The development of ethics in medical and social sciences in the last half of the twentieth century

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Abstract

The purpose of this paper is to describe both the establishment of some important research ethics protocols and some major controversial studies during the second half of the twentieth century. The focus will be on how the discussion about ethics in medical and social science has developed over time. Studies of different forms of ethical misconduct will be reviewed in an attempt to provide insight into different ways in which ethical guidelines could be violated. Further attention will be given to the influence of the media and the growing mistrust towards researchers, which might be important predictors for the subjects of concern within ethical discussions in medical and social science. Integration of a number of different scientific literature reviews lead to the conclusion that the focus on specific ethical behavior changes over time.

Keywords: ethics, controversial studies, twentieth century.

Introduction

Ethics have always been a hotly debated subject in the social sciences. Research has been conducted on this issue for decades, but has typically been limited in several ways. Beliefs about what is right and wrong in academic practice have always existed. Currently, there seems to be a shift from a system based on the assumption that researchers know how to take their responsibility to a formal system in which ethical rules are clearly prescribed (Haggerty, 2004). In academic culture, there seems to be a high need to produce, and practitioners of science all want to achieve tangible results. In past decades many different ethical violations were the focus of discussion. The present paper will focus on some controversial studies conducted in medical and social sciences in the US in the second half of the twentieth century. Furthermore, the discussion about how ethics have developed through time will be reviewed, using Berg (2009) as a frame of reference. Scientific literature, obtained from online databases (e.g., Web of Knowledge) was used for this review.

The Nuremberg Code, which was established in 1949, will be the starting point of our exposition, because it was one of the first codes containing written principles of human rights in research that gained wide acceptance (Shuster, 1997). We will consider whether this code played a role in reducing ethical violations in medical studies. Second, there will be a focus on the development of some new ethical guidelines concerning the protection of participants. In relation to these guidelines, some unethical psychological studies will be discussed. Third, some important ethical codes and studies that involved violations of privacy will be reviewed. Meanwhile, each section will discuss some of the possible causes of unethical studies, like public pressure and the public trust in science. It should be noted that not all aspects of scientific misbehavior have been addressed in this review. The purpose of this study is to provide insight into the development of ethics by showing the changing nature of ethical guidelines, and by examining different cases of ethical violations that have been occurred in the US during the past 60 years.

Unethical medical studies

As previously noted, an important ethical protocol for researchers in the twentieth century was the Nuremberg Code, published in 1949 in Germany as a reaction to the atrocities committed in the name of medical research during the Second World War (Berg, 2009). This code stipulated the human rights of research subjects. The Nuremberg Code has served as an important model for research regulations in the US (Shuster, 1997). Although this protocol was primarily designed to govern the behavior of medical researchers, it also influenced research practices in social science, as will be explained later. In the present section, two unethical medical studies will be examined.

The Tuskegee Syphilis Study

A famous controversial study in which medical ethics were violated, is the Tuskegee Syphilis Study, conducted in the US state of Alabama. The purpose of this study was to discover the consequences of untreated syphilis in black people, and to find out if there are racial differences in the natural course and the clinical manifestations of the disease. From 1932 to 1972, a population of 400 black men in Alabama who suffered from syphilis was not told about the illness. In addition, these men were not told that they were participating in an experiment. Instead they were told they were being treated for “bad blood.” They were compared to 200 uninfected men. Several untreated syphilitic men died due to not receiving any treatment for syphilis, despite the ready availability of effective medical treatment (Berg, 2009; Brandt, 1978; Corbie-Smith, 1999; Reverby, 2001). The researchers who were engaged in the experiment believed that the findings of the study could only be scientifically confirmed by conducting autopsies. Therefore, the victim’s family was promised that their burial expenses would be covered if the family brought their severely ill family member to the hospital, where the researchers were conducting their experiment. In this way, autopsies could be done without consent of the family (Berg, 2009; Brandt, 1978).

