, while an amount perceived as 'too little' to satisfactorily reward efforts may be perceived as insulting and preclude participation (Mkandawire-Valhmu et al, 2009).

Furthermore, bodies that provide ethical approval for research may quibble over providing financial incentives to individuals who may then use it to indulge in illegal behaviour such as the purchase of Class A, B or C drugs (The Misuse of Drugs Act, 1971). The unwritten message is hardly subtle; that participants are only partners in the research up to a point, as they cannot be trusted to spend the 'payment' in a way that the general public might consider acceptable. However, this is an element that may be beyond the influence of the everyday researcher. The proposal that the reward for participation rests in the long-term potential of influencing and improving the future design and delivery of services can be emphasised and used as an aid to encourage participation (Bower and de Gasfaris, 1978) is laudable. In addition, this approach may also reduce the risk of individuals feeling coerced or obliged to participate. However, it is not that simple when working with vulnerable individuals who already may be filled with self-loathing due to their awareness of the effects of their actions, but who are unable to initiate behaviour change due to barriers created by stigmatisation (Lloyd, 2010; Mkandawire-Valhmu et al, 2009).

Anonymity and confidentiality

Research is frequently focused on the exploration of subjects that may be considered personal or behaviours that may be concealed (Bell and Newby, 1977; Bower and de Gasfaris, 1978). The research must consider the personal cost of revealing what may otherwise remain buried (Mkandawire-Valhmu et al, 2009; Kerrigan and Houghton, 2010; Sherlock and Thynne, 2010). Qualitative research can itself present an enhanced risk of unintentional identification as it characteristically involves relatively small numbers of participants (Baker, 2006). The qualitative researcher is obliged to take methodological precautions to ensure due care and respect is given to protecting the privacy and identity of those participants willing to share their stories with others. This is particularly important when researching sensitive or illegal issues such as substance use where identification could have a significant impact upon the participant or others close to them (Mkandawire-Valhmu et al, 2009). Requiring written consent could dissuade potential participants from contributing to research due to fears of a breach of their identity, or refusal could possibly stem from a conditioned aversion towards procedures perceived as overly and menacingly bureaucratic (Bower and Gasfaris, 1978).

Participants must be informed of (in a variety of different media) and reassured of the basics (Kerrigan and Houghton, 2010; Sherlock and Thynne, 2010). The safe and confidential storage of information; the coding system to be used to ensure confidentiality of demographic data; and the ways in which they can opt-out of the research, from taking a break for a few minutes to complete withdrawal from the research with no detriment to themselves.

My research presented an additional dilemma due to my desire to audio-record the semi-structured interviews from phase two to allow full transcription of the narrative with no gaps of potentially valuable information. While the collection of experiences 'second-hand' may be regarded as acceptable, the act of recording and retaining participants' actual words

may be perceived as antagonistic; in some ways analogous to the hostile act of arming a weapon that could then be used destructively against participants at some future point in time. Furthermore, a qualitative approach embraces the unpredictable and the researcher cannot control what information they are given (Hunter, 2007). Clear explanation of the rationale for recording, arrangements for storage and subsequent deletion of the recorded material is crucial, but those participants who remain apprehensive (possibly due to past encounters with various enforcement agencies) must be clear that they retain the power to opt-out of being recorded with no disadvantage to themselves (Mkandawire-Valhmu et al, 2009; Kerrigan and Houghton, 2009).

In addition to this an iterative model of consent (Mackenzie et al, 2007) advocates systematic implementation of verification throughout the data collection process to ensure the participant remains aware of the purpose of the research and their role within it. This model encourages the establishment of a strategy of continuous negotiation that is ethically more responsive to the needs of the participant than a model advocating the collection of consent at a single point, possibly before the participant has gained an accurate understanding of the research and their role within it (Sherlock and Thynne, 2010).

Reflection

It is vital the researcher takes methodological precautions to consider the interplay of their particular set of costs, benefits and risks (Israel and Hay, 2006; Kaplan and Bryan, 2009; Sherlock and Thynne, 2010), both in relation to existence and extent. My experience of undertaking midwifery research as an 'outsider' to the profession appeared to influence participants in two ways. My perceived objectivity acted as a reassurance that experiences would be reported impartially and would remain anonymous, so would not influence any services received in the future. Participants appeared comforted by the fact that no conflict of interest existed that might influence the research to favour a particular outcome (Lexchin et al, 2003; Mkandawire-Valhmu et al, 2009). However, I believe my identity as a social worker produced a different but no less potent effect. The fact that I was no longer in practice made no difference to the participants' perceptions of me as an individual with the power to remove their children. It is important to acknowledge that women who had their children removed by Social Services would find discussing this experience with another member of the profession extremely difficult.

In addition, not being a midwife meant that I was not party to the wealth of information that lay beneath relatively simple and familiar midwifery terms: for example, a 'nice normal delivery' (Hunter, 2007: 78). However, the development of ethically sound methodological approaches that encourage diversity rather than exploitation or paternalism (Israel and Hay, 2006; Kaplan and Bryan, 2009; Gray, 2010; Sherlock and Thynne, 2010) plus an acknowledgement of the centrality of the relationship between researcher and participant (Hunter 2007; Mkandawire-Valhmu et al, 2009) tip the balance in favour of research that provides benefits while minimising harm to participants (Gray, 2010; Sherlock and Thynne, 2010). Research utilising a collaborative approach with participants and other professionals that is based on principles of trust, clear communication and respect may bring us closer to our aim of research that is both scientifically rigorous and ethically sensitive (Mkandawire-Valhmu et al, 2009; Sherlock and Thynne, 2010).

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Informed consent: ethical issues for midwife research

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Abstract

Background. It is respect for the woman's autonomy that underpins the requirement for informed consent. Midwives with obstetricians are the only healthcare professionals who have the delicate task of balancing two parties' interests, that is the autonomy and beneficence-based obligations to the woman and beneficence-based obligations to the fetus. This is because the fetus is non-autonomous and is incapable of having its own perspective on its best interests. Therefore the obligations owed to the fetus are beneficence-based.

Aim. This philosophically-based paper aims to critically evaluate the ethical dimensions of informed consent relating to research in pregnancy. The main point is that the midwifery knowledge-base should be increased, but the wider implications of such research should be appropriately weighted towards ensuring maternal autonomy and fetal wellbeing. Included in the paper will be a debate pertaining to some of the complexities of informed consent. In this respect, guidance for midwives which is central to the theoretical aspect of the paper and ethically justifiable will be identified.

Method. The paper examines the three threshold elements of informed consent in turn: namely information, competence and voluntariness (Montgomery, 1997). In so doing, some of the dilemmas which beset the woman and midwife in the research process will be debated and discussed and an ethical framework for midwives suggested. Clinical examples illustrate specific points.

