ETHICAL ASPECTS OF DISASTER RESEARCH

by

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Introduction

I was somewhat surprised when I was given this topic to speak on by Dr Sandy McFarlane because the issue of ethical aspects of disaster research is not one that is commonly considered. I think it is a reflection of the state of the art in this area firstly, to be having a conference such as this at the Australian Counter Disaster College and secondly, that a topic such as ethical issues in disaster research is being addressed. It is my experience that the state of knowledge in an area has to reach a certain point before issues of ethics are seriously considered. In the beginning of the development of a new field of study, workers do various pieces of research building up a picture of the field until the point is reached when the 'gestalt' of the field can be seen, and only then does an interest in the more subtle aspects of a field develop such as aspects of the ethical considerations in such research.

Ethical issues in disaster research have particular importance because the research is being done on people who have neither assumed the role of patients nor are likely to do so. The importance of the study of human behaviour during and following disasters is well known. It can provide valuable insights into the psychology of coping particularly in extreme environmental circumstances and provides clues about the etiology of psychiatric disorder. The nature of the crisis however, the extent of the personal distress and the helplessness of individuals affected, make those afflicted by disaster a particularly vulnerable group, whose distress may be increased by the researcher.

Recent Interest in Psychiatric Ethics

The reasons for an increased interest in ethical issues in Psychiatry in general, and in psychiatric research in particular have been well summarised by Bloch and Chodoff in their recently published book 'Psychiatric Ethics'. They summarised the factors contributing as being the following. Firstly, the medical consumer movement has in recent years come to constitute a potent and more or less coherent social force. The physician and other members of the helping professions no longer compel blind reverence nor is there unquestioning compliance with their methods. There is a much more general sceptical attitude towards authority. Secondly, an increased interest in ethics has been associated with vehement repeated attacks on all professionals by what might be broadly termed the civil libertarians. Thirdly, the treatment and research of the mentally distressed has traditionally conjured up the image of manipulator and helpless victim, particularly in situations where because of acute distress or psychosis the patient is unable to provide informed consent. Fourthly, there has been increasing dialogue between the medical disciplines particularly psychiatry and other professional disciplines such as sociology and philosophy and fifthly, it has been becoming increasingly apparent that psychiatry has been abused in various countries particularly the Soviet Union.

Two Ethical Positions

The word ethics is derived from the Greek adjective ethikos, from ethos meaning 'nature' or 'disposition' and is commonly used in one of two ways which we can refer to as the philosophical and the practical. In tackling the questions of what constitutes ethical behaviour and how values are derived, the moral philospher constructs a conceptual model or theory. The two most simple theories can be contrasted as the 'utilitarian approach' and the 'absolutist approach'. The utilitarian position has been much influenced by John Stuart Mill. Here the emphasis is on the consequence of acts, on the balance between good and bad consequences between benefits and harms. A persons's action should be chosen so that it produces the best result by recognizing the needs of all those persons who will be affected by that action. The final consequences will be the greatest possible happiness of all concerned. The competing position which is the absolutist, has as its core thesis that certain acts are intrinsically wrong regardless of their consequences, can never be made right and that moral judgements have universal applicability; for example, an act like the murder of an innocent person or the theft of another person's property are judged in the absolutist approach to be totally wrong. In a similar vein the notion that research subjects must always be able to give totally informed consent is an absolutist's view point.

Ethicals Principles in Psychiatric Research

John Wing in his chapter entitled 'Ethics and Psychiatric Research' in the previously mentioned book on Psychiatric Ethics has summarised three general principles that he feels have to be dealt with in all psychiatric research. They are firstly, the balance of good and harm, secondly, informed consent and thirdly, confidentiality. The balance of good and harm or the principle of least harm, has as its central ethical principle that the doctor must not knowingly act against the interest of his patient and must take all reasonable steps to ensure that he does not do so unwittingly. The vast majority of research projects do not involves any probability of serious harm coming to those involved but even studies where there is little or no risk to the patient do require reconsideration of the balance of good versus harm.

The notion of informed consent, involves the general rule that people chosen to participate in research projects should be told frankly what the risk and benefits are likely to be and what the purpose of the research is. There are however many difficulties in the way of achieving completely informed consent. First it is impossible for the clinician to tell the patient everything in his mind. Secondly, the patient can only rarely be as well informed as the clinician and thirdly, even if it were feasible to spend a very long time with each patient it would often be undesirable to do so on ethical grounds since the patient might well receive the impression that the clinician was unwilling to take responsibility. The particular problem of consent by people whose judgement is impaired or not free must be raised. In many psychiatric situations an attempt is made to get around this by obtaining consents from relatives or guardians. The difficulty that individuals who are in states of great distress have in making rational decisions in regards to giving consent is one that must always be in the mind of the disaster researcher.

Confidentiality is a basic ethical principle in research that the doctor should take all reasonable precautions to preserve the confidentiality of the information given to him by patients. However, in today's world it is no longer practicable to look upon the single health-care giver as the patient's sole confidant in any serious illness and it is assumed by public and professionals alike that any contact with the complex helping professions today implies acquiescence in some degree of confidence extended to the team.

