ETHICAL DILEMMAS IN NONCLINICAL HEALTH RESEARCH FROM A UK PERSPECTIVE

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This article examines the ethical dilemmas faced by professional and academic researchers in the health field who undertake nonclinical or social research among patients or staff. The experiences of health researchers and health professionals in the UK are directly relevant to those undertaking similar health-related research in other parts of the world at a time when nonclinical research in health care is becoming widespread in all countries and cultures. This article addresses ethical dilemmas as they relate to researchers’ ability to maintain confidentiality, their commitment to the welfare of respondents, and the tensions that arise from undertaking research for an employer. In addition, the danger of conducting covert research inadvertently may present unexpected ethical problems, which are discussed. Although it is impossible to provide a policy document to address all ethical dilemmas, this article does attempt to address the question of how best to approach health-related research in order to minimize the possibility of running into ethical problems at a later stage.

Introduction

The domain of (nonclinical) health research has traditionally rested with the academic community. However, in the UK, as a result of recent National Health Service (NHS) initiatives that have recognized the value of research-trained staff, many health professionals are currently being trained in social research techniques through MA and diploma courses at universities, and are themselves undertaking health-related research projects. Such developments are not confined to the UK, as is demonstrated by the study of the needs of caregivers of clinic and hospice cancer patients undertaken by Harrington (a nurse practitioner) et al.\(^1\) in the USA.

Health practitioners will already be familiar with having to work within codes of ethical conduct governed by their own professional bodies. However, some of the ethical issues that may be encountered in the type of research undertaken as...
a result of social research training could differ from those dilemmas that professional codes will cover, thus presenting new ethical dilemmas. In addition, researchers who are also employees at the research site may find that their loyalties are divided and they are subject to conflicting pressures.

The aim of this article is to address a number of ethical dilemmas related to health research by both academic and health professionals when researching health-related areas. Many of the observations are based upon my own experience as an academic researcher in the health field, but I also draw on my observations as a teacher of health professionals and use examples of research undertaken elsewhere in the world to demonstrate that the issues cross national and cultural boundaries.

The article begins by considering the researcher’s ethical responsibilities when in possession of data of a confidential nature and the pressures that may be exerted on them to disclose respondents’ identities. It then moves on to examine the problems that arise when the commissioner of the research, or the employer, challenges the researcher’s findings. The ethical problems that result from the inadvertent practice of covert research are then discussed, as are the dangers of causing alarm or distress among respondents in what is often an area of great sensitivity. Finally, some solutions are suggested that may act to mitigate some of these problems if integrated into research design at an early stage.

It may seem that many of the issues discussed here should have been anticipated ahead of the research. Some may be, but it is unrealistic to assume that all problems will be correctly predicted on every occasion. Most research begins in a spirit of optimism and of course many health professionals who are undertaking social research for the first time will not have experience of such issues. However, rather than being negative, the recognition of the potential for harm to respondents, institutions and researchers needs to be built into the research design to reap positive benefits.

The disclosure of confidential information: who has right of access?

Although this is an issue that is apparently covered by many codes of practice, it can prove to be very problematic for researchers. The researcher’s relationship with the respondent, who may or may not be a patient, will differ when the health professional is carrying out social research rather than treating the person medically; while there may be clear guidelines about confidentiality between the practitioner and the patient, the boundaries may not be so well defined when the researcher steps out of the therapeutic role.

During data collection using social research methods it is usual at the start of an interview to assure the respondent that the interview data will remain anonymous and/or confidential. This is particularly important if the research topic is of a sensitive nature. Much health-related research is regarded as sensitive by respondents. However, as a result of an assurance of confidentiality, a respondent may disclose information of a kind that places the researcher in an ethically problematic position. The problem may be compounded further if the respondent is
also a fellow health professional rather than a patient.

An example may be of a health care worker with direct patient contact who leads the researcher to believe that he or she had at some stage been at risk from an occupational infection with hepatitis B, but that the diagnosis remained unconfirmed. Under such circumstances the researcher has to make a judgement about whether he or she should break confidentiality for the greater good, or maintain confidentiality and remain silent.

The researcher also has to decide if such a disclosure should be acknowledged in the research report. If it is acknowledged and the researcher is put under pressure to divulge the identity of the respondent, the health professional will have to consider his or her position as an employee as well as a researcher. Academic researchers are unlikely to be dependent upon the NHS for their income, whereas health professionals may be under pressure from those directly responsible for their employment and promotion.