Conclusion. Midwives have a responsibility to be cognisant with the three key elements necessary for the woman's consent to participate in a research study, that is, disclosure of information, this must include benefits and risks and details of participation for both woman and fetus, ratification that the woman is mentally competent to understand the given information and finally that her decision is made freely, that is without resort to coercion. These three elements are informed by the principle of respect for maternal autonomy, which is the yardstick by which acceptable intervention can be measured. Seeking the woman's valid informed consent to participate in research raises distinct ethical concerns among midwives.

Concepts explained: The ethical principles of respect for autonomy and beneficence, when applied in practice, generate obligations that safeguard the patient's best interests (Beauchamp and McCullough, 1984). 'Respect for autonomy' promotes the woman's freedom of choice, which incorporates her wish to bring her own perspective to bear on her decision-making. 'Beneficence' is to act for others' benefit by securing the best possible options (Chervenak and McCullough, 1985: 442).

Key words: Midwives, pregnancy, research, maternal autonomy, fetal considerations, informed consent, information, competence, voluntariness, evidence-based midwifery

Introduction

In order to advance medical science, research must be performed into the interventions that work best. It is no longer acceptable to base clinical practice solely on professional experience and tradition, but upon evidence in practice. Furthermore, certain types of care may be ineffective or even harmful and have resource implications. There is a need, therefore, to establish the evidence-base for the effectiveness of an intervention. Research is not treatment. Its aim is 'To obtain new information that is true, ie verifiable and predictive' (Rodeck, 1994: 268). It should be seen as distinct from clinical care, hence the ethical justification for research differs. It would be a narrow interpretation to assume that a research study will always offer potential benefit to research participants. There may sometimes be elements of direct benefit to participants (therapeutic research), or the research may offer a degree of benefit to both participants and future patients. However, research most frequently has the objective of benefiting others in the future (non-therapeutic research) (Gillon, 1991). On a broad spectrum, some research studies may not introduce any aspect of harm or create any effect on the person being researched, others may have far-reaching implications. Examples of these might include a randomised controlled trial (RCT) comparing the effects of medicinal products or research involving human tissue.

The role of the research ethics committee (REC)

The overriding consideration of the researcher must be the welfare of the research participants. To this end, all research proposals involving human subjects in the NHS must be reviewed and approved by a research ethics committee (REC), which functions under the auspices of the National Patient Safety Agency (NPSA) – National Research Ethics Service (NRES). Each study's scientific merit is adjudicated upon by the designated NHS research and development department. The REC is composed of a panel of independent people, both expert and lay. Its remit is to protect the interests of participants, researchers and to promote research that has a sound ethical basis. Space does not permit me to present a detailed account of the REC's role, but of relevance to this paper is that specific attention is paid to each study's patient information sheet, methods of recruiting participants and the mechanisms for obtaining and documenting the participants' informed consent.

The midwifery perspective: an overview

The importance of midwifery research to practice cannot be overstated. This is because 'the notion that the care we provide should be supported and justified by some tangible means has been driven by a number of factors, including the desire to provide optimum care, the needs of women to know the rationale for care provided, and the increasing need to defend practice in

case of litigation' (Lavender, 2008: 95). This is reflected in the International Code of Ethics for Midwives (International Confederation of Midwives, 1993). The midwife researcher is a midwife who conducts her own research and/or as a member of a research team responsible for the accuracy and completeness of information and data (Foster and Lasser, 2010).

Throughout the paper, for clarity and stylistic reasons, 'woman' will refer to the pregnant woman aged 18 years or above and 'midwife' will refer to the midwife clinical researcher in her role as principal investigator (as opposed to midwives who assume the dual role of carer and researcher).

The ethical imperative of maternity care is the welfare of the pregnant woman and her fetus(es). It is a truism that research shifts the normal patient/clinician therapeutic relationship a tier (Gillon, 1991). For the purposes of this paper, the shift is brought into sharp focus from that of the pregnant woman as client and the midwife as clinician to that of the midwife as researcher. This is the framework that will be used throughout the paper.

Ethical principles

In this respect, the cardinal ethical principles of respect for autonomy (self-governance), beneficence (do good), non-maleficence (do no harm) and justice as fairness (behaving fairly) have to be translated into the specific context of individual research studies. As a broad principle, a research study should offer potential benefit to someone while minimising harm. Midwifery research in pregnancy should be clinically relevant and should aim to encompass not only the physical aspects of the study where appropriate, but also engage with the woman's wishes, her hopes, fears and expectations.

Against this background, and central to the paper, it will be argued that, as in clinical practice, the midwife owes the pregnant woman obligations of autonomy and beneficence and beneficence-based obligations to the fetus, if we accept the premise that the fetus is non-autonomous but is valuable and deserving of protection, that is, it has interests. Autonomy, in this sense, means making one's own decisions on how one's life should run, coupled with a vision of the implementation and consequences of those decisions. It is almost certain that most pregnant women would fit those criteria. Arguably, there is an ethically relevant difference from other situations in health care and there may be good grounds to claim that the midwife researcher's obligations add a further dimension 'over and above' those owed by the researcher to the mentally competent non-pregnant adult. This is because there are two (or maybe more to consider). As Elkins et al put it: 'Those who propose that therapy always be directed toward the patient's (or patients' in this situation) best interests are compelled to take both mother and fetus into consideration...' (1989: 153). The midwife researcher has the delicate task of respecting maternal autonomy and weighting the benefits and harms for both woman and fetus in advancing the interests of health science.

A further point relevant to our discussion is that the maternal-fetal interdependence is a unique one. As Purdy puts it, 'Because of their location and state, fetuses are dependent on women in an unusually fundamental and continuous way' (1990: 279). In this respect, there are ethical obligations incumbent on the woman to promote beneficence to her fetus. In view of the maternal-fetal interdependence, the pregnant woman is uniquely placed to influence her fetus' development and pregnancy outcome (Mahowald, 1992). An important point is that different women will determine the weight of their obligations in their own way and the way in which they might be translated into the context of a research study. This may indicate that the woman should give the principle of beneficence towards her fetus greater weight than her own autonomous preferences in certain instances. For instance, in a therapeutic research study that directly involves the fetus, some women may be prepared to accept greater sacrifices to themselves in order to benefit the fetus, whereas others may perceive the maternal sacrifice as too great.

Informed consent

Bound up with the principle of respect for the woman's autonomy is the doctrine of informed consent. Informed consent to treatment is an ethical (and legal) requirement and is the cornerstone of good clinical practice. Likewise, obtaining and clearly documenting valid consent is a crucial part of the research process. This is borne out in the Declaration of Helsinki (World Health Organization, 2008).

For our purposes, we need a working definition of consent: 'Informed consent is a consent obtained freely, without threat or improper inducements, after appropriate disclosure to the patient of adequate and understandable information in a form and language understood by the patient' (UN Resolution, as quoted and endorsed by the FIGO Committee for the Study of Ethical Aspects of Human Reproduction, 1996: 300).

