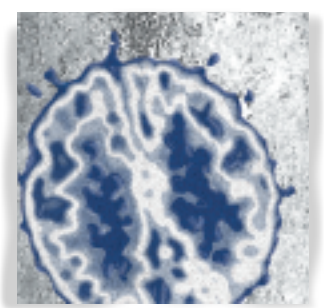
Ethical aspects of research on psychological trauma

Dan J. Stein, MB; Allen Herman, MD, PhD; Debra Kaminer, MA; Solomon Rataemane, MB; Soraya Seedat, MB; Ronald C. Kessler, PhD; David Williams, PhD, MPH



Research in the area of psychological trauma raises a number of complex ethical issues. These include questions about unjustified medicalization of suffering, retraumatization of survivors, the morality of also investigating perpetrators of trauma, and neglecting to provide appropriate intervention. We discuss some of these issues against the backdrop of a study of trauma in South Africa, and the recent work of the Truth and Reconciliation Commission in that country.

In the early part of the twentieth century, science was seen by its practitioners and by professional philosophers as a value-free enterprise.[1,2] By careful observation of the phenomena of the world, and by rigorous analysis of their relationships, the laws of nature would be gradually deciphered and science would resolutely advance. Such advances would, in turn, pave the way for general progress in human affairs.

As the century grew older, however, and theoretical physics provided the foundation for the practicalities and horrors of such phenomena as atomic warfare, the line between science and values blurred. Many twentieth-century philosophers have since portrayed science as simply one way of understanding the world, one more game with its own particular rules, no more accurate or appropriate than any other.[1,2]

Medical science has perhaps the advantage of often appearing intrinsically valuable. Diseases, almost by definition, involve harmful effects[3,4]; thus research that leads to their defeat would seem valuable. When the costs of research (eg, the adverse effects of a new drug) potentially outweigh the benefits (eg, the therapeutic effects of the same agent), however, ethical issues obviously become more apparent. Other important ethical issues include those of informed consent, confidentiality and privacy protection, and disclosure of results.[5,6]

In the field of psychological trauma and posttraumatic trauma, controversy is not uncommon, and questions about the ethics of research on trauma are no less subject to debate. In this paper, we discuss some of the ethical questions that surround work in this area, questions which have been inspired by some of our work in South Africa on trauma, posttraumatic stress disorder (PTSD), and the recent proceedings of the South African Truth and Reconciliation Commission (TRC).

Author affiliations: MRC Research Unit on Anxiety Disorders, University of Stellenbosch, Cape Town, South Africa (Dan J. Stein, Debra Kaminer, Soraya Seedat); Faculty of Public Health, Medical University of South Africa, Medunsa, South Africa (Allen Herman); Dept of Psychiatry, University of the Orange Free State, Bloemfontein, South Africa (Solomon Rataemane); Dept of Health Care Policy, Harvard University Medical School, Boston, Mass, USA (Ronald C. Kessler); and Institute for Social Research, University of Michigan, Ann Arbor, Mich, USA (David Williams)

Address for correspondence: Prof Dan J. Stein, Director MRC Research Unit on Anxiety Disorders, Cape Town, PO Box 19063, Tygerberg 7505, South Africa
(e-mail: DJS2@GERGA.SUN.AC.ZA)

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Background

Before moving on to discussing ethical issues per se, it may be helpful to provide some general background on South Africa and the TRC. In 1994, after decades of political struggle, the apartheid regime of the Nationalist Party was replaced by a democratically elected government in which the African National Congress held the majority of seats. In response to the gross violations of human rights in the past, the new government passed the Promotion of National Unity and Reconcilation Act. This act was a negotiated settlement between the old and new regimes, and at its heart was a move away from the concept of retributive justice for past crimes (as in the Nuremberg trials), and towards a prudential focus on the common good.[7-9]

The act provided for a Truth and Reconciliation Commission, which would: (i) provide survivors a chance to relate the violations that they had suffered and recommend reparations where indicated; and (ii) provide perpetrators with the opportunity to receive amnesty if they gave full disclosure of facts related to politically motivated acts. By establishing "as complete a picture as possible of the nature, causes, and extent of gross violations of human rights," the act aimed "to promote national unity and reconciliation in a spirit of understanding which transcends the conflicts and divisions of the past."

