

## Improving the assessment and treatment of pain in torture survivors

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### Improving the assessment and treatment of pain in torture survivors

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## **Key points**

Ask patients about torture; do not expect spontaneous disclosure.

Explore the patient's understanding of pain, and correct any misunderstandings.

There is almost no research on pain from torture or its effective treatment.

Treat to the highest standards and monitor and share outcomes.

Recognise that the patient may lack social support or financial resources, and health may not be his or her highest priority.

## **Learning objectives**

By reading this article, you should be able to:

- Appreciate some of the wider problems facing the torture survivor with pain attempting to settle in the UK
- Address possible causes of under-recognition of torture survivors among your patients with pain
- Develop confidence in asking patients if they have been tortured

## Improving the assessment and treatment of pain in torture survivors

Torture occurs in many countries,<sup>1</sup> including many that are signatories to the United Nations Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment;<sup>2</sup> it occurs both in stable states and in those with ongoing armed conflict. By the UN definition, torture is "any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purpose as obtaining from him or a third person information or a confession, punishing him for an act 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, or with the consent or acquiescence of, a public official or other person acting in an official capacity. It does not include pain or suffering arising only from, inherent in, or incidental to lawful sanctions."<sup>2</sup> The number of victims and survivors is impossible to estimate but, among refugees and people seeking asylum in the UK and in other high income countries, it is likely that at least 30% and possibly over 40% have experienced torture.<sup>3,4</sup>

Prevalence of post-traumatic stress symptoms, depression, and other psychological disorders have been more thoroughly investigated than chronic pain, <sup>3,5</sup> which is often dismissed as a non-specific aspect of psychological disorder by mental health services. Torture survivors (and refugees in general) also struggle with the effects of dislocation, loss of family, occupation, culture, language, and financial resources. <sup>5,6</sup> Most refugees remain in their own or neighbouring countries; it takes substantial resources to reach host countries such as the UK, <sup>4</sup> by which time many refugees are destitute and in poor health. The process of obtaining asylum and leave to remain is protracted and stressful. Further, poverty, discrimination, lack of safe accommodation or opportunity to work worsen refugees' mental health. <sup>6</sup> Although torture survivors are unlikely to be referred to specialist pain services until years after arrival, their chronic pain cannot be adequately understood or treated without recognition of the wider context outlined above.

Among clinical populations of torture survivors, prevalence of chronic pain appears to be very high<sup>3,7,8</sup> but it has not been estimated with any reliability in unselected non-clinical refugee populations. Among the most common reported sites of pain are the head, back, musculoskeletal system, and limbs,<sup>3,7,8</sup> with pelvic and urogenital pain very probably underreported. Although chronic pain can be severely limiting, the survivor's priorities may lie in addressing other social,

family, housing or financial problems. He or she may also be uncertain about investing effort in settling, and have the active intention of returning home when conditions allow.

#### Assessment

#### Access

Torture survivor patients are seen in primary care, emergency services, and as inpatients, but specialist services such as pain management centres often present barriers to attendance (see diagram). These barriers may prevent referral, such as the assumption that trauma services are the only appropriate referral destination. Barriers are also created by systems of charging non-residents for certain health services that make survivors anxious about being required to pay for consultations; concerns that their information may be passed to the Home Office, a practice that began in 2010 and only stopped in 2019, (after facilitating many thousands of internments and deportations); or language barriers with appointment letters and phone calls in English to the patient who does not understand them. Such barriers can be largely mitigated where there is commitment to do so, by the education of staff and the provision of clear public information in multiple languages.

## Figure 1 about here

#### *Interpreting services*

Interpreting should always be offered, even when survivors appear fluent at first meeting, they may only be competent in areas associated with education or work but not be fluent in describing emotions. Interpreters should be trained and, preferably, experienced in working with torture survivors. Interpreters should be briefed and debriefed at the first and, if possible, subsequent consultations. In some cases, phone interpreting may be preferred because it is anonymous, particularly where a face-to-face interpreter may come from the survivor's community. Phone interpretation is much less sensitive to non-verbal behaviour, and this can complicate conversation. The survivor may have particular needs for the gender and ethnicity, as well as preferred language, of interpreters and these should be respected. Untrained interpreters, such as family members, or service staff in the hospital from the same language group as the patient, should not be used for reasons of confidentiality.