It has been well documented that it is respect for patient autonomy that underpins the requirement to obtain informed consent (Kirby, 1983; Downie and Calman, 1994; Worthington, 2002). Clearly, when conducting research, some of which may or may not involve the fetus, explicit maternal consent is sought in most cases. An exception to this might be in the context of an observational study. If participants are aware that they are being watched, it is likely that they will modify their behaviour accordingly. Hence, in such a study they may be unaware they are being observed. If private and personal behaviour is being watched, this could be seen as an invasion of privacy and an affront to maternal autonomy (Hicks, 2004).

An important strategy of the consent process is to provide a mechanism for women to be involved in the decision-making process inherent in their involvement in the research. Thus, women making such decisions could be seen as a promotion of their autonomy. As Harris puts it: 'Fully informed consent is the best guarantor of the interests of research subjects' (2005: 245). This objective should be reflected in the woman-midwife exchange of information in a way that is meaningful and has a sound ethical basis – this will be discussed further.

Not all research will require formal written consent, although it will require REC approval. Exceptions might include the completion of a postal questionnaire where the act of returning the completed script indicates a woman's consent. Some research may involve the retrospective examination of a woman's case notes and her consent would not be sought.

The paper will now examine the three threshold elements of informed consent: information, competence and voluntariness (Montgomery, 1997). In so doing, some of the dilemmas that

beset the woman and midwife in the research process will be discussed and an ethical framework will be suggested. Clinical examples will be provided so as to illustrate specific points.

Information-giving

Practical considerations

Information is a necessary prerequisite for valid consent and, in this respect, it is the midwife's ethical duty to inform the woman. She should be given adequate time to deliberate over the information, that is a minimum of 24 hours and preferably up to two weeks. This should normally include an invitation letter, giving a brief introduction to the research study and must include a patient information sheet, presented on institution-headed notepaper in legible font size bearing a short title directly relevant to the research study. Factors such as clarity and general readability in the woman's native language are also key.

Information to be communicated on the patient information sheet should convey key factual elements relevant to the study:

- Purpose of the research and its justification
- Processes – including the nature of any procedure involved
- The voluntary nature of the research
- Benefits/harms, alternatives, risks and side-effects (if known)
- Assurance regarding confidentiality and the ways in which her data will be stored, disseminated and published
- In some instances, the need for the woman's GP to be informed
- Follow-up arrangements at a later date (if applicable)
- Contact details of the researcher whom the woman may approach for further information/enquiries
- Designated person (not a member of research team) who may be approached regarding concerns or complaints
- Compensation arrangements in the event of negligent or non-negligent harm
- Practical details, such as claiming travel expenses
- Further information relating to the study, for example if it is part of an educational qualification, sponsorship details
- Approval by a designated REC
- Procedure for withdrawing from the study and confirmation that withdrawal will not affect the quality of care (English et al, 2004; NRES, 2009).

These features form the basis of the woman's decision and will normally be the main criteria against which she will be asked to adjudicate and (subject to her approval) subsequently authorise her decision to participate by signing the designated consent form. An important point here is that the consent form should be completed in triplicate: one copy of which the woman retains, the second is held in the researcher site file and the third is retained in the woman's case notes. This is an official record of her wishes. For further information, the reader's attention is drawn to *Explaining research*, which sets out guidelines for researchers (NRES, 2009).

The presentation of information also has an important function. This can enhance the woman's decision-making. In this context, Pfeffer advises that 'information and consent forms should use short words and sentences' (1996: 186). For example, suppose that a qualitative research study plans investigating women's views of carrying their own case notes. The study involves the woman attending an initial interview at 24 weeks' gestation and a follow-up interview at 36 weeks, both scheduled to last approximately one hour, that is time 'over and above' those appointments ringfenced for regular antenatal care. The woman should decide whether the perceived inconvenience is at an acceptable level. This objective will be more achievable if the information is presented concisely, indicating to the woman the exact nature of her involvement over which she can deliberate. The woman may decide that a 'minor' inconvenience for a 'major' degree of benefit (as she perceives it) justifies participation or it may be what she autonomously wishes to do or she may feel that the reasons for participating are, in her view, insufficiently compelling. These are matters for her to determine.

Let us suppose the conduct of a clinical trial directly involves the fetus. For example, hospital versus domiciliary fetal monitoring in the case of an uncomplicated post-mature pregnancy. As is generally accepted, nothing can be done to the fetus without maternal consent. It rests with the woman to decide whether any sacrifice involved by what (as she may or may not perceive it) is consistent with the obligations of beneficence she owes her fetus. The decision to consent (or decline) can only be reached if the woman possesses information based on firm evidence. For further information, the reader's attention is drawn to *Medical research and you* (Consumers for Ethics in Research (CERES), 2003). This sets out general guidelines for research participants.

Levels of information-giving

Of course, a major obstacle associated with research is that of establishing the correct level of information a woman needs. Women are not a homogeneous group – different women require different levels of information (Lavender et al, 2000; Singh et al, 2002). For example, let us suppose a research study involves the use of a focus group investigating women's feelings on adaptation to pregnancy. Some women might welcome the opportunity to share their views, whereas others may be more reticent. By its very nature, this type of qualitative study may involve note-taking and/or audio- taping of women's quotations by the researcher. The women should be informed that what they say will in due course be analysed by the researcher and may subsequently be published and used as a basis to inform future practice. Hence the women should be familiarised with the study's design and methodology. Such facts collectively form the basis of her decision to consent (or decline) to participate. A woman seeking additional information should merit the opportunity to articulate any concerns and the midwife should respond including those aspects of information the woman considers she needs. This could be seen as a promotion of maternal autonomy.

A further point is that information-giving should be congruous with the nature of the research study. For example, a short concise explanation may suffice for a woman requested to complete a brief, relatively simple questionnaire. However, information relating to the complexities of participation in a clinical trial would warrant meticulous explanation detailing the process of randomisation. The timely giving of information is also important, as is the opportunity for the woman to reflect, deliberate and discuss matters further if that is what she autonomously wishes to do. Slowther and her colleagues (2006) sum up these points very well. They claim that consideration should be given to the presentation of the information, its content, the importance of information-sharing and adequate time to reflect upon it (Slowther et al, 2006). These points cannot be emphasised enough. They could be seen as

consistent with the autonomy and beneficence-based obligations the midwife owes the woman.

