Re-Defining the Event: with the focus on ethical issues in nursing practice and research

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Abstract

This article is based on a presentation given at the Leeds Beckett University PORESO 2015 Conference. The theme of the Conference was “Re-defining the boundaries of the event” and I used the opportunity to reflect on two themes. The first theme reflected on is my own research and how over the years I have been carrying out research the ethical requirements have changed and the second theme is how some health care students I have been involved with in my current lecturing role appear to emphasis seeking ethical approval for research studies as an event and one which once they have completed the ethical requirements. Whereas my own position is that rather than considering ethical approval as an event and seeing this as a stage which needs to be completed prior to carrying out any research, ethical approval is only one aspect of the wider ethical process which should underpin every stage of their work. Ultimately, I conclude that when discussing the ethical process and ethical considerations with students and especially research students, the emphasis needs to be that ethical considerations need to inform and underpin all aspects of their practice and the research process and it is important to emphasis the conceptualisation of ethics is an approach rather than as an event.

Introduction

Since qualify as a Registered Nurse and a Specialist Community Public Health Nurse (SCPHN-Health Visiting) in the UK, I have always been interested in research and under took my first research study in the mid 1980s. This interest in carrying out my own research in a practice setting has been combined with showcasing and publicising the work of the nursing and medical students I have worked with. Publicising the students’ work is a way of acknowledging the time spent studying, writing assignments and also a means of disseminating understanding and promoting awareness of the particular subjects they have studied. I have chosen some key events from my research career to illustrate how my own thinking about ethics has developed, particularly in my current role as a senior lecturer at Leeds Beckett University. I feel it is important students move beyond ethical approval as an event and for students to think more about ethics as an overarching approach to be considered at every stage of their practice and research.

Humphries (2000) suggests that codes of ethics have two main functions, one being the enhancement of a particular group’s or discipline’s reputation and the other the protection of research subjects. If a code of ethics is going to influence either of these functions it needs to be embedded in practice as an approach. Similarly, if ethics is

defined as a set of moral principles or acting in a way that is morally correct (Oxford English Dictionary, 2005) this supports the idea of ethics needing to be seen as an overarching approach. The issue with any principles or expectations of the way people will or should behave is that these expectations can change and shift over time and can vary according to the situation or context within which they are being considered (Edwards, 1994). This is especially true with research studies carried out in different counties, where practice standards and expectations can be very different from the UK. Ethical principles are useful when considering and justifying particular actions or decisions (BACP, 2007). However focusing on principles alone may mean professional knowledge and practice expertise is overlooked and professional judgements undermined (Munro, et al., 2005; BACP, 2007). With research ethics, and the process of gaining ethical approval for a study, individuals are encouraged to think about and consider the effect their actions may have before any data collection starts, in order to protect the research subjects. However, this is no guarantee that unforeseen or incompatible situations will not occur that need to be addressed while in the process of implementing the research plan.

Early research and publications

In the mid 1980s for my first study I did a small piece of health visitor practice based research, with several health visitor colleagues. At this time the question of applying for ethical approval never arose during discussions and was not asked for by the professional journal the research was ultimately published in. From my standpoint today, this now seems extraordinary but was acceptable practice at that time. Possibly the study was seen more as an audit rather than research, but equally this point was not discussed or questioned. However, as a registered nurse and health visitor, I and my colleagues were aware of the bio-ethical issues to consider as they underpinned our professional code of conduct. The current code states that nurses, midwives and SCPHNs have to uphold the reputation of their profession by being open and honest but also acting with integrity (NMC, 2015).