In such circumstances, to what authority does the researcher turn for guidance? In the UK, for a sociologist, citing the British Sociological Association ‘Statement of ethical practice’ may be a starting point: ‘Guarantees of confidentiality and anonymity given to research participants must be honoured unless there are clear and overriding reasons to do otherwise’ (p. 706; emphasis added). However, exactly what would constitute ‘clear and overriding reasons’ is at the very least open to interpretation. The ‘Statement of ethical practice’ goes on to note that research data given in confidence do not enjoy legal privilege and may be liable to subpoena by a court. The British Sociological Association document suggests that the research participant should be made aware of the fact that it may not be possible to avoid legal threats to the privacy of the data. However, if the researcher began the interview by issuing such a warning, it seems likely that information of a sensitive nature would be withheld, and thus the quality of the resulting data would be directly affected.

This leaves researchers in an ethical quandary. Should they proffer a warning and limit the response, or risk being in possession of data that may become the subject of legal action, or at the least pressure from managers to divulge identities. Even if researchers decide to ‘forget’ the information they have been given, this still leaves them with a private burden to carry.

However, we have to remember that researchers using social research methods may consider other codes of practice to be more appropriate, and the guidelines may vary considerably between different disciplines and professions. For example, the British Psychological Society ‘Ethical principles for conducting research with human participants’ states that:

Subject to the requirements of legislation, including the Data Protection Act, information obtained about a participant during an investigation is confidential unless otherwise agreed in advance. Investigators who are put under pressure to disclose confidential information should draw this point to the attention of those exerting such pressure. Participants in psychological research have the right to expect that information they provide will be treated confidentially and, if published, will not be identifiable (p. 473).

The situation may become even more complex if the researcher has only had access to the data because the NHS trust or health authority has allowed access.
The question of the ownership of the data then becomes problematic. It could be argued that the true owner of the data is the respondent rather than the researcher, but, if senior managers claim to have rights over data resulting from their power as gatekeepers, both respondent and researcher may find this position challenged. The result may be the exertion of pressure on the researcher to divulge identities, which, according to the British Psychological Society, is unacceptable.

The role of ethics committees is also worth consideration. Most research undertaken in the health field will have had to be presented to a local research ethics committee for approval. However, there appears to be little consistency across ethics committees either nationally or internationally. In my own observation of teaching health professionals from a variety of trusts and health authorities, I have noted great variation in their positions on a number of ethical issues. For example, some ethics committees demand that all research projects undertaken, with either patients or staff, should be approved, while others require only that research involving patients is approved, with staff apparently not being considered as in need of the same protection awarded to patients. It is also likely that, once permission for a research project has been granted, the ethics committee will not be involved in subsequent ethical dilemmas. Thus, we may assume, paradoxically, that ethics committees are unlikely to be involved in such decisions and, ultimately, the result may rest on the perceived penalty of refusing to disclose confidential data.

Uncomfortable findings

The issue of contract-related research that makes discoveries that the client refutes, objects to or would rather remained unpublished, is not confined either to health-related research or to the UK, as is shown by Koebben and Tromp’s experience while carrying out research in the Netherlands. Alternatively, it may be that an absence of best practice is revealed by researchers, as Bazzoli and colleagues discovered while researching community-based trauma systems in the USA. They observed that leaders failed in many of the dimensions being researched in some of the communities under scrutiny.

However, for health professionals undertaking research within their clinical setting, in effect for their employer, the implications are even more far reaching. Under such circumstances, the discovery of practices, particularly those instituted by management policies, which may be less than satisfactory, sets a thorny problem for the researcher. While management policies may be well intentioned, they may at times show a misunderstanding of the nature of the working environment in which they are to be implemented. Researchers uncovering such discrepancies between theory and practice may find themselves unpopular with their employer should they point out the failure of the policy. The resulting resentment engendered may be perceived by health care workers as inappropriate or insensitive management practice.

Such perceptions among respondents in my own research had led to an assumption that the health authority simply did not care about the safety of staff, and that any protective measures that were going to cost money would be with-
held. Although such perceptions are unlikely to be an accurate reflection of management’s attitude, data suggesting such a position have to be addressed by the researcher. Under such circumstances researchers must decide whether or not to communicate their findings to management (a difficult option if that management is also their own employer), omit mention of such findings as politically too divisive, or try to placate the respondents, offering reassurances and acting as mediators.

In some cases researchers may be asked to provide practical assistance. In my own research, many respondents have asked me to help them to obtain protective clothing or granules to mop up blood spillages. If researchers are additionally in a relatively senior position, they may be asked by respondents to intervene on their behalf. One has to ask if it is a proper response for researchers to act as the emissaries or representatives of research participants. On the other hand, is it acceptable to know that the respondents have a need that could be facilitated by the researcher’s intervention?

**When overt research becomes covert**

There are those who argue that covert research is justifiable in certain circumstances, usually when it would have been impossible to access the data overtly. Most researchers condemn covert research and the vulnerability of many of the subjects of health-related research seems to suggest that it would never be acceptable to undertake such research. However, there are those, such as Holman, who argue that the likely benefits of such research must be taken into account, yet, as Grbich maintains, the knowledge of being researched may in itself have the potential to produce harm. She uses the example of a carer researching the process of dying. If the carer is open about this, the persons being cared for may well be caused additional distress as they might not have fully accepted the fact that they are dying.