Consenting process not episodic

Information 'overload', that is attempting to provide the woman with information relating to all eventualities (assuming they were known) could have the adverse effect of her becoming overwhelmed. Likewise, insufficient information could be seen as an unethical constraint on the woman's autonomy as her consent will be less than adequately informed. It would be ethically incorrect, for example, for a woman to discover in retrospect that relevant facts had been omitted, which would have influenced her decision, had they been disclosed to her (Marteau, 1989; Press and Browner, 1997). The midwife should always draw maternal autonomy and preferences and fetal wellbeing into the equation, and together the woman and midwife should weight any competing considerations. Too much (or too little) information or insufficient clarity between options that might be construed as 'near alternatives' may in certain instances have the potential to confuse and distress the woman. This could be seen as counter to beneficence and will invalidate the woman's consent. The woman may not always make her decision based solely on the information she receives. For example, strong religious beliefs socio-cultural beliefs and personal lifestyle choices may influence her decision (Young, 1986; Wyatt, 2001). She may also want to involve her partner and/or others close to her. Above all, in order to uphold the woman's autonomy and promote beneficence, the woman should understand the nature of the research study to which she is giving her informed consent. It is important therefore that midwives recognise when information may be inappropriate. For example, there may be a need to minimise technical terms and the use of medical jargon in information-giving (Northouse and Northouse, 1998). Those that must be used to capture the essence of the research should be explained clearly and accurately in terms comprehensible to a layperson. Based upon the information, it is the woman's prerogative to reject the study initially, change her mind and make a deferred decision, particularly if participation in research was not something she had previously considered. In addition, should new information become available during the course of the research, the woman should be made aware of it and the woman and midwife should revisit the consent process accordingly. Consent in this respect should be seen as a 'process' not 'episodic' (Lidz et al, 1988).

Throughout this paper I have argued that women should be adequately informed in order to give their consent to participate in a research study. However, there is disagreement among theorists about the extent to which participants should be informed. This raises the question as to whether there are special circumstances when it may be justifiable not to disclose all information.

Let us examine three different theories put forward. There are those who have claimed that full disclosure of information may not always be necessary (Emmanuel and Emmanuel, 1992; Tobias and Souhami, 1993). Such information, claim the authors, which would include details relating to the study's aims, methodology and a risk/benefit analysis might have the potential to distress participants (Emmanuel and Emmanuel, 1992; Tobias and Houghton, 1994). This could be seen as counter to beneficence, and there is a danger that the research participant may discover retrospectively that for whatever reason, she did not merit a full explanation initially. This may result in her mistrust of the service she receives and could be seen as a violation of her autonomy, which the midwife should respect. It also places grave doubts on the validity of her consent. There is much evidence to support the premise that patients wish to be adequately informed and are not necessarily upset by what could be seen as sensitive or distressing information (Kerrigan et al, 1993; Fallowfield et al, 1994; Coulter, 1998). Arguably, the midwife should never underestimate the potential for distress, but this could be seen as insufficient grounds for failing to provide adequate information. The important point here is that the midwife uses a sensitive caring approach and is mindful of the study's potential to cause distress. This could be seen as consistent with the autonomy and beneficence-based obligations she owes the woman.

Another argument relates to the use of randomisation in clinical trials. Barer (1994) argues that participant knowledge of the randomisation process, that is the possibility of being included in the placebo arm, may have the effect of biasing the participants' behaviour. Furthermore, if the study is worthwhile and the risks are negligible, then the research should proceed (Barer, 1994). This is a distinct ethical concern. On the one hand, there is the need to increase the midwifery knowledge-base, but on the other hand, it would require very robust justification not to disclose pivotal information relating to the process of randomisation. It could be argued that even if women lack knowledge relating to which 'arm' of the trial they will be allocated, they still need adequate information on which to base their decision to participate. Hicks (2004) gives an example of a clinical trial investigating the effects of folic acid on neural tube development. The trial could involve women being randomly allocated into the folic acid (intervention group) or the placebo (non-active intervention) group. It might follow that the incidence of neural tube defect will be higher in the non-intervention group. As Hicks points out, participants are unable to express a preference about which intervention they may or may not receive (Hicks, 2004). A failure to disclose details pertaining to the research design could result in serious curtailments being placed on maternal autonomy and could be seen as contrary to the beneficence-based obligations the midwife owes the woman and her fetus. It is difficult therefore to accept Barer's claims as valid.

The third argument relates to the fact that research that could be seen to be in the public interest might be jeopardised by the promotion of individual autonomy (Baum, 1995). This raises the question as to whether it can ever be justifiable to compromise individual autonomy in society's interest. Doyal likens the practice to 'exploitation of individuals' (Doyal, 1997: 1109). Arguably, tensions may arise as potentially valuable research may go untapped as a result of under-recruitment of participants. Much research is aimed at improving treatments (and hence outcomes), which could be seen as a good thing. However, taking into the equation the potential harm that may be inflicted upon the uninformed volunteer (Crisp, 1990), there may be justification for saying that society as a whole cannot be the beneficiary at the expense of others' autonomy – that is the obligation to benefit future generations may be less stringent than the need to preserve the autonomy of any potential participants.

Competence

There is a second element in the decision-making process – the woman needs to be mentally competent to make her decision and thereby give her consent. As Beauchamp and Childress put it: 'Patients or subjects are competent to make a decision if they have the capacity to understand the material information, to make a judgment about the information in light of their values, to intend a certain outcome, and communicate freely their wishes to caregivers or investigators' (Beauchamp and Childress, 2009: 113). The legal definition of capacity (in English law) is that 'the person understands the relevant information, believes the information and is able to evaluate the information and make a choice' (Re C Adult, Refusal of medical treatment, 1995). What is important is that the woman understands that she is being asked to make a decision and, to this end, understands the information that has to be weighed in the balance to arrive at that decision. A further precondition is that the woman is able to communicate her decision (Draper, 2004). Of course, a woman could be competent and yet fail to understand what was explained to her. This may be explainable for several reasons, for example, educational, social and psychological. In this respect, it may be difficult for the midwife to ascertain that the woman has understood the information given to her. This may be more achievable when the information is presented in a concise form (Epstein and Lasagna, 1969). The midwife should draw on her professional skills and judgement and facilitate discussion by means of verbal negotiation and exchange of information thereby promoting maternal autonomy.

Cassileth et al maintain that one of the difficulties in seeking patients' informed consent is the difficulty in determining their ability to recall and retain the information they are given (Cassileth et al, 1980). In order for consent to be valid, the patient should be able, after an interval, to recall the study's most salient features. If they are unable to, then it begs the question of whether they are adequately informed and the true validity of their consent. While their recall need not be immense, they should have a recollection of the main features. Arguably, women will select out the information they feel is most appropriate to their level of comprehension, and will process it in their own way. By adopting an assessment of the woman's comprehension, the midwife can help promote her autonomy (Griffith et al, 1999).

A further problem is that some women may be competent to understand the information, but may be rendered incompetent by the poor communication skills of healthcare professionals (Lidz et al, 1983). This could be seen as an affront to her autonomy and contrary to beneficence. Women have much faith in the profession (Department of Health, 1993) and the woman may feel let down by the system in which she had placed her trust.