The research question addressed in the study was developed after I had completed a family planning course. The course had highlighted a gap in my knowledge about whether nurses who were carrying out routine cervical smears were also talking to the women they screened about self-examination for the detection of breast lumps and changes which might have been indicative of early breast cancer. This information was not available from any other sources, thus justifying the need for this small study. From a practice perspective talking to women about detecting one type of cancer, which was most common in women, while screening for another appeared appropriate. At the time of carrying out this study, the death rate from cervical cancer was declining but the rate for breast cancer was not declining as quickly. To answer the research question I developed a short questionnaire which myself and colleagues used during each home visit we had planned for a particular week. The women were asked if they would like to participate or not once the planned reason for the visit had been completed. No formal consent form was signed and there is an argument that

formal consent processes can cause some participants to disengage with the research process (Wiles et al, 2006). The identity of the women was protected as they were a sample from a much larger caseload and the caseload was not identified in the article. If the women verbally agreed, they were asked the questions and were informed they did not have to answer any of them if they did not want to. My colleagues and myself had written information about breast self –examination which we discussed with the individual women. We left the information with any of the women who said they would like to have written information on self-examination as a consequence of us raising the subject with them. Also because of our professional role all the women who were approached and participated had information about how to contact us, should they need to in the future. With hindsight I think the study was conducted in an ethical way, primarily because of our professional training and the code of conduct which underpins how we approach and work with our client group.

Research overseas in Nepal and Bangladesh

Several years later, while I was working as a community nursing tutor at a nursing campus in Nepal, I wrote two papers for publication based on data collected my Nepali nursing students. Nursing was a relatively new professional course to be taught in Nepal and the curriculum we worked with had been introduced just prior to our arrival at the campus. The student nurses did a community placement in the first year of their three year nurse training, in one of the wards of the town surrounding the nursing campus. The 30 students working in pairs collected information from 10 families each. The data they collected provided a snapshot of that point in time of the population profile in the ward, the common health conditions experienced in the community. The student nurses addressed any untreated conditions they identified, reinforced key health promotion messages and organised community based health promotion activities. I compiled the data collected by the students as the data provided an important baseline for monitoring health needs and trends in this community. Prior to compiling this data there was no base line data available on the health of the community so no way of knowing whether any of the conditions identified were increasing or decreasing or new conditions emerging and if there were public health issues which could be addressed. I also felt it was important to use this data to raise awareness of the work the students were doing during their community placement by treating the conditions they encountered or making referrals. The publications hopefully had an additional purpose which was to promote nursing more generally, in a country where it was not seen as a very suitable career for education women. Equally, there was emphasis on community outreach nursing in the curriculum, but once qualified there were very few opportunities for nurses to work in a community setting. Demonstrating what these students were able to do might begin to change this situation.

The two articles stated that they were based on the data collected by the nursing students and acknowledged their work and contribution. Research that does not directly involve human subjects such as secondary data analysis is usually excluded

from research ethics scrutiny (Haggerty, 2004) and there was no formal ethical procedure to follow in Nepal. The main issue that retrospectively concerned me is the ownership of the data. With hindsight and if I was doing a similar thing now I would wish to develop a more collaborative approach and involve some if not all of the students and the other community nursing tutors at the nursing campus, in the process of writing the articles. There was no culture at the nursing campus of nurses writing for publication and the two articles I wrote were the first ever published on the role of student nurses and were published in the Nepal Medical Journal as there was no nursing journal. As a tutor and lecturer, part of my role is to promote the academic development of my students, and support colleagues in their academic development. While it was acceptable for me to use secondary data in articles as long as the source is acknowledged, I think the active involvement of either the students or the other tutors, would have had more impact on promoting nursing in Nepal. By actively engaging the students and tutors they might possibly have been inspired or encouraged to either do more research in the future or use secondary data collected subsequent cohorts of students for monitoring the impact of the student's placements or more publications by themselves.

In the early 1990s I had the opportunity to carry out some research in Bangladesh. The data collection was carried out as part of my MSc. from the University of London. Potentially there was a huge imbalance of power with me as the researcher coming from a university in the West carrying out research in a developing country. This placed me in a privilidged position as a researcher. Ethical approval was sought and granted by the University of London's Research Ethics Committee (REC). The Non - Government Organisation (NGO) in Bangladesh, where the data collection was to be carried out was funded by the same organisation which asked me to carry out the research. Despite having ethical approval from the University of London's REC, several ethical questions were raised around regarding the implementation of the data collection. Firstly whether participation was or could ever be entirely voluntary and secondly ensuring the purpose of the research was clear to the participants.

