Ethical issues

But deontological principles and procedural ethics also demand consideration. The relevant principles include beneficence, consent, and non-maleficence. Here investigators have firmer moral ground to stand on, articulated by the recently revised Declaration of Helsinki[2]: considerations related to the well being of human subjects should take precedence over the interests of science and society; subjects must be volunteers and informed participants in the research project; and research involving humans should be conducted only if the importance of the objective outweighs the inherent risks and burdens to the subject. As Lièvre and colleagues observe, once the usefulness is lost, the risk becomes unacceptable. With the usefulness gone, so too are the grounds on which both patient consent and ethical approval were given; and to the moral insult, injury may be added. The latest revision of Helsinki warns that some research populations are vulnerable and need special protection and states that the needs of the economically and medically disadvantaged must be recognised. Lièvre and colleagues suggest that there may be a particular risk of harm in the case of elderly patients like those in the fluvastatin study.

Legal claims on behalf of such patients may be precluded by the usual clause reserving the right of the sponsor to discontinue the study for administrative reasons at any time. But the moral claim that Helsinki principles are violated by unilateral economic discontinuation of clinical trials is difficult to dispute. In terms of procedural ethics, the new rules outlined by Lièvre and colleagues suggest a reasonable remedy, and their reference to the example of AIDS trials is pertinent.[3] Discontinuing a clinical trial for economic reasons may not always be wrong, but that needs to be determined by transparently equitable decision making procedures involving representatives of patients and investigators. The legitimate commercial concerns of pharmaceutical companies may make such procedures difficult to negotiate. But Lièvre and colleagues' interim negotiating position—that, before agreeing to participate, trialists should require sponsors to commit to complete trials—deserves support. If drug companies need investigators as much as investigators need drug companies, it might be the first Lysistrata-like step towards a happier marriage between medicine and the market.

1 Horton R. How sick is modern medicine? *New York Review of Books* 2000;XLVII (No 17):46-50.
2 World Medical Association. Declaration of Helsinki (amended October 2000) www.wma.net/e/policy/17-c_e.html (accessed 18 December 2000).
3 Institute of Medical Ethics Working Party. AIDS, ethics and clinical trials. *BMJ* 1992;305:699-701.

We invited three pharmaceutical companies—Novartis, GlaxoWellcome, and SmithKline Beecham—to comment on this article; all declined.

Asylum seekers and refugees in Britain

The health of survivors of torture and organised violence

Angela Burnett, Michael Peel

This is the last in a series of three articles

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This final article in the series describes how torture and organised violence may affect the health of survivors. A definition of torture, often used for asylum purposes, is shown in the box. It should be noted, however, that not all those who employ torture are acting in an official capacity.

Organised violence is defined as violence which has a political motive. Survivors of torture or organised violence have often been ill treated by government agents such as the army, police, or security forces or other groups perpetrating organised violence, including rebel groups. States have a duty to prevent, investigate, and prosecute cases of torture, but if those who are supposed to do this are themselves the torturers, then there is no official protection. Systematic torture is designed to break the spirit of an individual,[2] but in many countries the intention is also to intimidate a minority or dissident group or even an entire population.

United Nations' definition of torture[1]

Any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as:
obtaining from him or a third person information or a confession,
punishing him for an act that he or a third person has committed or is suspected of having committed,
or intimidating or coercing him or a third person,
or for any reason based on discrimination of any kind,
when such pain or suffering is inflicted by or at the instigation of a public official acting in an official capacity.

Summary points

Torture and organised violence are still prevalent in many countries and have previously been experienced by some refugees in the United Kingdom

The problems of survivors of torture and organised violence are not fully appreciated within the health services

Survivors of torture may not volunteer their history due to feelings of guilt, shame, or mistrust; consideration must be given to building a relationship of trust

Much can be done by health workers to alleviate the physical and psychological difficulties that face survivors

Estimates of the proportion of asylum seekers who have been tortured vary from 5-30%, depending on the definition of torture used and their country of origin.[3 4] In 1999 approximately 6000 people (8.4% of all applications) sought asylum in the United Kingdom on the basis of torture,[5] but the actual figure is likely to be higher than this, as some people do not initially admit to their experiences of torture. This may be through shame or unwillingness to disclose sensitive information—about, for example, sexual violation—to an immigration officer of the opposite sex. Some methods of torture are common, such as beating, kicking, and slapping. Many women and some men are survivors of rape and sexual violation. Some methods are typical of certain geographical areas, such as falaka (beating on the sole of the feet) in the Middle East and Turkey, "Palestinian hanging" (suspension by the arms tied behind the body) in the Middle East and Asia, and in India the ghotna (a pole, placed across the legs, on which the torturer stands). People may be burned with cigarettes, sometimes in neat patterns, or given electric shocks.

KEVIN CAPOON/AP PHOTO

A British soldier surveys paraphernalia possibly used for torture at the Serb police headquarters; elsewhere in the building knives, rubber and wooden batons, and a crate full of brass knuckles were found

General considerations

The effects of torture are an accumulation of those of physical violence and conditions of detention (unhygienic cells, inadequate diet) and the psychological consequences of one's own and witnessing others' experiences. When working with a survivor of torture, the essentials are time, a sympathetic approach, and, if language is not shared, a trained interpreter who is not a family member or friend. The initial focus should be on those events to which the patient attributes the symptoms, and the work should be patient led. A fuller picture may be built up over a period of time.