A further problem that can be raised relates to cognitive ability (Foster and Lasser, 2010). Most pregnant women are competent. However, 'individuals with intellectual and developmental disabilities may be deemed incompetent to consent for themselves, largely because they may have difficulty understanding and processing the information provided to them' (Foster and Lasser, 2010: 52). In general, research should not be carried out on those who lack capacity to consent, unless it can be shown that the said research could not be carried out on those competent to consent, for example, neonates (Slowther et al, 2006).

Some women may be competent to decide some things, but not others. Competence should not be seen as an 'all or nothing' concept, but might be dependent on the type of decision to be made, in which case a higher level of competence would be required for a more significant decision. If the woman does not understand, then it is the midwife's role to re-phrase the information in such a way that she does and in so doing, she should be mindful that the woman is usually being asked to assimilate unfamiliar information. This goal may be more achievable by promoting the woman's participation, drawing out the essential features of the research and making explanations more prominent, while balancing this objective against those features that could be seen as less important.

There are instances where it may be overlooked that if a woman is competent to understand the implications of her participation in a study and give her consent, then she is equally competent to decline or withdraw her consent at any time without giving a reason. She should have the assurance that her clinical care will be unaffected. These measures are consistent with the autonomy and beneficence-based obligations owed to the woman and the beneficence-based obligations owed to the fetus.

Voluntariness

If a woman consents to participate, it should be determined whether her consent was voluntary, that is freely given, without resort to coercion (for consent to be valid, it must be feasible for the woman to refuse). Some research studies are therapeutic in intent, that is there are perceived benefits for the participant, whereas others are non-therapeutic, that is to say there is no direct benefit to the participants, but it is to be hoped that others may in future derive benefit. Some research is at neither end of the spectrum, that is there are elements of the research that will benefit participants along with the shared intention of benefiting others with the development of new types of care (Gillon, 1991). It is the woman who will exercise her autonomy and will decide whether, in her view, for a non-therapeutic study, the benefits to others outweigh any risks/inconvenience to her. There may be women who would choose to help others, regardless of the perceived inconvenience. This could be seen as a beneficent act.

Information should never be presented in such a way that a woman is led to believe her pregnancy condition is such that she should be included in the research study. Furthermore, what would be censurable is a situation whereby the research was presented to the woman as a routine care package. This would invalidate her consent and could be seen as flagrant coercion. There may also be instances where the information over-emphasises the perceived benefits of the research to try to ensure the woman arrives at the decision the midwife favours. For example, the main objective might be to try to maximise the numbers to be included in a research study. This might be seen as ethical in certain circumstances. For example, if a designated number of participants were statistically required in order to provide the researcher with sufficient sensitivity to answer a specific research question. (It could be seen as unethical to hinder potentially useful research). However, the researcher may be under pressure from a sponsor to recruit a designated number into the study (Jones, 1999). There is a risk here that an act of coercion by deception may occur. Because the decision

to be made calls for a decision by the woman on information known to the midwife, it seems imperative that it is explained in a transparent way. The woman's decision is final.

The midwife should be mindful of influences, which may be present in such a way that they are barely noticeable, that is a subtle form of coercion. For example, over-rigorous follow-up to an initial invitation letter to participate. On balance, whereas one telephone call as a reminder could be seen as helpful, the midwife should beware of over-policing the situation. Arguably, the midwife is making a request to the woman for her help. It is a moot point whether women have a duty to participate in research and another set of arguments would be needed to debate the issue, which is beyond the scope of this paper (Jonas, 1970).

Beauchamp and Childress (2009) have claimed that there is another precondition for coercion. They state that whether or not an act of coercion occurs may depend on the response of the person targeted. This is a useful point. In order to illustrate it, consider the following scenario. A midwife is inviting women who smoke to participate in a series of semi-structured qualitative interviews investigating their views of smoking in pregnancy. This issue is of considerable importance to clinicians and the multidisciplinary healthcare team. In addition to the adverse effects on her own health, the pregnant woman cannot segregate what she wishes to do (that is smoke) from harm to her fetus. The conflict (where it exists) lies within the maternal-fetal unit. No one except a pregnant woman could claim that their acts or omissions stood to benefit or harm another person in the same way, that is, the issue is more complex than in non-obstetric cases. Smoking in pregnancy is regarded by many as a sensitive issue. In addition, the situation presents a challenge to the midwife who needs to be self-critical as regards personal bias and this trait should subsequently be borne out in the questions posed. Woman 'A' who has significantly reduced her cigarette consumption and wishes to discontinue smoking is invited to enrol in the study. Although not 'absolute', rarely would an act of coercion occur as the woman autonomously welcomes the opportunity for reflection and discussion, so for her, the research has a therapeutic element. Contrast the situation with woman 'B' who wishes to continue smoking. She claims that smoking is her sole relaxation and that she takes her responsibilities to her fetus and her own welfare seriously in every other way – for example, eating a healthy diet and exercising. Woman 'B 'might regard the study as an attempt to discredit her behaviour in some way.

While it should be emphasised that the decision to consent or decline to participate rests with the woman, whether or not coercion occurs, may depend on her interpretation of the study's objectives and what she is led to believe will happen to her. It is imperative therefore that the patient information sheet is clear about the purpose of the study and that the language and explanatory terms used are (as far as is practically possible) value-neutral. The midwife's position needs to take account of the fact that maternal autonomy and fetal welfare should be balanced against maternal autonomy, which the midwife should respect. This raises the question of the extent to which the midwife should go to promote beneficence in the case of lifestyle choices such as this. Although the midwife has a duty to inform regarding the detrimental effects of smoking, measures should not go beyond advice in the form of information-giving and general encouragement. The midwife should vehemently resist the temptation to probe around those questions most likely to yield the information she desires. This could be seen as the antithesis of what the woman believed she was giving her consent to, and secondly, as a form of coercion by deception. It may also markedly distort the validity of the findings.

Finally, it is noteworthy that some women, relatively unaccustomed to asserting themselves, may feel overwhelmed at the prospect of their involvement in research as decision-making in health care can be complex (Waterworth and Luker, 1990). In order to maintain their autonomy at a consistent level, they may decline to choose. The midwife should guard against directing wanton responsibility onto these women and beneficence dictates that she should relieve them of the burden of complex information.

Ethical framework for midwives

In this paper, good ethical practice for midwives seeking informed consent from women for research in pregnancy has been suggested. The guidance gives prominence to the ethical obligations of autonomy and beneficence owed by the midwife to the woman and the beneficence-based obligations owed to the fetus. The guidance recognises that tensions may arise between the need to advance the midwifery knowledge-base and a woman's autonomy and preferences. Although there are instances when the course of action is clear-cut, in less well-defined cases, one strategy might be to opt for the least restrictive course of action in order to preserve maternal autonomy at a reasonable level – that is the advancement of knowledge is not the ultimate good. Although it is highly improbable that the correct balance is achievable in every case, the guidance may be useful to midwives adjudicating between some of the complexities raised. It is to be hoped that the guidance will help lead to fewer decision-making conflicts.