For medical practitioners and researchers, a whole series of questions immediately springs to mind: What, if any, was the impact of gross human rights violations on health? Did the TRC have a therapeutic effect for survivors who gave testimony, or were they retraumatized? Was the effect of the TRC on the nation as a whole beneficial or not?[10]

Medical research was, of course, not at the head of the TRC's agenda and, unfortunately, there was no prospective attempt to investigate such questions. Nevertheless, we recently obtained funding to study a cross-sectional probability sample of South Africans with the aim of assessing exposure to trauma, posttraumatic psychiatric symptoms, and attitudes toward the TRC. In formulating this study, a range of different ethical issues were raised by investigators and by focus groups comprised of participant–observers (eg, people who had themselves suffered gross human rights violations). We review some of these here.

Is it justifiable to medicalize suffering?

There is of course an enormous amount of literature documenting a relationship between psychosocial adversity and stress, and medical and psychiatric disorders.[11,12] It would seem incumbent upon clinicians to recognize these relationships, and use this knowledge to help motivate for appropriate changes to improve health. Certainly, in the South African context, during the time of apartheid, it was common for progressive clinicians and researchers to argue that the oppressive political system exacerbated the prevalence and severity of medical and psychiatric disorders,[13] and that a democratic dispensation would ultimately result in improved health for all.

On the other hand, there is also a body of literature that adopts a critical stance towards the medicalization of a range of phenomena including sexual deviance, violent behavior, and even stress.[14,15] This work argues that the use of medical terms and constructs in such areas comprises an inappropriate extension of the health professions, and undermines recognition of the sociopolitical nature of these phenomena. In writing about the suffering of individuals who lived through the Cultural Revolution in China, Kleinman,[16] a leading medical anthropologist, writes that "To interpret such problems, because of the bodily idioms that frequently accompany them, solely as illness is to medicalize (and thereby trivialize and distort) their significance."

The entity of posttraumatic stress disorder (PTSD) itself exemplifies some of these issues. Some might emphasize the "normality" of posttraumatic stress responses; these are in some ways ordinary responses to extraordinary events. Similarly, there is a body of work that argues that the diagnosis of PTSD, is merely the medicalization of a sociopolitical arena. Young,[17,18] for example, has argued that the use of notions of stress reproduces conventional knowledge about individual vulnerability (rather than emphasizing resilience and the need for sociopolitical change), and that the construct of PTSD should be seen primarily as a cultural product. On the other hand, there is a growing body of data that shows that only a minority of those exposed to trauma go on to develop PTSD, and that PTSD is mediated by specific psychobiological dysfunctions, indicating that this condition is best characterized as a medical disorder.[19]

It may be possible to reach a compromise between these dichotomous viewpoints.[20] After all, medical disorders involve psychobiological dysfunctions, but also

occur within sociocultural contexts that may contribute to their pathogenesis and mold the experience of suffering from symptoms. Similarly, it is important to appreciate and investigate both the particular cognitive and biological dysfunctions that characterize PTSD and the social factors that affect vulnerability and resilience, and that influence its course, experience, and outcome. Indeed, in good clinical and epidemiological research it is precisely this kind of complex interplay that is the focus of the work. Scientific data can, for example, be used to justify medical resources for those who suffer from psychiatric symptoms, without losing sight of the resilience people show in the face of adverse circumstances and the need for appropriate sociopolitical interventions.

Do trauma interviews retraumatize the individual?

In one model of the mind, favored by early psychoanalysts, psychopathology results when suppressed impulses appear in a disguised form. In this model, expression of these impulses resolves the unconscious conflict, and is therefore cathartic. Indeed, many programs for the treatment of PTSD insist that patients verbalize their past traumas, explaining that this articulation is in and of itself therapeutic.[21] Pennebaker and colleagues have published a series of studies suggesting that disclosure of trauma, even if only in writing, is therapeutic.[22,23] Relatively simple interviews in Holocaust survivors,[24] as well as more complex forms of "testimony psychotherapy,"[25] have been found beneficial.