One of the doctors who conducted these autopsies later said: “We now know, where we could only surmise before, that we have contributed to their ailments and shortened their lives.” (Brandt, 1978, p. 10). When the ethical violations concerning this study were revealed on the front page of a prominent newspaper, the New York Times, in 1972 and public pressure increased, the study was finally ended (Berg, 2009; Cave & Holm, 2003). The Tuskegee Syphilis Study attributed to a general public mistrust of scientific research (Brandt, 1978; Corbie-Smith, 1999). According to a final report, the study’s major ethical violation was not providing available medical treatment to a large number of ill men. This gross misconduct compromised the public’s trust in medical professionals, and in scientific research in general. Brandt himself (1978) elucidates the causes of the feelings of mistrust as follows: “The Tuskegee Syphilis Study revealed more about the pathology of racism than it did about the pathology of syphilis; more about the nature of scientific enquiry than the nature of the disease process. The degree of deception and damages have been seriously underestimated. As this history of the study suggests, the notion that science is a value-free discipline must be rejected” (Brandt, 1978, p. 13). Corbie-Smith (1999) agrees, and argues that this study represents the exploitation of blacks in medical history. The mistrust towards scientific research, especially towards medical research, resulting from the Tuskegee Study and other high-profile cases of misconduct, forms a possible important obstacle to many people’s willingness to participate in scientific studies. This general mistrust made it more difficult for researchers to conduct studies within vulnerable groups, such as ethnic minorities or people from lower social classes (Corbie-Smith, 1999).

CIA's ARTICHOKE program

Another unethical medical study was the CIA's ARTICHOKE program, which was mentioned for the first time in 1952. In this study the Central Intelligence Agency (CIA) of the US Government attempted to discover how human behavior could be controlled. One of the objectives was to obtain information from a person against his will. Researchers attempted to control subjects' minds and behavior "through use of drugs and chemicals that could create psychological and physiological changes. These included the use of electroshock, LSD, hypnosis, and various drugs thought to induce memory loss and amnesia" (Berg, 2009, p.65). After public disclosure in 1963 the study was terminated.

Even today, this CIA study raises a lot of questions. Social scientists still do not understand why so many psychologists participated in a study that involved mind control and behavioral manipulation in such an unethical way (Berg, 2009). It is hard to find scientific literature on this subject other than Berg's 2009 essay. One comes away from a search of the literature about this study with the impression that a good deal of information has not yet been revealed. Despite the lack of details and further scientific studies about ARTICHOKE, this study might have contributed to the growing mistrust towards medical scientists and researchers as well.

After the public attention that such unethical studies attracted, ethical violations in medical research seemed to decrease. The general consensus appeared to be that this kind of research was highly unacceptable (Haggerty, 2004). According to Shuster (1997) the Nuremberg Code may have had an important influence in changing the way in which researchers and the public view the right way to conduct scientific studies with human subjects. She states that, four decades after the establishment of the Nuremberg Code, its human-rights legacy is recognized and human rights are more and more protected. However, the influence of this code seems to be delayed. Controversial studies being revealed to the public resulted in more careful revision of ethical protocols (Shuster. 1997). In any case, while unethical medical research seemed to diminish as a possible result of the public pressure, the growing mistrust, the revision of ethical protocols and a better application of the Nuremberg Code, attention was gradually drawn to other forms of unethical research in different areas of science (Haggerty, 2004; Shuster 1997). The next two sections will discuss ethical guidelines and controversial studies in the field of psychology.

Unethical psychological studies

While medical science was initially considered the most ethically risky branch of science, social sciences began to be recognized as involving their own ethical dilemmas beginning in the late 1960s (Haggerty, 2004). Beginning during that time period, and continuing into the 1970's several authorities in the academic world tried to diminish unethical research practices in the social sciences by adopting more research protocols. American institutes like the Public Health Service (PHS) and the Department of Health, Education and Welfare (DHEW), which financed social scientific research projects, demanded that studies conducted with their financial support be reviewed by an institutional committee. These committees would judge whether the studies had the potential to inflict harm on their subjects, and whether the subjects in such studies were informed about the possible harm or benefits they might experience while participating in the project (i.e. the committees sought to determine if subjects had given their informed consent). These two measures were also components of the 1974 The National Research Act, which led to the transformation of the aforementioned institutional committees into institutional review boards (IRB's). The IRB's were not only responsible for the protection of the subjects and for assuring that informed consent was obtained. They were also expected to weigh the risks and benefits of the study, and to examine whether important scientific knowledge could potentially be obtained from them (Berg, 2009). Ever since 1953, the American Psychological Association ([APA], 2010) has published the "Ethical principles of psychologists and code of conduct." In the most current version of this document (APA, 2010) five general ethical principles are described, and a description is given of the ethical standards that are derived from these principles. Among these principles are the requirement that experiments have the potential to benefit the participants, do no harm, and that they be honest, be fair, and respect the dignity of all participants (APA, 2010). The remainder of this section will discuss specific unethical research projects in the field of psychology. Well-known examples of studies in which participants were psychologically or emotionally harmed are Milgram's "Behavioral Study of Obedience" and Zimbardo's "Stanford Prison Experiment." The studies themselves, and the criticism they gave rise to, will be discussed in order to illustrate the consequences of the violation or absence of the IRB system.