Conclusion

This paper has illustrated that the correct balance of information is not easily captured. Competence should be seen as a relative concept. However, midwives should ensure that they do not use the woman's competence as an explanation for what they may see as inappropriate reasoning. Whether coercion actually occurs may depend on the woman's response to what is being proposed. There should at least be a strong presumption in favour of maternal autonomy. It would be seen as ethically incorrect to overlook the woman's preferences and concerns within reasonable ethical boundaries. Women's decision-making is a complex process and all decisions are bound by maternal consent. The issue is not whether a competent woman gave her consent to participate in a research study, but whether her consent was adequately informed and freely given. It is imperative that midwives do not use the advancement of the corpus of midwifery knowledge as the guiding principle in the decision-making process. Research evidence and outcomes need to be well supported in the scientific sense and may provide the impetus for further research, which could be seen as a good thing. Above all, the decision relating to whether or not to participate in a research study rests with the woman whose consent is being sought, not the midwife who is seeking to obtain it.

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Students as valuable but vulnerable participants in research: getting the balance right using a feminist approach and focus group interviews

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Abstract

Background. This approach to data collection was undertaken as part of a Master of Science in midwifery study exploring student midwives' perception of the meaning of 'normal birth'. Ethical consideration indicated students may be a vulnerable group. Guided by a feminist approach and using focus group interviews aimed to balance the valuable contribution of students as a resource with their potential vulnerability.

Aim. To explore the challenges and value of using students as research participants.

Outline of the main content. As a resource it has been suggested that students are an underused group particularly in relation to their own experience and preferences. Although described as a valuable resource students might also be identified as vulnerable due to a possible lack of autonomy. Students may be described as vulnerable because the researcher holds multiple roles such as a midwife who is both a researcher and a lecturer. Although students are considered as autonomous adults capable and competent of providing informed consent, their competence to refuse may be impaired. Although the definitions of focus groups vary there is general consensus with regard to the distinguishing features which are also incorporated within a feminist framework. Focus groups are particularly naturalistic when members know each other and apart from the supportive nature this creates it may offer a relatively safe environment in which to share their experiences and also address any power imbalance between the participant(s) and the researcher. Interactive analysis provides additional support of the findings and improves rigour.

Conclusions. Using focus groups with vulnerable groups such as students balances power relations. Careful planning creates an environment in which students feel safe to share their experiences and reduces their potential vulnerability. Thus the potential of students as valuable resources of information could be more widely used in healthcare research.

Key words: Midwifery students; ethical integrity; focus groups; feminist framework; vulnerable; evidence-based midwifery.

Background

This paper was written as a reflection on the ethical consideration required to undertake a research study as part of a Master of Science (MSc) in midwifery award. The study aimed to explore student midwives' perception of 'normal birth'. Research involving people is laden with ethical concerns and maintaining ethical integrity in research that involves students as participants is particularly challenging, especially if the researcher is also a lecturer involved in the facilitation of their learning (Ferguson et al, 2006). As a resource, students are valuable participants in research, both in developing education curricula and providing fresh insight into clinical practice (table 1). It has been suggested that students are an under used group in research, particularly in relation to their experience and preferences (Kevern and Webb, 2001).

However, although described as a valuable resource, students may also be identified as vulnerable due to a possible lack of autonomy (Hurst, 2008) and because the researcher holds multiple roles such as a midwife who is both researcher and a lecturer (Clarke and McCann, 2005; Ferguson et al, 2006). Students may be considered autonomous adults capable and competent of providing informed consent, however, their competence to refuse may be impaired due to perceived coercion or even altruism.

The purpose of this paper is to reflect on how the potential vulnerabilities of students as research participants may be reduced and thus the valuable, even essential, contribution that students make to the development of knowledge and practice may be further enhanced. Using focus groups within a feminist framework aimed to balance power relations and with careful planning create an environment in which students felt safe to share their experiences and reduce potential vulnerability (see table 2). This would then demonstrate the potential of students as valuable resources of knowledge, which could be more widely used within health care and educational research. Integrity is paramount within qualitative research and the onus lies with the researcher in terms of rigour of analysis, reflexivity and honesty in writing up the research (Manning, 2004). Reflexivity is considered a crucial element of a feminist approach to research.

The feminist view of the methodology of any study is concerned with the place of women throughout the research process. In keeping with the study that was undertaken. Carter (1995) indicates that feminist approaches require understanding women's experiences in relation to patriarchal social relations. More central than the questions asked are the intentions behind the research, the ways in which responses are understood and the theoretical perspectives that frame

the discussion (Carter, 1995). Lavender et al (2004) suggest that there are three characteristics, although not unique to feminist approaches, within a feminist qualitative study that are strongly identified. Firstly, they consider reflexivity to be crucial. Reflexivity being the continuous process of reflection by researchers of how their own values, perceptions, behaviour or presence and those of the participants can affect the data collected (Parahoo, 2006). The remaining characteristics are a consideration of a transformative and emancipatory potential, and the awareness of inter-subjectivity. The feminist perspective centre upon the challenge to dominant assumptions, inequities and social injustice that relate to women. It is critical in the sense that it seeks transformation and emancipation (Lavender et al, 2004).

Inter-subjectivity indicates the common feelings, opinions and empathy of individuals who share a common world (student midwives) and meaning is mutually constructed by the researcher and participants. These three characteristics will become evident within the discussion of the data collection tool, namely focus group interviews. However, it is important to discuss the ethical concerns of informed consent and confidentiality.

The issues of informed consent and confidentiality require careful consideration in all research studies involving people. Informed consent is fundamental. The principle of informed consent aims to ensure that participants are not coerced, persuaded or induced into research against their will, but should be based on voluntary participation and on a full understanding of the implications of participation (Green and Thorogood, 2004). Bradbury-Jones and Alcock (2010) advise that there should be a balance of understandable information provided. However, the process of informed consent will be undermined if the assumption is made that, as students of midwifery, the participants understand the research process (Holzhausser et al, 2008). Therefore, balanced information about participation in a research study needs to be provided in a timely fashion allowing participants the opportunity to clarify issues and reassure the researcher that indeed the implications of participation are understood. This was achieved through careful planning within this study. The students were provided with balanced information about the study at the beginning of a seven week tuition period, and the focus group interviews were scheduled to take place in the seventh week of tuition. This schedule allowed time, space and a safe environment for students to discuss and clarify any issues arising and for the researcher to seek assurance of their understanding.