However, the issue may be more complex than a simple dichotomy between overt and covert methods would suggest because covert research may be carried out inadvertently. In other words, researchers begin the research process overtly, but find themselves in situations where they are making covert observations, or are in possession of information pertinent to the research but given as a confidence.

The problem of what constitutes privileged information and what are legitimate data applies to both academic and medical professionals as researchers, but the latter will have access to greater opportunities for what amounts to ‘covert observation’. As Punch states, codes of ethics fail to solve the situational ethics in the field. Although a research project may be overt and researchers’ area of interest known to colleagues, patients and management, these researchers will, once sensitized to the topic, observe data that are not collected formally through interviews, questionnaires or focus groups, but simply by carrying out their daily duties. The status of data collected in such a manner must be questioned.

Although the focus of the research may be entirely overt, researchers may find it difficult to ‘switch off’ when in a privileged situation. For example, during the initial period of my research in a health authority, I was obliged to attend a
number of meetings. It was not until my research progressed that I began to realize that I had absorbed a wealth of information from these meetings that could be crucial to my study. This posed some ethical dilemmas because I had been an invited member, not a researcher, at these meetings. Thus, all my observations were in some sense ‘privileged’ information. Was it legitimate to use these data in my study as I had, in effect, become an unwitting participant observer, engaged in covert rather than overt research, a position that is considered to be a violation of the principle of informed consent by Homan and Bulmer. What had begun as a straightforward piece of overt qualitative interviewing had, in effect, become something quite different.

For many health professionals this problem could be even more acute as they may be employees of the commissioners of the research and are thus in an ideal situation to carry out covert participant observation of both management and patient groups. Punch acknowledges that there may be an element of impression management and a concealment of the whole truth, which allow researchers to build up relationships that subsequently allow access to certain types of data that would be otherwise inaccessible. He suggests that this is in some circumstances unavoidable and is tolerable, provided it is not consciously and cynically manipulated by researchers to the disadvantage of the researched.

The risk of causing alarm or distress

Finally, health related research may, on occasion, address the perception of risk from particular illnesses. HIV/AIDS is a case in point. During the 1990s many academics in the UK and elsewhere used the AIDS ‘epidemic’ as a case study to examine the way in which a newly identified medical condition was understood in the public domain. The very specific connotations attached to AIDS, its connection with supposedly deviant sexual practices and illegal drug use meant that, initially, in the public mind AIDS was associated with groups of people outside the mainstream. However, as AIDS and HIV began to emerge in an ever-widening sector of the population, increasingly the perception of the risk of infection extended to the ‘worried well’. AIDS provided an ideal case study for knowing how the public understood and acted on health education information, including issues of: over-reaction to the chance of infection; the effect of the social environment on the implementation of health education messages; and the ability to put knowledge into practice.

Researchers from my own discipline, the sociology of scientific knowledge (SSK), are particularly interested in the construction of medical and scientific knowledge and role of social influences in the closure round an orthodox account. ‘Closure’ indicates the general acceptance of a theory among the scientific and medical community; the resulting ‘orthodoxy’ may form the basis for health policy. This orthodoxy may, however, be riddled with scientific uncertainty and may or may not later be challenged in the public domain (bovine spongiform encephalopathy (BSE) provides an excellent example). Thus, in SSK, the rationalization of anomalous data and the elimination of uncertainty are frequently foci for research. Any element of uncertainty in the orthodox account of the aetiology of an illness is of central interest in such an approach and may become the focus...
of health-related research. Such academic perspectives are no longer confined to the academic community and health professionals may well undertake courses that lead them to use such an approach that is critically analytical of the construction of medical knowledge and practice.

When raising the topic of risk in relation to something like HIV/AIDS, it is more than possible that underlying fears will be exposed or new fears will be created. The particular characteristics of HIV/AIDS meant that, while I was ostensibly addressing the risks as they related to the occupational life of the respondents, I had no means of knowing if I was tapping into fears that related to their private lives.

It seems that interviewing of this kind, which attempts to access people’s underlying fears or may undermine their faith in an orthodoxy that could be flawed, has far reaching ethical implications. For example, to interview mothers of young children about their understanding of the theories relating to cot death and the attendant uncertainties (V Singleton and A Grinyer, unpublished manuscript) may undermine their peace of mind. They might have thought that either changing the type of mattress or placing their baby on his or her back to sleep eliminated the risk. Thus, the question of research causing anxiety must be addressed in many health-related areas.