Milgram's 'Behavioral study of obedience'

In 1963 Milgram's study of obedience was published in the *Journal of Abnormal and Social Psychology*. In this study, Milgram (1963) told subjects that they were participating in a "learning experiment" on the effects of punishment on memory (p. 373). But instead of participating in a learning experiment, the subjects participated in a study of obedience. The naive subjects got assigned to the role of teacher and were asked to administer an electric shock whenever the learner (an actor) would answer the assigned questions incorrectly. The subjects were told to increase the intensity of the shocks as the experiment proceeded. The responses to the increasing shocks of the learner were standardized (i.e. recorded) and the shock generator was fake, but the subjects were unaware of these facts. There were 30 marked voltage levels ranging from 15 to 450 volts, supported by verbal descriptions of the shocks ranging from '"Slight Shock" to "Danger: Severe Shock"' (p. 373). Milgram expected that the subjects would refuse to continue administering the shocks at one point and the highest voltage administered would be the quantitative value of the obedience of the subject. Shockingly, more than half of the subjects went on administering the shock of 450 volts, which could be lethal. Many of the subjects seemed to experience extreme tension when the voltage increased. This tension was observed in the form of sweating, trembling, stuttering, biting lips, groaning and digging their fingernails into their flesh. Milgram also described nervous laughing fits and seizures in some subjects (Milgram, 1963).

Milgram's work was highly criticized by other psychologists. The lack of informed consent was regarded as harmful to the experimenter-subject relationship (Baumrind, 1964; Kelman, 1966). Baumrind (1964) argued that an experimenter is expected to be concerned with the welfare of his subjects, which makes the experimenter responsible. This responsibility is especially important when subjects are not informed about the actual aim of the study, to assure that subjects do not alter their behavior to a socially desirable standard. When subjects are harmed, their trust in the experimenter is harmed too. Moreover, not informing the subjects about the aim of the study makes the researcher solely responsible for weighing its costs and benefits (Cave & Holm, 2003; Kelman, 1966). The fundamental question here is whether Milgram had the right to decide that the value of the knowledge obtained from his study was higher than the harm he caused during and after the experiment (Kelman, 1966). There is still no consensus on whether the subjects were harmed temporarily or permanently (Baumrind, 1964; Cave & Holm, 2003; Patten, 1977). Milgram (1963) argued that the harm was only temporary, while Baumrind (1964) referred to possible long-term harm to the self-image of the participants. In addition, Kelman (1966) critically noted that Milgram never gave his subjects the choice of gaining potentially disturbing insights about themselves.

Zimbardo's Stanford Prison Experiment

Another highly controversial study in which subjects were psychologically harmed was the "Stanford Prison Experiment" conducted by Philip Zimbardo (Zimbardo, 1971). Zimbardo aimed to find out what the behavioral and psychological consequences were of being a prisoner and prison guard. To this end he built a prison in the basement of Stanford University and randomly assigned students to the role of guard and prisoner. To depersonalize the students, both guards and prisoners, were required to wear uniforms. Prisoners wore ill fitting smocks and caps and no underclothes; guards wore a uniform and reflecting glasses which made it impossible to see their eyes. (Zimbardo, 1971). The subjects signed an informed consent, which specifically mentioned "that there would be an invasion of privacy, loss of some civil rights and harassment" (Zimbardo, 1973, p. 254). Although Zimbardo intended to let the experiment last for 14 days, it was called off after six days, because the situation had escalated to the point where it had gotten out of control. Guards humiliated and harassed prisoners, and several prisoners left with "acute emotional disturbance, disorganized thinking, uncontrollable crying, screaming and rage" (Zimbardo, 1971, p. 8). Moreover, the guards, the prisoners and even Zimbardo himself lost touch with reality and could no longer distinguish between the experiment and real life (Zimbardo, 1971). There was an extensive debriefing after the experiment, in which there was candid conversation about feelings, experiences were shared, and there was time for moral reorientation (Zimbardo, 1971).