Physical effects

Fractures and soft tissue injuries

Refugees may have been injured by torture, landmines, or other violent trauma, and injuries will rarely have received adequate medical attention, either because none was available or to avoid attracting the attention of the authorities. Malunited fractures or osteomyelitis may result, which may benefit from an orthopaedic opinion. Falaka results in exquisite tenderness but no physical signs. More commonly there are non-specific musculoskeletal symptoms such as pain and weakness. Physiotherapy[6] and complementary therapies such as massage, relaxation, non-steroidal analgesics, and techniques to manage symptoms may produce some improvement.

Prolonged suspension by the arms, including Palestinian hanging, can lead to neuropathies and muscle weakness, much of which subsequently recovers but which can lead to permanent disability.[7] In the Indian subcontinent techniques such as the ghotna tear and crush muscles, sometimes permanently.[8] Keloid scars from burns and cuts may be distressing to the individual. Electric shocks are a very painful method of torture, yet equipment for this purpose is still exported to countries in which torture is common.[9]

Head injuries and epilepsy

Many people subjected to violence have been hit on the head, and this sometimes results in epileptiform convulsions. These should be managed as for all post-traumatic head injuries. Post-concussion syndromes may present with problems of memory and concentration, and these symptoms can also be related to stress.

Ears and eyes

Slapping around the ears is common during interrogations. There is usually a history of pain, bloody discharge from the ears, and persistent hearing loss. Otitis media may result from traumatic perforation, and the drum may be scarred.

People who have been detained in darkness for long periods often complain of soreness and watering of the eyes in bright light but this finding has not yet been fully documented or investigated. Occasionally on a very bright day redness of the eyes can be observed, but it is rarely bright enough in Britain for this to be apparent.

Sexual violence

As has been mentioned above, many female and some male asylum seekers are survivors of sexual violence and rape, which has throughout history been used as a weapon of warfare to degrade and humiliate an enemy. In many cultures sexual violence and rape are taboo subjects, and survivors may feel very uncomfortable discussing their experiences. Survivors of sexual violence should be able to choose the sex of both their healthcare worker and interpreter, and the latter should not be a relative. Persistent unexplained distress and anxiety may be due to a history of sexual violation.

Sexual violence is a very powerful weapon against individuals, families, and communities; motivated by a wish to dominate and degrade, it is a violent rather than a sexual act.[10] For both men and women the dominant subsequent emotion is usually deep shame. Women may be shunned by their community and family as having been defiled and no longer being fit to be accepted.[11 12]

Some may have been placed at risk of HIV as a result of sexual violation, particularly as in many countries the incidence of HIV is higher among soldiers, who are often the perpetrators of sexual violence. Victims may not voice their concerns about the possibility of HIV infection because of fears about confidentiality and stigma. It is important to offer testing for sexually transmitted infections and, if appropriate, for pregnancy. It is inappropriate to routinely screen all asylum applicants for HIV infection, and mandatory screening is against World Health Organization guidelines.[13] The 45th World Health Assembly noted that "there is no public health rationale for any measures that limit the rights of the individual, notably measures establishing mandatory screening."[14] It is important to offer confidential voluntary testing and support to those at risk. Refugees may have had sexual contacts in areas of high HIV prevalence; refugee women, in particular, may have had to resort to sex work during their flight in order to survive.

Rape and other sexual violation, including electric shocks applied to the genital area, rarely leave any long term physical signs, particularly in women,[15] but forced abduction of the their hip joints may give rise to problems later (C Naughton, personal communication, 2000). Absence of physical signs does not mean that sexual violation has not taken place. For men, objects forced into the urethral meatus may lead to scarring, and sometimes thickening can be felt. It should not be assumed that dysuria is due to a sexually transmitted infection. Men tend to greatly underreport experiences of sexual violence.[16] They may have doubts about their sexuality and fear infertility, and both sexes commonly experience sexual difficulties following sexual violence and may need reassurance about sexual function. It may be more effective to enable people to develop their own support networks by facilitating the development of meetings and activities and by helping with current practical difficulties. It is important to view sexual violation in the context of the other traumas and losses experienced.[17]

Physical expressions of emotional distress

Survivors of torture and organised violence commonly complain of symptoms, such as sleeplessness, nightmares, weakness, lethargy, headaches, abdominal pain, and neck and back pains, which do not seem to have a physical basis and may last for up to two years. They may think these are of physical origin and expect investigations and treatment, but they are often in fact aware of the interrelations between physical and psychological symptoms. It is preferable to try to treat these symptoms by non-pharmacological means—the combined effects of poor concentration and sedatives can make it very difficult to function properly. Above all, management should be realistic, with no false reassurances that symptoms will subside quickly (G Hinshelwood, personal communication, 2000).