Since I was being funded by the organisation that also funded the NGO there was a question whether the Head of the NGO really have the freedom to choose whether I came to do the research or not. Equally did any of the employees working in the NGO have a completely free choice regarding participation? In this situation negotiating access and developing an open working relationship was fundamental, but in this scenario I had no control over how I was introduced to the Head of the NGO and do not know what they had been told about the purpose of my research. This was my first experience of arriving somewhere overseas to carry out some research without prior contact or being involved in any discussions. It was a very different situation to the one in Nepal where I had been for over a year and was integrated into the community of the nursing campus before beginning to talk about using the data collected by the students for a publication. Alternatively, maybe people working in NGOs in developing countries as used to and familiar with the way external funders work and expect some

form of external scrutiny from outsiders. In this and similar situations the researcher is required to adopt an ethical decision making approach based on their own ethical or moral perspective (Wiles et al., 2006; Goodwin et al., 2003). In this situation reflection and awareness of my professional code of conduct again provided me with a basis for discussing various topics with the staff at the NGO.

While the research was for my MSc some aspects of it focused on the impact the NGO's interventions had on the health of the target population of adolescent women. An example of an ethical issue that arose was around being able to establish the number of beneficiaries of the project delivered by the NGO. During my initially discussions about selecting the sample of adolescent women to interview it became clear that the records of the number of women enrolled on the programme did to correlate with the figures on beneficiaries that the NGO had previously reported. This issue could not have been foreseen and only arose once I started to implement my research plan. This meant I could not sample in the way I had intended but equally they did not actually know how many adolescent women had been enrolled in the past or were currently enrolled. I was able to develop a different way of sampling but the issue remained about the lack of clarity regarding the number of beneficiaries of the project which was important to the funder. The dilemma presented involved the sharing information; the funders having a right to know what the real situation was and respect for the autonomy of staff of the NGO who were running the programme. Having identified this as a potential problem an alternative recording method was developed after discussions with the Head of the NGO and the funders.

The second concern, which was closely linked to the first, was ensuring the research was clearly explained to the staff working at the NGO and particularly to my translator who I was dependent on for the data collection. Being an outsider, and particularly being a foreigner doing research, raises its own ethical considerations, especially in cultures when people are not willing to not openly contradict or suggest that what you are planning maybe not practical because of some issue or custom you are not aware of. Equally, it could be possible that a number of things can be hidden from an outsider either intentionally or more likely because they are not seen as important. Another potential issue is that respondents will have a tendency to give what is considered an acceptable public account, especially if colleagues and/or their employer may find out what they have said as opposed to responses which as truly anonymised. This can be a real issue when working with translators who have links with the organisation where the research is being conducted.

Both these issues can impact significantly on the quality of the data gathered. One incident which highlighted this for me occurred during one of the interviews, while listening to the translator asking a question. The question being asked should have been about green leafy vegetable- a very specific topic. Although I did not speak Bangla, having listened to the questions being asked many times I realised the question asked this time was different and somehow the question had turned into one about vegetables more generally. What was difficult to establishing was whether this

the first time this question had been asked differently or was it simply the first time I had noticed it was being asked differently? Equally had other questions also been changed that I was not aware of and how did this ultimately impact on the findings and any conclusions and recommendations I made on the basis of the data analysis.

Changes in research ethics in the UK

Prior to carrying out my doctoral research in the UK in the late 2000s, the context of research involving the NHS had fundamentally changed when compared to my earlier research. The first major influence for this changed was the Alder Hey Children's Hospital Scandal. In 1988 a new Chair of Foetal Pathology had been appointed at the hospital and worked there until 1995. During this period it was considered normal practice to retain all or parts of deceased children's organs for future research. This practice became public knowledge in 1999 when questions were raised about what to do with the remaining organs and samples, and this created a scandal when it became clear that the organs or samples had been removed without the knowledge and informed consent of the children's parents. The practice of retaining organs and samples, which had once been considered routine medical practice and had not involved seeking parental consent appeared to be out of step with the parents' view that they should have been informed and their consent sought. There is an argument that approaching parents immediately after bereavement would have added to their distress and might be one reason why their consent had traditionally not been sought. Additionally providing full information about the number of organs they wishes to remove might have led to parents withholding their consent which would have impacted on the research being carried out, which some researchers might consider sufficient justification for not seeking informed consent (Humphries, 2000).