#### **Disclosure**

Most torture survivor patients do not disclose their history of torture if not asked. <sup>10</sup> There are many reasons why clinicians do not ask, including concern at causing further distress, but **asking is essential**. Torture survivors do not conform to any stereotype; some will be destitute, while others will be well-established professionals, including doctors. There are many ways to ask (see Table 1). The clinician can prepare by finding out the likelihood of torture in the patient's home country from websites such as Amnesty International or Human Rights Watch. The act of asking signals to the patient the clinician's concern, a wish to understand, and readiness to listen. If patients have not been tortured, they are unlikely to be offended.

#### Table 1 about here

## Content and process of assessment

This section concerns clinical assessment, not medicolegal assessment that requires training and supervision. Haoussou, writing both as a torture survivor and a doctor, advises clinicians to first establish trust and assure confidentiality, and then to aim for continuity of care and to avoid repeated questioning on torture by each member of the team or referral network<sup>11</sup>. They should be sensitive to the shame of recounting torture, particularly but not only sexual torture, and should treat survivors with dignity and respect, both of which can be destroyed in the patient by torture. Establishing trust is particularly important, and can be disrupted by cultural differences in nonverbal behaviour such as a proscription of physical contact, even shaking hands, or lack of direct eye contact (for reasons ranging from embarrassment to cultural expressions of respect).

Pain from torture can have profound and complex meanings for the survivor, from symbolising the loss of the old life and the dreadful experiences endured to representing survival and a mission to right wrongs. The context of justice and reparation may be ingrained with concerns about pain and other sequelae of torture and with their treatment. This is often an unfamiliar dimension for the clinician, but awareness of these issues contributes to a better basis for treatment or onward referral.

The clinician assessing a torture survivor for pain must take a very different frame of reference in addition to his or her usual understandings of possible cause. Torture is inflicted by a huge range of methods, some of which the survivor may find hard to describe for varied reasons, including loss of consciousness, lack of knowledge (of injected substances, for instance), memory losses from head injury, anxiety and post-traumatic symptoms induced by recall, shame, humiliation, and

others. Some methods leave clear marks that would be hard to account for other than by deliberate infliction, and there are a few high quality studies of characteristic pain syndromes after falanga (beating the soles of the feet³) and suspension by the arms.¹³ Many other torture methods (such as electric shock, sexual assault, severe strain to joints) do not leave marks, intentionally making it harder for the asylum seeker to substantiate his or her case. Multiple ways of inflicting pain and terror are used at the same time, in conditions of poor nutrition, hygiene, lack of health care, and extreme and prolonged stress. There is, for obvious reasons, no animal literature to help us understand what such practices do to the human body, short- or long-term. Nevertheless, intensity of acute pain and of concomitant distress are consistent predictors of the persistence of pain in the longer term,¹⁴ so high prevalence is to be expected.

Some familiarity with commoner torture methods is helpful for the clinician, but sufficiently detailed description should be obtained (within the limits of the patient's distress) for the clinician to have a reasonable understanding of what damage and pain the patient underwent, where on the body, and over what time scales. The patient may struggle with the appropriate vocabulary for body parts, as well as with associated shame; drawings of the human body can be offered. Rape, of both sexes, is increasingly reported and may be particularly difficult to disclose; asking directly is helpful.

It can be difficult to balance the ideal conditions of privacy, time, and a well-prepared interpreter to explore the survivor's pain and its meanings with the reality of most clinics, or even of a recovery room where the survivor has woken from general anaesthesia with flashbacks and severe distress. Nevertheless, since refugees often live difficult and unstable lives and may not attend further appointments, the opportunity to assess as fully as possible should be taken when it first arises, in the initial consultation.