What do Disaster Researchers Need to Know Before Embarking on a Project

There is no doubt that disasters fascinate people. It is also well recognised as there is a convergence phenomenon both from the public and helping agents at the time of disaster. The motivations of such fascinations and involvement range from the altruistic fully conscious motivations to much more complex unconscious motivations. We from the Mental Health Professions need to be constantly alert to our possible biases. We may very much need to find psychopathology in the victims. We may let our own 'survivor guilt' influence our perceptions. I would hate to think that we were as cynical as the Professor of Community Medicine at Newcastle who has said that 'clinical epidemiology is the science of turning death certificates into plane tickets'. There is no doubt however that many of us may be attempting to improve our curriculum vitae rather than have genuine concerns for the victims of the disaster.

I believe that disaster researchers need to know some basic principles before they embark on research in human behaviour in disasters. In particular I believe they need to know what is already known about the psychology of disaster victims. They need to have a good understanding of concepts of stress and crisis and how these are modified. They need to know that crises are crucial periods in a persons's life and that interventions both therapeutic and non-therapeutic can have a profound effect at times of crises. Workers in addition need to know the concepts of loss, mourning and grieving. All disaster victims experience various degrees of loss, the most serious of course being the loss of a loved one. The mourning and grieving of these losses are complicated by the chaotic aftermath. Even in disasters which do not involve deaths there will be losses of home, mementoes, neighborhood and income. Thirdly, I think that it is important that disaster researchers know about social and emotional resources and how individuals utilize such resources. They need to know about coping and adaptation strategies behaviours that protect the individual from internal and external stresses and finally, they need to know about the attribution theory, ie the way individuals make sense of events that have happened to them. It is very important that researchers know the stage individuals go through following a disaster, because they are going to be asking questions whether by questionnaire or by interview that may have the effect of opening up old wounds. Researchers need to be experienced in dealing with such responses. I know, for example, that in John Clayer's study in South Australia a number of people have been affected by merely receiving a follow-up questionnaire.

Particular Ethical Issues for Disaster Research

One particular important issue for disaster researchers is the timing of their research. There are ethical issues in attempting to look at individuals in the immediate post-disaster phase when distress is greatest as against intermediate and longer term follow-up. Each has particular issues and these need to be thought through.

In any disaster research the question of sanctions from relevant other authorities and co-ordination of the research with the services that might be being offered needs to be considered. As part of the convergence phenomenon following disasters victims often do not know who is talking to them. We know that mental health workers have only grudgingly been recently accepted into helping teams and researchers are generally even less welcome. It is important that researchers have clear goals and use the most appropriate methodology to answer the questions posed. A particular issue of research with helpers is to be aware of the need of helpers not to know about their own limitations and the wish they may have to appear strong. The most critical issue for the research worker is to believe in what he is doing and to have achieved some validation of his methodology by sharing his ideas with critical others.

Conclusion

I have briefly dealt here with some of the ethical issues for disaster researchers. There are a number of documents which provide guidelines for example, those of the NH&MRC and Declaration of Helsinki which are important for all researchers to be aware of (Appendix 1). I believe that it is very important to continue to research human behaviour in disaster but that we do this in a unified and co-ordinated way and that the needs of unbiased research must be balanced against care and consideration of those who have suffered horrific experiences.

References

Psychiatric Ethics. 1981. Ed. by S Bloch and P Chodoff, Oxford University Press.

Handbook for Mental Health Care of Disaster Victims by R E Cohen and F L Ahearn, 1980. The Johns Hopkins University Press, Baltimore.

F Redlich and R F Mollica. 1976. Overview: Ethical Issues in Contemporary Psychiatry. The American Journal of Psychiatry, 133:2 February, pp 125-136.

Appendix 1

Basic Principles of Declaration of Helsinki are reproduced below:

1. Medical progress is based on research which ultimately must rest in part on experimentation involving human subjects.

2. In the field of biomedical research a fundamental distinction must be recognized between medical research in which the aim is essentially diagnostic or therapeutic for a patient, and medical research, the essential object of which is purely scientific and without direct diagnostic or therapeutic value to the person subjected to the research.

3. Biomedical research involving human subjects must conform to generally accepted scientific principles and should be based on adequately performed laboratory and animal experimentation and on a thorough knowledge of the scientific literature.

4. The design and performance of each experimental procedure involving human subjects should be clearly formulated in an experimental protocol which should be transmitted to a specially appointed independent committee for consideration, comment and guidance.

5. Biomedical research involving human subjects cannot legitimately be carried out unless the importance of the objective is in proportion to the inherent risk to the subject.

6. The right of the research subject to safeguard his or her integrity must always be respected. Every precaution should be taken to study the privacy of the subject and to minimize the impact of the study on the subject's physical and mental integrity and on the personality of the subject.

7. Doctors should abstain from engaging in research projects involving human subjects unless they are satisfied that the hazards involved are believed to be predictable. Doctors should cease any investigation if the hazards are found to outweigh the potential benefits.

8. In publication of the results of his or her research, the doctor is obliged to preserve the accuracy of the results. Reports of experimentation not in accordance with the principles laid down in this Declaration should not be accepted for publication.

9. In case of legal incompetence, informed consent should be obtained from the legal guardian in accordance with national legislation. Where physical or mental incapacity makes it impossible to obtain informed consent, or when the subject is a minor, permission from the responsible relative replaces that of the subject in accordance with national legislation.