The second major influence for the change was the findings of the Inquiry led by Professor Ian Kennedy (Bristol Royal Infirmary, 2001) into the high death rate at the Bristol Children's Hospital following heart surgery. Concerns were raised in the 1990s by staff working in the hospital about the high death rate compared to other children's heart surgery units in other hospitals in the UK. There had been 53 cases of child heart surgery in which 29 of the children had died. Between 1991 and 1995 up to 35 children less than one year of age had died following surgery. The surgeons justified this high death rate by claiming they were on a 'learning curve' while developing new procedures, but due to their powerful positions on both the wards and in management a situation arose where no-one was able to question or challenge them. The anaesthetist on the surgical unit had asked that no further surgery was performed until the reasons for the high death rate was addressed but was over-ruled. Finally he went public with his concerns and this led to the Inquiry. It was revealed that parents had been given partial, confusing and unclear information about the surgical procedures that their children were undergoing. Equally the parents were unaware of the wide-spread concerns amongst the staff about the care provided by the children's heart unit. The Inquiry found that it appeared that the pioneering aspect of developing new surgical procedures had over –ridden consideration of the rights of the parents and

their children. This was an issue around justice and fair treatment and parents not being fully informed about the surgery being performed by the children's heart surgery team, which had serious consequences for the children and their families.

Both these examples illustrate that when it becomes public knowledge that researchers have failed to adhere to their professional code of ethics, their conduct brings into question the reliability and value of their research and the impacts on the reputation of their profession as well. The doctors being in a powerful position and being able to interpret or justify their actions unrestrained by other professionals, has ultimately led to increased regulation and governance in health care practice and research. The surgeons had sought consent to carry out the operations from the children's parents but it was not fully informed consent. The concept of informed consent embodies legal, moral and ethical issues. Consent is freely agreeing to something but informed consent means knowing all the facts, and this is what was missing regarding the risks of the children's heart surgery. If the parents had known all the risks they might still have agreed to the surgery or not or chosen to seek a second opinion elsewhere. In this respect, having a comprehensive information sheet of booklet supports the consent process. Such an information sheet informs the participants and is evidence, if it should be needed, regarding what information the participants were given. While this makes the process of gaining informed consent formal and potentially off-putting for some participants, they do have something to re-read at a later time. In some studies giving all the facts as required for informed consent can or may distort the data collected as the information provided might lead to the participants acting differently.

Another separate but related change which impacts on health care practice and research has been the implementation of the 1998 Data Protection Act. This Act has improved the way sensitive information is collected and stored and shared. Ethical approval for research studies usually includes demonstrating there are robust mechanisms in place to protect individuals from being identified, such as using unique codes, data anonymisation and secure storage of data on encrypted devices or password protected computers.

NHS Ethical Approval

The two high profile events described above had the effect of making ethical approval for research involving the NHS much more rigorous. Any research involving children needs to be especially rigorous as they are considered vulnerable group. Currently, research involving all patients and/or employees is now also much more closely scrutinised and monitored. The process for my research after securing University research approval was to apply for NHS research approval and permission to approach NHS employees and request an interview. Prior to applying for NHS ethical approval and permission, I had heard accounts from other students that it was a difficult and daunting process- and in some ways it was. However, despite the bureaucracy and all the documentation that needed to be produced and the online

application it was clear what needed to be done and the processes that needed to be followed. Retrospectively I think it was a very useful process to go through as I had to think very carefully about the different aspects of my study and be able to write about each stage in a way that people who knew nothing about the study were able to understand. The feedback from the NHS research ethics committee was very positive, the adjustment they suggested were constructive and improved the clarity of one of my information sheets by suggesting two separate ones would be clearer. In addition when I applied to several other organisations which had less bureaucratic processes but less clear what was required and therefore more challenging to know what the criteria were that had to be met. The NHS process, once achieve was viewed as a "gold standard" for ethical approval and is often accepted by other organisation as an indicator that the study design is of a good standard and therefore acceptable for their organisation as well. Overall the process of applying for ethical approval for the study and negotiating access to the participants was a long process, which impacted on the research timetable and delayed the beginning of data collection and all the subsequent stages of the research process as well.