#### **Treatment**

#### Sharing understanding of pain

Although it is important to bear in mind the possibility that the cause of pain may warrant further investigation (there may be a malunited fracture, or foreign bodies such as shrapnel), torture would usually have occurred years before the patient presents with pain and central mechanisms are likely to be important in explanations of pain. There may be a substantial gap between the torture survivor's understanding of the cause of pain and its possible resolution, and a

biopsychosocial model that does not expect to find unhealed damage nor to treat by invasive methods. This gap is often exacerbated by cultural differences in expectations of medicine and respect for Western medicine and the resources it commands; by alienation of the survivor from his or her own body that may have roots in surviving trauma; and by the stigma attached to suggestions of psychiatric or psychological symptoms in countries where psychiatry is reserved for the frankly psychotic members of the population, with less dramatic problems addressed within the family. Reframing persistent pain not as irreparable damage and deterioration but as plastic changes in the central and peripheral nervous systems provides a basis for more optimistic discussions of recovery of function and changes in ways of managing pain.

Unfortunately, no good resources to bridge these gaps exist (to the authors' knowledge) in relevant languages, and the explanation of pain is best negotiated on a basis of trust and of drawing for examples on the torture survivor's own experience. It is unhelpful that many trauma services (to which survivors are more likely to be referred than to pain services) see all symptoms through the lens of psychological disorder, and either dismiss pain as 'psychosomatic' or assure the survivor that pain will resolve with trauma treatment, which is not the case.<sup>3,16</sup>

Notwithstanding these comments, post-traumatic stress symptoms, depression and anxiety are common in torture survivors, with sleep disturbance and specific fears and triggers to flashbacks (such as of cell-like rooms, people in uniform, screams... all of which can be encountered in hospitals), so psychological assessment is very helpful in identifying problems for which treatment should be offered. Where psychological assessment is unavailable, liaison with psychological or psychiatric colleagues and sensitive use of screening instruments can help to identify problems that need consideration in treating pain, because they may in their own right complicate treatment.

Most pain clinicians have routine explanations of the pathophysiology of persistent pain but it may be even more important than usual to acknowledge the reality of the original injuries, and to convey how common it is to feel distressed. Neuropathic pain may be induced by methods of suspension, constriction and traction, and by sustained postures, such as in a small cage. It may be associated with sensory and motor symptoms; partial lesion of the brachial plexus or lumbar plexus can produce feelings of heaviness and unresponsiveness and apparent neglect and underuse of the affected limb/s; these phenomena need systematic investigation. Nociplastic mechanisms (with central descending amplification and reduced inhibition) may be suspected

where there is peripheral hypersensitivity, widespread pain, and fatigue.<sup>15</sup> A physiotherapist's assessment may identify idiosyncratic habits of tension, guarding, posture and gait that have developed as protective mechanisms, exacerbated by prolonged stress, and not remitted despite contributing to disability.<sup>3</sup>

#### **Treatment modalities**

There are very few systematic studies of pain treatment in this population; a systematic review and meta-analysis found two randomised controlled trials of psychologically-based rehabilitative treatments and one of hands-on physiotherapy.<sup>17</sup> Such trials are hard to conduct and the population is unusually heterogeneous. Yet the complexity of their pain, the unfamiliarity of the biopsychosocial formulation of pain for many survivors, and the complications of distress and difficult circumstances, mean that pain may not be as responsive to evidence-based treatments as it is in more familiar clinical populations. This should not deter plans to deliver the highest standard treatments but is an argument for careful monitoring and comparison with best evidence.

Although these patients present in many clinics there is no clear pathway for management. Few clinics will see or recognise large enough numbers of survivors to develop a specific service for their needs. Language is a significant barrier at both the individual and group treatment level. Management follows the same principles as for any chronic pain condition: a multidisciplinary approach focused on aspects of pain and treatment methods agreed with the patient. Several interventions may be required to run concurrently across the biological, psychological and social domains. There is an opportunity for a more structured and integrated pathway to be developed for this complex patient population.

Despite healthcare staff's concerns about triggering flashbacks or exacerbating distress by use of particular equipment (e.g. electrical), investigations or procedures, with clear explanation (and illustration, often available on websites) of what is involved, and willingness to allow the patient control as far as possible, there is no reason to exclude any procedure. Possible side-effects of drugs should be described, and understanding checked; for instance, tricyclic antidepressants could be helpful in restoring sleep as well as treating pain, but the sedating effects may also be unmanageable or intolerable for some survivors. Adherence to drug treatment is often low, for reasons such as inability to afford prescription charges, lack of understanding of what the drug is for, or experience of forcible medication during torture.