Psychological effects

As a result not only of past experiences but also because of their current situation in Britain, refugees may show symptoms of anxiety, depression, guilt, and shame.[12] These are common responses and need to be viewed in context. Very few such people need specialist psychiatric assessment, although a minority may develop psychological problems or frank mental illness as a result of the stresses of conflict and exile. Some of these have a history of psychological health problems and contact with mental health services.[18]

For many refugees, restoration as far as possible of their normal life can be an effective promoter of mental health. Most people would rather be active independent citizens than recipients of benefits. Supportive listening is valuable to help people to cope with their memories and with their current situation. It is important not to turn into a medical problem the normal expression of grief and distress concerning highly abnormal experiences. However, symptoms which may need specialist help include consistent failure to function properly, frequently expressed suicidal ideas or plans, marked social withdrawal, self neglect, behaviour or talk that is seen as abnormal or strange within the person's own culture, and aggression towards others.[19]

One diagnosis that may be made in assessment is that of post-traumatic stress disorder.[20] The difficulty with this is that it turns very common reactions into medical problems and assumes a universally valid and applicable model.[21] The symptoms of post-traumatic stress disorder do not necessarily mean the same in different cultural and social settings, and many people whose symptoms fit its checklist continue to manage their lives and should not be labelled as having a psychiatric condition.[22] Symptoms need to be understood in the context in which they occur and through the meaning they represent to the individual experiencing them: distress and suffering are not in themselves pathological conditions.[23] There is a wide range of reactions to similar experiences. Someone politically active and familiar with use of torture may be able to make more sense of it than someone to whom detention and ill treatment appear more arbitrary. People who have been unable to explain events and who find what has happened incomprehensible are likely to feel the most helpless and unsure what to do.[18] Post-traumatic stress disorder also consigns the traumatic experience to the past, implying that trauma was something experienced before or during flight, but much of the trauma that refugees experience is in their country of resettlement, through isolation, hostility, violence, and racism.[24] It is important to recognise that post-traumatic stress disorder is not in itself an indicator of past torture.[18]

Recovery over time is intrinsically linked to the reconstruction of social networks, achievement of economic independence, and making contact with appropriate cultural institutions against a background of respect for human rights and justice.[25] It is important to acknowledge the resilience of individuals and communities and not label people with diagnoses that may add to their stigma and powerlessness. There is a difficulty here, however, as often a medical diagnosis is an essential passport to scarce social resources, and perhaps even asylum.

Immigration detainees

Governments are increasingly detaining asylum seekers in either detention centres or prisons although they are not charged with any crime. Theoretically

detention is used either for a short period to confirm identity or for those who are thought likely not to comply with temporary admission terms. In many cases, however, the decision to detain seems to be arbitrary.[26 27] There are no centrally available figures for the number of asylum seekers held in detention annually, only "snapshot" figures for an individual day. On one day in April 2000 a total of 1107 people were detained solely under the powers of immigration officers.[28] Similarly there are no figures on the average length of detention, but a third of all such detainees are held for more than six months.[29]

For an asylum seeker such detention is distressing. Even when detention establishments make efforts to appear "friendly" the feeling is that of a prison. The detainees have committed no crime, do not understand why they have been detained, and realise that the detention could be indefinite. For those who have been detained in their own country, the experience of subsequent detention can be devastating. However comfortable the conditions, the experience of being locked up will generally evoke powerful memories. Survivors of torture often describe the feelings of fear and powerlessness caused by the clanging of cell doors, footsteps in the corridor and uniforms,[30] which restimulate their distress.[29]

Conclusion

Victims of torture and organised violence may present with many non-specific health problems. Some will be a direct result of the physical trauma, but most will be of mixed physical and psychological origin. These problems can be dealt with in the same way as any other patient with the same condition, although cultural and language difficulties may interfere. Considerable time and patience is required, but the outcomes can be good. Advice and support is available from organisations including the Medical Foundation for the Care of Victims of Torture.

We acknowledge and than our clients and our colleagues, too numerous to mention individually, who have inspired our thinking and have provided valuable comments on our work.

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Endpiece

My Englishness

For some days the silent work at the back of my mind has been prompting me to give into something: my Englishness, our Englishness. I notice it most acutely in my many conversations with Isabel. Her instinct is to explore, and if necessary exhaust, all medical-remedial possibilities before thinking further. I see myself, or I don't see myself, wheeling Kingsley on to a plane to go and see that top man in Zurich or Toronto. I see myself, or I don't see myself, administering to Kingsley an innovative diet consisting of barium and basmati rice. Isabel comes from a place where the first thing you do about death is throw your life-savings at it.

She wants, at the least, a second opinion, and I don't even want a *first* opinion, and had to will myself to keep the phone to my ear while Kingsley's case-doctor, named Croker (and no, this is not an irony that Kingsley would have "relished"), brayingly and yet with full professional sympathy spoke about the brain damage, the loss of motor control, and the incontinence now being visited on "your poor father." I engage in my discussions with Isabel behind a net curtain of Englishness, Old Englishness. How palpable, how commonplace it is. In England, when you see death coming, you just ask if you've joined the right queue.

Martin Amis, *Experience.*
London: Jonathan Cape, 2000