Later psychodynamic models of the mind, however, have emphasized the importance of the relationships on which psychopathology and psychotherapy are based. Certainly, therapeutic reprocessing of traumatic experience is more complex than simply talking about past trauma; there is also a need for restructuring of the emotional memories and acquisition of new and adaptive responses.[26,27] Similarly, testimony is arguably effective only within certain contexts; talking about trauma may only be useful at a particular time for a particular individual, and it may be countertherapeutic to encourage the traumatized person to relate his or her story when time and/or context are inappropriate.

Debate about the value of the TRC exemplifies some of these issues. On the one hand, there were many anecdotal reports that those who testified before the TRC found this a healing experience.[28] The historical significance of the event possibly facilitated a therapeutic process. On the other hand, it should be pointed out that there were also significant negative aspects, including sometimes having to face cross-examination, not receiving long-term psychological care, and not receiving reparations in a timely fashion. Certainly, we would warn that people who suffer from PTSD may require a great deal more than merely the one-off opportunity to testify about their experience.[29]

In the research setting, interviews about psychological trauma typically comprise ratings scales and structured interviews. In our anecdotal experience, research subjects who complete realms of self-rating scales often have ambivalent feelings, experiencing many of these as inapplicable or inaccurate. Structured interviews, for their part, are often experienced as supportive (and rarely as traumatic). An interesting recent study provides empirical confirmation of this positive experience in a study of childhood victimization.[30] Nevertheless, it has been noted that a minority of subjects in epidemiological surveys do report distress, suggesting that intended respondents should be warned of this.[31,32] The experience that the research subject has of the research interviewer (the research transference!) is likely determined by multiple factors, including whether the subject views the research as important, the rapport established with the interviewer, and the extent to which the subject feels adequately heard and appreciated.

Such considerations reinforce the necessity for researchers to liaise closely with the community in order to clearly convey the aims of the research, and its potential risks and benefits. In terms of a modern understanding of trauma responses, which incorporates an appreciation of both the underlying dysfunctional psychobiology of disorders such as PTSD, as well as of the experience of suffering in the aftermath of trauma, the research interview (perhaps particularly if it is part of a broader effort to archive trauma histories[25]) provides the opportunity for a supportive, meaningful experience of giving testimony about the past. At the same time, it should be recognized that in order to help those with significant psychosocial stressors, or medical disorders such as PTSD, a research interview alone will be insufficient.

What about investigating perpetrators?

A number of people in our focus groups have felt that the most important group of people in the country are survivors. Why concentrate, they ask, on such questions as the motivation and psychological status of perpetrators? Clearly, the most important victims of the horrors of apartheid are the survivors of gross human rights violations. Such people surely deserve the bulk of clinical care and research attention.

At times, however, it can be problematic to draw an overly simplistic distinction between survivor and perpetrator. For one thing, it turns out that people who are survivors are at times also perpetrators.[28] During the liberation struggle in South Africa, for example, victims of apartheid at times perpetrated tremendous violence against alleged traitors. Conversely, for example, soldiers and policemen (white and black) who were recruited against their will were arguably both perpetrators (fighting against liberation forces) and victims (at times coerced or tortured into their roles).

These phenomena, although somewhat unusual, are perhaps reminiscent of the object-relations perspective that emphasizes the prevention of splitting of idealized "good" and devalued "bad" objects, and working towards integration of mental representations. Such a perspective could be useful in several areas of trauma practice and research. For example, in the clinic, in working with disorders such as borderline personality disorder, which may be characterized by significant rage and aggression, it is useful to appreciate that many patients with this disorder have significant histories of childhood trauma.

From a research perspective, much remains unknown about perpetrators, and work in this area may in theory ultimately prove of practical importance. In the aftermath of the second World War, writers were motivated to tackle such issues as the concept of the authoritarian personality.[33] While more recent research has continued to investigate antisocial personality disorder, there appears to be a relative dearth of information about "ordinary" perpetrators, and about the sociocultural and psychobiological factors that may be relevant to preventing perpetration in the future.[34]

At the same time, of course, there is an immense gap between the average victim of apartheid and the average perpetrator of gross human rights violations in South Africa, and this must be clearly acknowledged. Ultimately, the pain and suffering of the survivor does and should remain paramount. It is important to emphasize, as have many authors who have undertaken research on perpetrators, that understanding perpetration by no means implies condoning it.[34,35]

Failure to provide intervention

Is it morally justifiable to spend resources on a study of people who have experienced gross human rights violations without subsequently receiving just recompense? Providing an assessment of needs is assuredly an important first step in directing resources towards survivors of human rights violations. However, in the South African setting, although the TRC has already documented the existence of past violations, it has so far failed to deliver the bulk of reparations. Is there an acceptable rationale for spending more money in order to demonstrate past trauma and current gaps in medical services?