This study was also highly criticized, even though informed consent of the subjects had been obtained. Savin (1973) focused his critical comments on the costs and benefits of this study. He questioned whether the experiment held out the hope of providing any new insights regarding real-life prison situations. In addition, he expressed shock at the fact that Zimbardo predicted that things would get out of control in advance and yet still chose to conduct his study. Furthermore, Savin (1973) noted that Zimbardo seemed unable to objectively judge whether the benefits outweighed the costs. Zimbardo (1973) himself made a numer of critical comments about his study. He contrasted absolute ethical standards and relative ethical standards. He described absolute ethical standards as "higher-order moral principles that can be postulated and which are invariant with regard to the conditions of [their] applicability across time, situations and expediency" (Zimbardo, 1973). If he had employed this definition, he would never have conducted his study, because it would have been morally wrong to harm people, despite of the possible benefits of the study. However, he called for a more relative definition of ethical standards in which it is justified to weigh costs and benefits (Zimbardo, 1973).

In Milgram's study as well as in Zimbardo's experiment subjects were harmed on many levels, although it remains debatable whether the harm was temporary or permanent (Baumrind, 1964; Cave & Holm, 2003; Patten, 1977; Savin, 1973; Zimbardo, 1973). However, the harm inflicted by this kind of research does not remain restricted to the individual level of the subject. Scientific research at the institutional level could be harmed by an increasing distrust of experimenters (Kelman, 1966), which arises from the violation of the experimenter-subject relationship (Baumrind, 1964; Kelman, 1966). Measures like the IRB system and the APA's (2010) general principles, therefore, are not only important tools in protecting subjects, but might also play an important role in the protection of scientific research itself.

Violation of privacy in research

In addition to the protection of the physical and psychological wellbeing of research subjects, a third field of unethical scientific behavior was restricted in the mid-1970's. In 1974, legislative measures were taken to protect the *privacy* of research subjects. In the Buckley Amendment, the privacy of parents and students was protected by the inclusion of provisions that prohibited researchers from releasing personal information without the written consent of the student (or the parent in cases of minor subjects) and limiting their access to official records of individuals (Berg, 2009). In the same year, the Privacy Acts were issued "to protect citizens from large private corporations and federal institutions, as well as from the release of erroneous information and records" (Berg, 2009, p. 68). In addition, the Privacy Acts could be used as a legal justification in any legal conflict involving alleged ethical misconduct in scientific research. Violation of these laws is often found in scientific field studies where the researcher assumes a 'complete participant' role in order to study his or her subjects as described in Gold (1958). In this type of research role the subjects are unaware of the identity of the researcher and do not know that they are being observed. The researcher participates as naturally as possible in activities in which he is interested. The 'complete participant' approach is used to study a population that is normally not accessible for research. The primary justification for the use of this research role is to prevent subjects from changing their behavior because they are aware that they are being studied (Gold, 1958).

Dan Rose's study of a black neighborhood

An example of a research in which the complete participant research role was used is Dan Rose's study of a black neighborhood in Philadelphia, Pennsylvania (1988). In order to study this population, he moved to the neighborhood with his wife and children and took a job at a local garage. He participated in the everyday activities in the neighborhood without revealing that he engaged in research, and he kept a journal of his findings (Rose, 1988). There has been a lot of debate about the complete participant research role. Because the identity of the researcher has to remain secret, informed consent cannot be obtained from the participant. This necessarily means that the participant cannot consent to be in the study or to leave the study (Bulmer, 1982; Punch, 1994). Furthermore, to successfully carry out this research role, a certain amount of deception has to be a part of the study. As mentioned earlier, deception harms the trust between researcher and subject (Baumrind, 1964; Bulmer, 1982; Kelman, 1966). Punch (1994) noted that deception is acceptable to a certain extent (which must be determined in terms of potential consequences for the subject). He clarified this viewpoint by noting that deception should only be used in exceptional situations, and that it is absolutely unacceptable to steal documents, lie directly to the subject, break promises and inflict harm on the subject. Finally, there has been debate about the public-private continuum (Punch, 1994). The question in this regard has to do with defining which behavior is public and can be studied, and which behavior is private and should be left unstudied.