Even in cases where scientific or medical uncertainty is not an issue, much health-related research touches on experiences that are painful for the respondent to recall and discuss. An example is the study undertaken on maternal death in Haiti by Barnes-Josiah and coworkers, who interviewed families and friends about the medical and social circumstances surrounding the deaths of these women. Another example is the research carried out by Khamis on the psychological distress caused to women during the Intifada. This was concerned with the traumatic experiences the women had endured and thus required that they to some extent would relive these experiences for the purpose of the research. Such research is crucial to our understanding of many health-related issues and most researchers would adopt approaches that are sensitive to their respondents, but these considerations often remain implicit rather than explicit, perhaps because they place researchers in an uncomfortable position in relation to their respondents.

Solutions?

The ethical dilemmas addressed in the discussion so far raise very practical issues about how researchers manage the research situation in an ethical and appropriate manner. There are no easy solutions, nor is it possible to imagine the myriad scenarios that may be faced by researchers. The essence of much of this debate has been on the insidious nature of the ethical problems faced by researchers. However much the researchers like to believe that they are ethically aware in their approach, it is still possible that they will encounter unexpected and subtle dilemmas.

The codes of ethical practice supplied by the various professional bodies may at first sight appear to offer clear guidance. However, they can also be contradictory and much is still left to the discretion of the individual researcher. Perhaps
that is all that codes can do, for to address all conceivable eventualities is clearly an impossible task. Ethics committees are also of limited benefit, as they rely on anticipating the ethical issues and are no longer involved once the research has been approved.

The answer lies partly in the training of researchers. All researchers are likely to have undergone some training in research methods. They know how to structure questionnaires, how to facilitate focus groups, how to conduct in-depth interviews, and how to do ethnographic research. However, fundamental to all these approaches to data collection, whether qualitative or quantitative, should be the central tenet of ethical practice. Without such an underpinning in the training of researchers we leave them floundering when faced with the unexpected situation that cannot be anticipated, planned for or encompassed by codes of ethical practice.

According to Grbich, postmodern and feminist researchers have moved beyond what they regard as the limited focus of what ethics committees address in terms of consent, confidentiality and harm reduction. Instead, the suggestion is that researchers take demonstrable responsibility and address the following questions: What will be achieved by the research and who will benefit? What changes can be anticipated? How will confidentiality and anonymity be maintained? How will accountability be addressed? How will decision making and knowledge be shared, and how will the needs of all participants be addressed? In addition, Grbich suggests that researchers should adopt a reflective critique of the research process and consider whether relationships were nonhierarchical and respectful, if the language used was accessible, and if the dialogues between the different parties were evident (e.g. between the researcher and the researched and between the researcher and the policy makers).

There may be general guidelines that can be drawn up in anticipation of ethical dilemmas, which may act as a framework within which to apply judgement to individual situations. They may include such issues as:

- Attempting to understand how the research is perceived from the respondents’ point of view;
- The meaning and implications that the questions have for the respondents;
- Establishing trust with respondents based on an explicit and mutually acceptable agreement of who will have access to the resulting data, and in what form;
- What obligations researchers have to other bodies within or outside the organization;
- Establishing at an early stage with the commissioner of the research (managers, employers or other powerful bodies) what their rights to access confidential data are, and who has ultimate ownership;
- Establishing clearly respondents’ right to withdraw at an early stage from the research without question;
- Defining what constitutes legitimate data: are the data those that have the explicit consent of the research participants or can they ethically be extended to less formal methods of observational data collection?
- Anticipating that some respondents may experience anxiety or distress and preparing to counsel them accordingly or direct them to someone else who could provide appropriate support;
• Discussing in advance who owns the data and how data that reflect both positively and negatively may be accessed and used by the institution;
• Discussing potential ways to remedy problems that may be exposed by the research.

Conclusion

This article has addressed ethical issues and dilemmas that may face researchers from both health professional and academic backgrounds. It has tried to address some of the more subtle nuances of ethics as they arise unexpectedly during the course of research and to demonstrate that such issues know no international borders. There are, however, few explicit acknowledgements of such dilemmas in published work, either because they are uncomfortable to discuss or because they are not considered of central importance to clinical concerns. Thus, much of the discussion has remained theoretical, based on my own empirical data or implied from other studies.

It is impossible to provide guidelines to address every eventuality, but if the researchers and institutions who engage in or allow research among their staff and patients are aware that such issues may arise, and take steps to put in place mechanisms to address any such issues at an early stage, some of the research problems discussed here may be avoided.

If the researched are seen as ‘collaborators’ in the research, rather than as ‘subjects’ then we should behave towards them as we are expected to behave towards friends and acquaintances in our own daily lives. Abandoning the field without consideration for the consequences is a form of betrayal (p. 83).13

If all researchers and commissioners of research were to heed Punch’s13 advice, then a framework for practice may be provided, which could encompass the uncertainties inherent in the research process.

References