We would argue that it is erroneous to draw too quick a distinction between science and research as value-free and processes such as the TRC as sociopolitical. Research on trauma and posttraumatic responses may be invaluable in making a statement about the need for appropriate resources for traumatized subjects. The TRC certainly reached a similar conclusion (about the need for additional resources for traumatized South Africans), but it did not provide detailed clinical and disability data that would indicate the extent of resources necessary.

Thus, there would appear to be a crucial need to demonstrate the extent of trauma and consequent psychopathology in South Africa, and to use these data as the basis for developing appropriate interventions. It is important to document not only suffering but also resilience to trauma. Similarly, there are a range of pathways to health; in South Africa these likely include the use of traditional healers and participation in religious communities. Given that medical resources are limited in many parts of South Africa, the use of nonmedical resources may be crucially helpful. Patients with PTSD do, however, deserve referral to appropriate medical services.

Interviewing traumatized people raises a range of thoughts and feelings for research interviewers (the research countertransference!). This may include guilt at having been spared trauma oneself, frustration at not being able to provide more help, and feeling that one is taking advantage of research subjects in order to

advance one's own professional career. Again, the experience of the interviewer is determined by multiple factors, including whether they view the research as important, the rapport established with the interviewee, and the extent to which they feel they are able to provide help (such as a medical referral).

In short, in the area of trauma, research interviews should not be idealized as providing a form of brief psychotherapy, but nor should they be demonized as being intrusive or as an inadequate substitute for treatment. It would seem reasonable to provide interviewees with a token gift in order to show the researcher's gratitude. In higher socioeconomic groups a similar token may be seen as insufficient in some ways; it certainly cannot recompense the interviewee adequately for their time and effort. In lower socioeconomic groups, however, too large a token might however be construed as a bribe and may lead to distortion of data.

Conclusion

We tend to agree with the critic who argued that while the TRC may not have provided "truth and reconciliation," it was beneficial insofar as it fostered "knowledge and acknowledgment."[36] Similarly, while research on psychological trauma may of course have significant shortcomings, it is welcome since it fosters awareness of trauma and facilitates appropriate intervention. Indeed, good medical research involves good clinical principles and fosters good clinical practices, and so the endeavors of trauma researcher and clinician go hand in hand. ❑

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Aspectos éticos de la investigación en el trauma psicológico

La investigación en el área del trauma psicológico genera diversas cuestiones éticas complejas. Estos aspectos éticos incluyen reflexiones acerca de la justificación de la medicalización del sufrimiento, de la nueva exposición al trauma por la que tienen que pasar los pacientes, de los aspectos morales de quienes investigan a los que han provocado algún trauma y también del rechazo que puede presentarse para proporcionar intervenciones apropiadas en víctimas de traumas. Se discuten algunos de estos temas en el contexto de un estudio de trauma realizado en Sudáfrica y del reciente trabajo de la Comisión de Verdad y Reconciliación en ese país.

Aspects éthiques de la recherche sur les traumatismes psychologiques

La recherche dans le domaine des traumatismes psychologiques génère un certain nombre de questions éthiques complexes : celles concernant la médicalisation injustifiée des survivants souffrants et exposés à nouveau au traumatisme, celles relatives aux implications morales de la conduite de recherches sur les auteurs de sévices, celles, enfin, liées à la négligence à apporter des mesures adaptées. Nous discutons certains de ces problèmes dans le contexte d'une étude de traumatismes survenus en Afrique du Sud, et sur les travaux récents de la Truth and Reconciliation (Commission pour la Vérité et la Réconciliation) dans ce pays.

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