Humphreys' Tearoom Trade: Impersonal Sex in Public Places

A study in which both the complete participant research role and the public-private continuum debate are represented is Humphreys' study on casual homosexual sex encounters in public restrooms (Humphreys, 1970a). In order to study the population of men who engage in casual homosexual sex encounters Humphreys (1970a) posed as a 'watchqueen' (i.e., a lookout to assure that intruders would not interrupt the tryists, which took place in public bathrooms). Humphreys gained access to this subculture and information about it by informing a group of twelve men, who were willing to help him of his study. They taught him appropriate behavior in the 'tearooms' (the public restrooms where the sexual encounters took place). After observing the encounters of about 100 respondents in the 'tearooms', Humphreys noted the participants' license plates (Humphreys, 1970b). He then obtained their names and home addresses from the license register, which he was given access to by a friendly policeman on the pretext that Humphreys was conducting market research. The final stage of his study consisted of his visiting their streets to record descriptions of their houses and the areas they lived in. The results of this observation, however, were unsatisfying. This led to Humphreys' decision to administer a social health survey. To make sure the respondents would not recognize him as the watch queen while he was administering the survey, he waited a year before doing so and used a disguise (Humphreys, 1970b). All this information eventually led to the distinction of four types of visitors in the 'tearooms', in terms of their marital and occupational status, and their sexual preferences (Humphreys, 1970a).

This study proved to be highly controversial. Humphreys himself defended the ethics of his study by posing several arguments (Humphreys, 1970). First, he contended that every research method can cause harm to the subjects, and he proposed a continuum in which a researcher uses "more or less misrepresentation of purposes and identity, more or less betrayal of confidence, and more or less positive or negative consequences for the subjects" (Humphreys, 1976, p. 112). He defended the misrepresentation in his study by stating that he did not lie to the subjects, but simply omitted telling them that he was a researcher. Furthermore, he defended his study by noting that the personal information that he obtained remained completely confidential. Finally, he argued that, by writing an honest report, he did not create problems for those who engage in such encounters (Humphreys, 1970). Critics posed the question of whether private activities in a public space ought to be observed (Von Hoffman, 1970; Warwick, 1973). In addition, they were worried about the fact that such highly sensitive information could have been used to blackmail the men involved or for to criminally prosecute them (Von Hoffman, 1970; Warwick, 1973). In response, Humphreys' defenders note that he in fact did keep the information confidential, because the personal information never was made public (Babbie, 2004; Lenza, 2004). They also noted that there is no prove that subjects were harmed (Babbie, 2004; Lenza, 2004), something that had been questioned by Warwick (1973), who noted that the media attention could have caused great anxiety in the subjects who recognized themselves. Finally, Warwick (1973) and Lenza (2004) agree on the fact that betraying the trust of subjects could harm the trustworthiness of science. However, they differ regarding the source of this mistrust. Warwick (1973) regards Humpreys as the culprit, yet Lenza (2004) believes that the media attention could have played an important role in the creation of mistrust towards social science researchers.

The use of the ‘complete participant’ role is highly controversial, because of the possible violation of privacy and the lack of informed consent (Gold, 1958). However, complete participant research is possibly the only way to study populations that are normally not accessible for research, a fact which is conceded by both critics and defenders of the ‘complete participant’ role (Bulmer, 1982; Punch, 1994; Warwick, 1973).

Legislative measures like the Buckley Amendment and the Privacy Acts are necessary to prevent researchers from using the complete participant role in order to violate privacy. Like the IRB’s, these legislative measures may help protecting both the subject and science from being harmed (Lenza, 2004; Punch, 1994; Von Hoffman, 1970; Warwick, 1973). There now seems to be a rise in process-oriented ethical misbehavior, which is expressed in currently widely discussed cases involving fraud, plagiarism or data modifications (De Vries, Anderson, & Martinson, 2006).