#### Rehabilitation

Multidisciplinary rehabilitation may appear to offer a way to enable a torture survivor with chronic pain to develop more effective methods of self-management, to reduce distress and disability, and to improve overall quality of life.<sup>5</sup> It can be offered in groups, in individual sessions (more usual where interpreting is required), or mixed. However, treatment trials overall have been very disappointing.<sup>17,18</sup> This is also the case when treatment methods effective elsewhere are used for survivors of torture with psychological problems, mainly post-traumatic stress symptoms (Hamid et al.<sup>19</sup>, although other systematic reviews are more optimistic, e.g. Tribe et al.<sup>20</sup>). It may be that in both cases, more naturalistic treatments with wider therapeutic aims may be promising [e.g.<sup>21</sup>]. There appear to be some common psychological processes in chronic pain and trauma symptoms, <sup>15</sup> and both may improve with the same treatment, <sup>22</sup> but integrated services designed for this population are very rare.<sup>16</sup>

As mentioned earlier, torture survivors often face prolonged struggles to obtain permission to stay, to establish a home and social network, and to obtain meaningful work, education or training.<sup>23</sup> Family and friends left in the country of origin may suffer persecution, and contact may not be possible; without a passport the survivor cannot travel, or travelling may be unsafe. Other survivors may be trying to find lost family members (often through the Red Cross). Life is fragmented, and the hostile environment policy in the UK has made settling even harder.<sup>9</sup> Support in the form of a letter or phone call from a healthcare professional can help, and should be provided where possible.

## Making the healthcare setting a better place for torture survivors

Torture is proscribed under human rights law and, just as they are obliged to provide asylum, countries are obliged to provide reparation and rehabilitation to torture survivors but few countries have taken any initiatives towards these. The right to asylum is widely recognized, but in practice is restricted by the requirement to authenticate torture claims to sceptical staff. Healthcare staff have been drawn into this by requirements to check eligibility for treatment of those they believe may not be entitled, and to report those they believe to have suspect political views.<sup>9</sup>

International and national organisations for doctors, nurses and physiotherapists have issued statements concerning the obligation on member professionals to inform themselves on torture,

its effects, and rehabilitation, as a human rights issue. There are various ways in which this can be realised: engaging with torture survivor community groups (usually charitably funded) for mutual education and liaison; ensuring that there are no invisible barriers to access and that interpreting is available for consultations; discussing with all staff, including those in reception, how to make the pain service more accessible to refugees; and signposting local support services for this complex patient population.

Treatment should be evaluated, not only for pain relief but for aspects of quality of life, such as social support, community involvement, general health, and, of course, distress. Since there are so few data on pain treatment of torture survivors, sharing any data is valuable, whatever the outcome. Over time, accumulating data will enable us to ask questions about efficacy more systematically, and to develop our understanding of the effects of torture and interactions of those effects with psychological problems arising from it. Single case methods, explained and exemplified in Morley,<sup>24</sup> make data sharing easier. Healthcare staff who are interested in developing their understanding and skills, or improving the situation for torture survivors, can can find a range of medical and campaigning organisations online.

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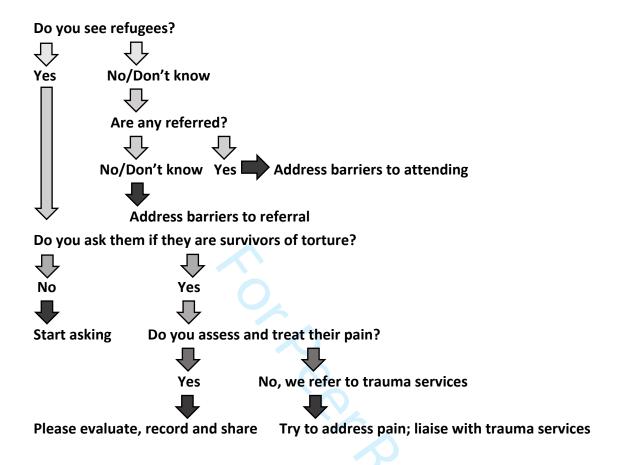
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 Table 1
 Ways to ask about experience of torture

Figure 1 Barriers to pain care for torture survivors

Figure 1



#### Table 1

Can you tell me why you left your home/country? Was your life in danger?