Table 1. Students as valuable

Accessible
Convenient
Voice of student experience
Fresh insight
Development of evidence for education

Table 2. Students as vulnerable

Captive participants
Convenient
Limited ability to freely consent
Perceived lack of autonomy
Perceived coercion
Unequal power relations
Restrictions of anonymity and confidentiality

The process of informed consent is set firmly within the principle of respect for autonomy (Holloway and Wheeler, 2010) and research governance. Researchers are obliged to respect the human rights of their participants, based on the ethical principles of beneficence, respect for human dignity and justice (Department of Health, 2001; Polit and Hungler, 1999). Particular care needs to be taken when involving people who have been identified as vulnerable to harm due to their lack of autonomy (Polit and Hungler, 1999).

Clark and McCann (2005) have suggested that students, although rarely described as a vulnerable group within research texts, may be considered a vulnerable group. Hurst (2008) urges caution in classifying groups as vulnerable due to the potential of stereotyping and the implication that vulnerable indicates an incapacity to make decisions. However, students may be considered vulnerable because the researcher holds multiple roles. Within this study the researcher was also a midwifery lecturer involved in the teaching of the participants and although the student participants were considered autonomous adults capable and competent of giving informed consent, their competence to refuse may have been impaired (Social Research Association, 2003). Polit and Hungler (1999) advise that participation must be both informed and voluntary as it is possible for consent to be informed but not voluntary if there is any perceived threat of coercion. In contrast Dalziel (1996) argues that the preoccupation with coercion in relation to students as research participants is misguided given that students participate with other equally coercive course expectations such as attendance, assignments and examinations. There is also contention that participation in research is actually beneficial for students in that it enhances the learning process and may be therapeutic (Dalziel, 1996; Dickson-Swift et al, 2006; Bradbury-Jones et al, 2010). Indeed, some students may perceive themselves disadvantaged if unable to participate (Bradbury-Jones and Alcock, 2010) therefore it is important that all eligible participants are offered the opportunity to participate.

However, potential participants must be assured that their refusal of, or withdrawal from, participation will not lead to any form of penalty or discrimination nor should the decision

whether or not to participate affect the relationship between researcher and student either positively or negatively (Polit and Hungler, 1999).

For this study it was not possible to disguise from the researcher which students agreed to participate and those who refused. However, each student was provided with written assurance that their refusal or consent to participate would neither affect them positively or negatively and that they could withdraw from the study at any time without fear of discrimination. In addition, the students were made aware that the study was being undertaken as part of a MSc in midwifery which in effect reduced the researcher/lecturer role to that of a student also and in doing so reduced any perceived unequal power relationship between student and lecturer. It may be argued that the knowledge of the study being undertaken as part of an academic award persuaded students to participate altruistically however the subsequent analysis of the collected data and particularly the group interaction supported their voluntary participation.

The ethical issue of confidentiality within a focus group method of data collection is described by Morgan (1998) as inevitably involving the sharing of information, with privacy becoming a crucial ethical concern. Few focus groups can offer true anonymity as participants can be identified by both the individuals of the group and also the facilitator but confidentiality can be assured by carefully protecting any identifying information (Morgan, 1998), although it is difficult to provide an absolute guarantee of confidentiality (Green and Thorogood, 2004).

Confidentiality was achieved within the study by ensuring that only the facilitator/researcher had access to the audiotapes (the tapes being transcribed by the researcher/facilitator); the audiotape and subsequent transcripts were kept securely in a locked cupboard and pseudonyms were used to protect the identity of the students. The author's study has not indicated which cohort of students participated or when the study was undertaken, nor have any of the clinical units utilized for clinical placements been identified. Prior to participating in the focus groups the students were reminded of their responsibility regarding confidentiality (including the possibility of disclosure which may necessitate breach of confidentiality) and to respect the privacy of any personal information which may be divulged during the focus groups.

Although definitions vary slightly within the literature there appears to be agreement with regard to the distinguishing characteristics of focus groups (Kevern and Webb, 2001). These characteristics are: flexibility; small group size and purposive selection; interaction of group participants; balance of power, and the interactive role of the facilitator within the group dynamics. With the exception of group size these characteristics are also incorporated within a feminist theoretical framework.

Focus group approaches are reported to be flexible (Kevern and Webb, 2001) and dynamic. This, Barbour (2005) suggests, enhances the creativity and innovation of research and for this reason advises against setting strict criteria, rather advantage should be taken of the possibilities of this flexible method (Barbour, 2005). Indeed, Davies (1999) indicates that the very nature of flexibility of focus groups has created a powerful tool in academic research.

Carey (1994) recommends that focus groups should be homogenous in terms of age, status, class, occupation and other characteristics, as these will influence whether participants interact with each other. Morgan (1998) indicates that the use of pre-existing groups is particularly beneficial when one wishes to re-create the context that is being explored. Focus groups are particularly naturalistic when group members are composed of participants who already know each other and are more easily tapped into the 'natural' processes of communication such as arguing, joking, challenge and disagreement (Wilkinson, 1999). This was a characteristic clearly evident within the author's study. Apart from the supportive nature of focus groups; which are composed of peers and friendships, Barbour (2005) indicates that homogenous groups offer participants a relatively safe environment in which to share their experiences and also address any power imbalance between the researcher and the participant by taking advantage of the naturally occurring peer group (Kevern and Webb, 2001; Wilkinson, 1999). The focus group is then collectively powerful (Lehoux et al, 2006) and members encouraged to engage positively in the research process (Rabiee, 2004). All of which is particularly relevant when undertaking focus group interviews with student midwives and which were clearly demonstrated during the focus group interviews in the author's study. Green and Thorogood (2004) also recommend the use of naturally occurring groups who already know each other as this not only achieves the content and context of the social knowledge, but it also maximises interaction between participants as well as between the facilitator/researcher and participants.

Focus groups capitalise on the interaction and communication between participants and also between facilitator/researcher and participants. Lehoux et al (2006) describe this social interaction as a unique quality of focus groups, although this quality may be missed during the analysis of data (Kitzinger, 2006; Kevern and Webb, 2001; Wilkinson; 1998). It is felt that as a method of data collection focus groups are less intimidating than one-to-one interviews, especially for students (Kevern and Webb, 2001; Lam et al, 2001); which was of benefit within the author's study as the participants were student midwives. Quite often participants are empowered and able to discuss freely while also being stimulated by the thoughts and comments of others in the group (Robinson, 1999). The role of the facilitator/researcher within the group is vital to creating this interaction between group participants.