Conclusion

This paper consisted of an overview of the construction of ethical protocols, and of some studies that violated these protocols in the US during the second half of the twentieth century. First, the establishment of the Nuremberg Code was described. In contrast to the current focus on academic dishonesty concerning violations like fraud and plagiarism (De Vries, Anderson, & Martinson, 2006), it can be concluded that the main focus in debates about ethics in the medical and social sciences during the second half of the twentieth century was on the rights of the participants. Despite the guidelines described in a growing amount of ethical protocols and the assumption that researchers are aware of their responsibilities, several unethical studies were conducted during the last half of the past century (Berg, 2009). Violations of human rights in medical studies like the Tuskegee Syphilis Study and the CIA’s ARTICHOKE program led to a growing mistrust towards researchers. In ethical protocols protecting human rights, priority was given to the provision of guidelines for the medical and natural sciences. From the 1960’s on however, ethics in other areas of science also became the subject of debate. In the social sciences for example, some controversial studies came to attention in which human rights were violated.

Two important psychological studies in which ethical violations were committed, were reviewed. First, Milgram’s behavioral study of obedience was considered. Subjects in this study did not provide informed consent and the procedures involved in the research appear to have led to damage of the participants’ self-image. Second, Zimbardo’s Stanford prison experiment was discussed. Although all the participants in this study were informed about its purpose, the way the participants were treated was not ethically appropriate. The study had to be ended earlier than planned because the situation got out of control. Zimbardo’s research is considered to be morally wrong by many critics because it may have caused psychological harm to the participants (Baumrind, 1964; Kelman, 1966; Savin, 1973). Lastly, violation of privacy was addressed. In this form of ethical misconduct, the privacy and anonymity of the participants were violated. Examples of studies with these kinds of ethical violations were Dan Rose’s study of a black neighborhood and Humphreys’ Tearoom Trade. In these kinds of studies, researchers conduct research without their subjects knowing that they are being studied. A side effect of the studies described was the media attention, which had the potential to make it difficult for future researchers to conduct similar studies (Youngpeter, 2008). In addition, studies like these may have fomented mistrust of social science research among the general public (Corbie-Smith, 1999, De Vries, Anderson, & Martinson, 2006).

Summarizing this paper, some factors that could be of importance in explaining the changing focus in discussions about ethical misconduct among researchers are the increasing presence of ethical guidelines, the better application of those guidelines, public pressure and growing mistrust towards researchers. Due to the increasing presence of ethical guidelines, current researchers are required to receive approval of the study they want to conduct, and to have their study monitored in order to ensure that they are acting ethically (Haggerty, 2004). However, considering ethics in history, we can be sure that ethical misconduct will never disappear entirely. The only thing that seems to have changed over time is the *form* of ethical misbehavior. Comparing discussions of ethics in science today with those of fifty years ago reveals different points of focus. It would be interesting to know how ethical discussions will look like in 2060.

Discussion

It is important to note here that the studies discussed in this paper were all conducted in the United States. In addition, the studies reviewed here were all conducted between 25 and 50 years ago. These facts limit the generalizability of the conclusions drawn here and, it must also be recognized, their applicability to any current ethical concerns, since the kinds of ethical concerns emerging from the research considered here are highly unlikely to arise today, due to the ethical oversight and safeguards now in place. Besides, it should be noted that only six studies have been reviewed, and additional examples of unethical research might have been relevant to the subject of this paper. Furthermore, only a few possible factors that could influence ethical behavior in science have received attention. Factors like changing moral convictions in society through time, the amount of subsidies provided for research, the actual academic culture or other possible factors have not explicitly been considered in this paper.

It could be interesting to weigh costs and benefits of the increasing presence and importance of ethical codes. It is possible that the many ethical protocols are an obstacle for publishing possibly innovative results. Another interesting line of research concerns the possible factors that influence unethical misbehavior. This paper was mainly descriptive, but further research and reviews could provide more insight into possible causal relations.

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