Negotiating access to the individual participants within an organisation, can involve a number of gatekeepers within that organisation, even after permission in principle has been granted at a higher level within the same organisation, especially if the topic of the research is of an emotive or sensitive nature. Munro et al. (2005) suggest that it is important to do research on emotive topics, in my case on different professional perspectives on child safeguarding practices in order to ensure policies are underpinned by a strong evidence base. Past experiences of being involved in research studies can deter participants especially if it was a negative experience. Equally there may be concerns about what might be revealed about the organisations especially if the practice area under consideration is a potentially or currently sensitive one, such as child safeguarding. Being unable to negotiate access to participants or individual participants choosing not to participate in the research can impact on the study design and subsequently because of the missing data this can also impact on the fullness of the data and maybe the conclusions drawn. Non participation may be a consequence of research being a distraction from the child welfare professionals' role of protecting children (Munro et al., 2005).

Protecting the anonyminity of the participants in my doctorate research was an issue which was discussed at length with my supervisory team. The child welfare professionals I interviewed all worked in identifiable safeguarding roles related to their specific professional backgrounds. The study was designed to explore the different constructions of child neglect by named professionals in specific safeguarding roles within their organisations. The named professionals came from a range of different professional backgrounds but since the professional background was likely to influence how they constructed cases of child neglect, it was necessary to include the background of the participants in the analysis and writing up stages. This potentially meant that the individual participants were identifiable, as there were only a small

number of named professional posts in each of the organisations involved in safeguarding children. The agreed solution, in order to limit identification as much as possible, was to ensure the location of the research was not revealed in any reports or publications and to use a pseudonym instead.

Students and ethics

In my current role there are occasions where discussions regarding ethical issues arise. I discuss here two examples one relating to Masters level students and the second to second year nursing students.

The example with Masters students (level 7) relates to them carrying out literature reviews and writing a dissertation based on their literature review. The students need to complete an online research ethics form which is straightforward as they are not doing data collection. During some conversations the attitude of the students seemed to be that they have been given ethical approval and that means all ethical issues have been addressed and they can now continue with their literature review. However, when they are reviewing published literature in order to address a research question and they need to demonstrate that the process by which they do this is fair and trustworthy- this process relates to the ethical principle of fidelity and honouring the trust placed in them as a research student. They have a responsibility to report all relevant finding, including those that do not necessarily support their argument or personal point of view or only the publications which were easily available. Reporting other people's work and ensuring it is a true representation of the point the authors were making is a fundamental skill.

Second year nursing students completing a module on evaluating research (APLL5) are asked to consider if the papers they are evaluating have addressed ethical issues while doing the research being reported. There was considerable variation in how this learning outcome was addressed but highlighted the importance of addressing ethical considerations when writing papers. Anyone reading a publish paper needs to evaluated whether the study was conducted in an ethical way, based on the information provided by the author(s). Many of the student's assignments noted points which authors may have considered in practice but not included when writing the papers. Examples of practices the students commented on include, it was not stated in the paper that Local Research Ethics Committee permission had not been sought, or whether there was any pre-existing relationship between the researchers and their participants which may have impacted on the data collected, and in longitudinal studies informed consent was mentioned at the initial sampling stage but not a subsequent data collection stages. Reading the students assignments high-lighted a tension when writing a paper between needing to be transparent regarding the ethical approach underpinning the study and focussing on reporting new information in a paper with a finite word count.

Conclusion

Rigid and proscriptive ethical guidance and procedures cannot ensure that researchers will always act in an ethical way. Equally formalised consent procedures does not always ensure participants and people receiving health care are able to make truly informed choices (Wiles, et al., 2006). Rather procedures and a culture of openness and reflexivity regarding the context within which data collection, professional practice and research takes place is to be encouraged.

When writing research reports and papers maintaining anonymity and confidentiality can sometimes be challenging and deciding on the best course of action often involves weighing up competing demands. Equally ensuring data is disseminated and is an accurate representation is essentially part of an ethical process to add to the body of knowledge.

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