I have seen other patients from [patient's country of origin] who have experienced violence from others. Has that happened to you?

Have you ever been arrested, put in prison or held captive? Has that happened to members of your family?

When you were in prison, were you tortured? Knowing what was done will help me to understand your pain.

Are you applying for asylum in the UK? If that is because of torture, can you tell me about it? Did your pain problem start after you were beaten or tortured?



#### Clinical scenario:

Ms X is 27 and referred to your pain clinic for widespread pain, particularly in her feet, by an orthopaedic surgeon who found nothing abnormal on assessment including foot X-ray and bone scan: he offered injections which she refused, and, noting her difficulty sleeping, prescribed amitriptyline [25mg]. She arrived in the UK four years ago and speaks good English.

She is thin, looks tired and walks slowly with an awkward gait. On taking her history you gather that she has no family in the UK, is sofa-surfing at the flats of people she met through English classes, and is otherwise homeless; she has an engineering degree but is not working. You ask why she came to the UK, and she replies "They tried to kill me, and they will kill me if I am sent back". On further questioning you find that she is appealing refusal of her asylum application and is considering suicide rather than be deported. You indicate your concern, offer her the contact details of a torture survivor organisation, and encourage her to seek help and advice there on strengthening her case.

She describes the pain as burning in the soles of her feet, with cramp-like pain in her calves, both worsening with weightbearing; the burning pain also occurs at night. It started when she was beaten repeatedly on the soles of her feet with cables, then made to stand until she lost consciousness; this happened at least twelve times. When you ask if she was tortured by other methods, she denies it. You make clear that you are appalled: that torture is wrong and that you will try to help her pain. (You do not ask why she was tortured, often understood by survivors as asking if they deserved it).

You explain neuropathic pain to her: although usually persistent it is worth trying to treat; you emphasise that walking does no harm. She seems relieved, and rather hesitantly asks

"so I am not mad?" Since pain often triggers flashbacks, she had started to doubt the reality of all her senses.

She admits she has not tried the amitriptyline, not understanding why she was prescribed an antidepressant. You explain its use in neuropathic pain, suggesting she starts on a low dose [10mg], titrating up depending on its effectiveness and side effects. You recommend taking it in the evening to promote sleep and minimise daytime drowsiness. You think it best to try this before gabapentinoids, because of once daily dosing and being relatively well tolerated. On review, other neuromodulation medications would be considered as part of the broader biopsychosocial pain management plan. You also offer to refer her to physiotherapy, to see if desensitisation might help, and to psychology, to help with her pain and distress; she seems overwhelmed so you decide to wait and discuss again at the next appointment. Meanwhile, you advise her to try to weight bear little and often rather than for prolonged periods.

As she leaves, she says "Thank you for believing me."

A new SpR in your pain service says that she has a particular interest in seeing survivors of torture, having done voluntary work with a torture survivor charity in the last few years. A consultant colleague replies that in his six years at the pain clinic, he has seen many refugees but none of them torture survivors. What is the most likely reason for this statement?

- a) Very few refugees are survivors of torture.
- b) Knowing the original cause of pain is irrelevant to treatment of chronic pain.
- c) The consultant has not asked refugees if they are torture survivors.
- d) Torture survivors are very unlikely to be referred, or to attend if referred.
- e) Torture survivors with pain should be referred to mental health services for treatment of PTSD.
  - a) False. There is no precise estimate, but it is likely to be at least 30%.
  - b) False. Pain from torture has particular meaning for the patient, and some treatment may retraumatise him or her if reminiscent of torture techniques or settings.
  - c) True. This is the most common reason for not identifying torture survivor patients.
  - d) False. It is possible that torture survivors are referred at a low rate, and they may have a poorer rate of attendance, associated with obstacles such as unstable living conditions, not being registered with a GP, not being able to read appointment letters or texts or to speak English when phoned with an appointment.
  - e) False. Referral to mental health services for treatment of PTSD is appropriate, but will not resolve pain.