The role of the facilitator/researcher is pivotal to the nature and quality of the data collected (Sim, 1998). The facilitator/researcher in their behaviour (verbal and non-verbal cues) has a powerful influence on how the participants interact. This influence may also create the possibility of introducing bias. Part of the difficulty is achieving a balance between too much control of the group, which can prevent discussion or lead it to reinforce pre-existing expectations, and too little control, which may prevent the issue of concern being discussed at all (Morgan, 1998; Sim, 1998). Carey (1994) suggests that the person undertaking the research may not always be the most suitable person to facilitate the focus group. This may be due

Table 3. Lecturer as researcher

Divided loyalties
Conflict of interest
Intention of research
Familiarity with topic and students
Relationship with participants is pivotal
Trust
Balance of power

to lack of skills with this method of data collection although it is the case that sometimes a less experienced facilitator who has more contact with the issues will produce better data than a facilitator who has never worked in the area (Millward, 2006). Krueger (1998) suggests that familiarity with the topic is an asset. The more the researcher/facilitator knows about the topic and the participants, the more comparisons can be made, inter-relationships understood and meaning derived from the comments made. Ultimately, according to Morgan (1998), the best facilitator is not the one with the most experience, but the one who will help learn the most from the participants who are being listened to (see table 3). Therefore for the purpose of the study the facilitator was not the person with the most experience at conducting focus groups but the person who was closest to the topic of the study. It was acknowledged that being close to the topic of discussion, and also being known to the student midwives, may introduce bias.

Mason (2002) suggests that one way of controlling for bias is to structure and standardise the interview process. Although this may control for bias, it would also in effect be counterproductive and diminish the value of undertaking the study. By standardising the interview process the student midwives would not have the same opportunity to discuss their perception of 'normal birth' in depth, and the social interaction, as a feature of focus groups, would be minimized. Therefore it was acknowledged that the researcher as facilitator may have an influence on the student midwives and the resulting discussion within the focus groups. However, in attempting to control for possible bias the facilitator/researcher provided a summary of the preceding discussion, at the end of each focus group, which each group of student midwives verified. In addition, preliminary findings were presented to the student participants ten weeks following the focus group interviews, and the electronic recordings and subsequent transcripts were made available for the author's research supervisor.

In a research study that conducted focus group interviews with students, Lam et al (2001) suggest that the students found the focus group interviews a more beneficial method of collecting their opinions as it allowed a more interactive discussion. However, the students also indicated that they preferred to have an unknown lecturer (perceived as neutral) as a facilitator as they felt they could not have been as interactive with a known lecturer for fear of being 'blacklisted' (Lam et al, 2001: 512). Students also admitted that a known facilitator would have been familiar with the medical terminology and would not have needed clarification of terms used. Therefore the issue of who should facilitate may rest on the concept of neutrality. Krueger and Casey (2009) support Lam et al (2001) in that the power differentials between facilitator and participants have the potential to inhibit discussion. The issue of power within the research process has also been a feminist concern (Wilkinson, 1998; 1999). Krueger and Casey (2009) suggest that with careful consideration this barrier can be redressed, and effective discussions ensued. This, he suggests, is accomplished by establishing confidence and trust; creating a friendly atmosphere; avoiding traditional classroom settings (particularly relevant if using students) and by remaining sensitive and reflexive as a facilitator. In the case of using students, Krueger and Casey (2009) recommend that students are informed that their participation is contributing to research, and ultimately developing knowledge, rather than for policy planning or decision making. Research also informs policy decisions and ultimately practice.

The benefit of using focus groups with students is twofold. Not only can it provide researchers with a greater insight into group norms and perceptions that students use to make sense of their experiences but it will also provide students with knowledge, support and self-awareness gained from that process (Kevern and Webb, 2001). Therefore, again redressing any issue of power imbalance.

Group interaction is a defining feature of focus group interviews (Lehoux et al, 2006), analysis of which provides the researcher with reassurance of the authenticity of findings. Literature on the analysis of group interaction is limited, but Kevern and Webb (2001) recommend guidance provided by Stevens (1996). This guidance was applied as an attempt to analyse the group interaction within this study. Analysis of group interaction indicated an equal sharing of power dynamics within the group interviews and verified the authenticity of the student voices. Indeed, within the analysis of group interaction, the assertiveness and empowerment of the student group was demonstrated with minimal evidence of student vulnerability. This supports Bradbury-Jones et al (2010) findings which indicate that students gain benefit from the opportunity to be research participants.

Conclusion

Using focus groups within a feminist framework enabled interactive, inductive, flexible and reflexive methods of data collection. In keeping with a feminist perspective the element of researcher power was addressed. These methods were considered to be more conducive to protecting students from potential harm yet also enabling the collection of rich data. Careful planning created an environment in which the students felt safe to share their experiences and reduced any potential vulnerability. Students were considered to be more relaxed and less intimidated by these methods and had the presence of their student colleagues for support. The concern

of the midwifery lecturer as researcher was overcome, in this instance, by reminding the students that the study was being undertaken as part of a MSc in midwifery award. This had the effect of reducing the role of the researcher to that of a student also and in doing so reduced any perceived unequal power relationship between student and lecturer/researcher. However, it is acknowledged that in future research the lecturer/researcher may not carry the status of a student. Therefore the issue of balancing power relations and who should facilitate focus group interviews may rest on the concept of neutrality and the intention driving the research. Student evaluations undertaken following the author's study indicated a perceived benefit from participation in the study in terms of learning achieved on the topic of discussion, knowledge of the research process and a sense of empowerment. Using focus group interviews within a feminist framework achieved a balance between the value and vulnerability of students, as participants in research, and increases the potential of students as resources for knowledge. This valuable source of information could therefore be more widely used within healthcare and education research whilst also maintaining ethical integrity.

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Information for authors

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News and resources

Research Excellence Framework (REF) panel members announced

The Higher Education Funding Council for England (HEFCE) has announced the membership of the expert panels for the Research Excellence Framework (REF) 2014. *Evidence Based Midwifery* editor Professor Marlene Sinclair and editorial panel member Professor Billie Hunter have been appointed to sub-panel 3 on allied health professions, dentistry, nursing and pharmacy, chaired by Professor Hugh McKenna (University of Ulster).

Iran event is new addition to the calendar

The latest event on the maternal health conference calendar will break new ground later this year when the first International Congress on Midwifery and Reproductive Health takes place in Iran from 24-26 May. More information is available at the congress website (www.mums.ac.ir/icmrh/en/index). Other events on the 2011 calender include 29th ICM Triennial Congress in Durban, South Africa from 19-23 June (www.midwives2011.org) and the RCM annual conference, taking place in Brighton on 15-16 November.

Pain relief study to explore hypnosis

More than 800 women from the north-west of England are to participate in the world's largest trial on the effectiveness of hypnosis in childbirth. The 18-month trial will be led by Soo Downe, professor of midwifery studies at the University of Central Lancashire (UCLAN). The aim is to measure the effectiveness of self-hypnosis in providing pain relief during labour and to give women the capacity to manage their labour themselves. If the results are promising, there will be further trials with the long-term aim being to provide free hypnobirthing training on the NHS.

RCM Communities

The new RCM Communities site is an online, member-only professional networking resource. It is a virtual meeting place where users can share ideas and advice, post the latest resources and contribute to discussion. To sign up visit: http://community.rcm.org.uk

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