A 25 year-old Kosovan woman is referred to a pain consultant by a GP who says that she believes the patient to be a torture survivor, but provides no details. The patient is referred for pain in the pelvic area, gynaecological investigations having found nothing abnormal, and the GP mentions that she also has panic attacks and very poor sleep, but has refused medication. She attends accompanied by a Kosovan man in his late forties. He comes into the consulting room with her, and says he can interpret for her. No interpreter was requested or booked, but the pain consultant is uncertain whether to accept his offer. What is the best course of action?

- a) Accept his offer of interpreting.
- b) Ask him to wait outside and use phone interpretation.
- c) Ask the patient if she would like him to interpret for her.
- d) Put out a call for any Kosovans on the domestic staff to come and interpret.
- e) Rearrange the appointment for a later date, with a hospital-approved interpreter.

False. Even if he is her father, or husband, that does not make him a suitable interpreter. But he may be controlling her and render her unable to give a full account of her pain and related problems.

True. The consultant needs to be able to take a history from the patient as best as possible.

False. The patient may not understand the question, or be free to answer honestly if she does understand it.

False. Interpreters should be trained to respect confidentiality and to be able to handle distressing material. Domestic staff are not trained as interpreters, and could find the patient's disclosure very disturbing, risking breaches of confidentiality.

False. This is a possible course of action, but not the best one, and risks the patient not attending a further appointment if the man with her is trying to control her and knows he will be excluded.

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A 42 year old Sri Lankan man is referred to the pain clinic by the spinal surgeons for left L5 nerve root block. He speaks good English, having been an English teacher before fleeing his country nine years ago, and is now working as a van driver for the local council. The pain consultant briefly describes the procedure to him in order to obtain informed consent, but the patient looks increasingly worried, and several times interrupts to ask for more detail of the setting, of the position he will need to hold, for how long, and eventually whether he can stop the procedure and leave if he needs to. The consultant tells him that he will lie face down on a plinth, much like the one in the consulting room (pointing to it), at which point he starts weeping and shaking, his head in his hands. What is the appropriate action for the consultant to take?

- a) Ask him why he is upset.
- b) Calm him by reminding him where he is, that he is safe, and that nothing will be done to him that he does not want.
- c) Leave the room to give him time to collect himself.
- d) Press the panic button for nearby staff to come and help.
- e) Promise to cancel the procedure.
  - a) False. He is having a flashback and will not be able to answer at this point.
  - b) True. This will help him come out of the flashback and lay the ground for discussion of his fears. The consultant should make a mental note to ask about torture and to ask specifically about rape.

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- c) False. This may exacerbate his fears as he will not know what could happen next.
- d) False. People rushing in will most likely increase his alarm.
- e) False. This may be the eventual outcome, but it is not what is needed to calm him.

A physiotherapist in a pain management centre asks for advice from a pain consultant colleague. He has just seen a patient referred from a local musculoskeletal triage system for widespread pain. The patient is a 38 year old from Iraq, living on benefits and attending courses in carpentry and English at the local college. The patient reported that the pain started when he was "beaten badly", and when asked further about this, described multiple beatings all over the head and body over a span of about two years. The physiotherapist stated that it sounded like torture, and the patient nodded, and said he had been arrested on a democracy demonstration, spent two years in prison with multiple events of torture, and escaped when his parents sold their shop and bribed prison staff. The physiotherapist wants the consultant's opinion on what to do next.

- a) Complete assessment of the pain problems, jointly with pain consultant.
- b) Discuss with the patient his priorities for treatment.
- c) Order X-rays to check for unhealed fractures.
- d) Refer the patient to psychology in the pain service to assess his mental health.
- e) Discharge the patient and refer to trauma services in adult mental health to address his PTSD.
  - a) True. Combined assessment would spare the patient repeating information unnecessarily and could underpin development of an integrated treatment plan.
  - b) True. The patient may have priorities for treatment or constraints concerning it that are not yet known.
  - c) False. This might be required after further assessment, but only after checking with the patient that he is comfortable with the requirements of the investigation.
  - d) True. Psychological assessment will require more than screening by formal or informal methods available to the physiotherapist. However, this must be as well as addressing his pain, not instead of, and liaison should be effective.
  - e) False. The patient may not have PTSD; if he does, it cannot be assumed that his pain complaint is attributable to it, nor that resolving PTSD will reduce his pain. He should not be discharged without his pain being addressed.