Patient-reported outcomes in post-traumatic stress disorder Part I: Focus on psychological treatment

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Since 2000, patient reports have contributed significantly to the widening diagnostic criteria for post-traumatic stress disorder, notably with the inclusion of complex, repeated, and indirect threat to people who develop symptoms. This paper describes and explains why patient reports matter, through worldwide mental health users' movements and the human rights movement. It looks at 46 recent patient-reported outcomes of preferred psychological treatments in clinical research and practice, and compares them with clinician-reported outcomes, using rating scales that diagnose and measure therapeutic gains. Attention is given to one qualitative study of survivors of the London bombings as an example of patients' personal traumatic experiences. Understanding patients' views and their limitations can help increase success in trauma-focused therapy outcomes, particularly where patients fail to engage with or complete treatment, where they doubt the validity of the treatment, or do not see it as culturally appropriate, or fear of revisiting the past. Specific recommendations are made for a more collaborative approach with patients in psychiatric and community care and clinical research.

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Introduction: why patient-reported outcomes in PTSD treatment matter

Patient reports on post-traumatic stress disorder (PTSD) tell us more than clinician-based reports alone, and may predict how patients will cope after treatment. PTSD and modern psychological treatment have been well researched, with reliable and increasingly valid outcome criteria, for over 100 years. World War veterans with shell shock (as PTSD was referred to at the time) were encouraged by families to forget their memories, and avoid the charge of "malingering," but psychiatrists like W. H. R. Rivers[1] recognized the vital importance of asking patients to talk about and make sense of their experiences. Following the use of this type of treatment with US veterans of the Vietnam War, the type of traumatic events treated included not just those associated with wars, but with assaults, torture, rape, accidents, and man-made and natural disasters, to which the victims responded with helplessness and horror.

Keywords: *PTSD diagnosis; patient report; trauma-focused CBT; engagement; attrition; EMDR; NET; users' movement; traumatic memory; London bombings survivors*

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PTSD is among the most widely used diagnoses in psychiatry and psychology worldwide.[2] In another issue of this journal, Van der Kolk[3] describes it thus: 'the human response to psychological trauma is one of the most important public health problems in the world.' Since the publication of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)-III*,[4] PTSD has incorporated the symptoms of re-experiencing the traumatic event, avoidance of stimuli associated with the trauma, and symptoms of increased arousal. These response criteria continue to expand, reflecting current cultural and political priorities.[5] Good examples include gender-based violence and the civilian victims of torture.[3] In all these contexts, the index trauma, an identifiable event, with a beginning and an end, results in simple PTSD. Reports from patients have expanded the debate about the classification of PTSD in the new *DSM-5* criteria[6] and proposed changes to the *International Classification of Diseases (ICD)-11*.[2] The biggest changes are the nature and range of potentially traumatic events, and also, how *DSM-5* now includes repeated, or extreme indirect exposure to threat, eg, for emergency personnel. It also includes the presence of persistent and distorted alterations in cognitions and mood. *ICD-11* proposes the inclusion of chronic and repeated abuse including childhood neglect, also known as complex PTSD.

These criteria for PTSD diagnosis now go beyond direct threat to life and limb, partly in response to patients' reports, and the perceived social acceptability of the disorder.[2] These changes therefore have implications for epidemiology, eg, in developing countries and conflict zones, as well as clinical practice and service organization. PTSD diagnosis depends essentially on the existence of an external threat to which the individual responds, and which impairs psychological and interpersonal functioning. It is that subjective response—horror or helplessness—that has to be recognized by the sufferer, and captured in clinical assessments. There is evidence that patients prefer to have this diagnosis to other psychiatric illnesses because the patient carries less blame or stigma, and because PTSD may carry financial and social rewards.[7] Patients may also ascribe to trauma *meaning* in two very different ways. Janoff-Bulman and Franz[8] define the first as comprehensibility; does a trauma "makes sense" ie, does it fit with a system of accepted rules or theories? The second meaning is one of significance; does the trauma have worth, or add meaning to life?

Wider influences

The User Movement

There has been criticism of mental health treatment provision services, including for PTSD, in the UK,[9] by patients, carers, and advocates (users), partly fueled by the growth of the User Movement in Mental Health since the 1980s, in the US and Europe.[10] This cultural change has led to patient groups meeting for support, information exchange, and empowerment, through patient participation programs and expert patient programs.[11] Key issues have included the medical model not addressing stigma, inequality of access to services, misdiagnosis due to cultural or racial bias, and patients being marginalized through psychiatric processes. For example, a users' and human rights movement in Europe says of *DSM-5*:

> Mental Health Europe calls on the World Health Organisation to take account of (these) widespread concerns in the forthcoming revision of the International Classification of Diseases. It asks that the WHO give much more weight to *service user experience* (our italics) and psychosocial approaches in classifying mental health problems and in assessing the effectiveness of interventions'.[12]

The director of Mental Health Europe stated:

> Mental health problems are not black and white. They can be fleeting or permanent, stem from a multitude of causes, and, depending on the individual person, respond to different interventions. The biomedical approach in DSM-V is thus restrictive and harmful, and should definitely be rethought.[12]

At a global level, the International Alliance of Patients' Organisations (IAPO) now has members in 60 countries with 200 member organizations worldwide, and has a voice within the WHO. It has raised the profile of patients in partnership with other stakeholders—including the clinician—and prioritizes access to health information for all. A culture of user involvement and user resilience to trauma has evolved. The World Federation for Mental Health convened a conference in 2011, which focused on culture and mental health, migration, the needs of users, including PTSD sufferers, as well as peer support studies in post conflict societies. This was in response to the shortage of mental health professionals in the developing or conflicted world, but it has also been about patients' stories giving encouragement and hope to others. Patients help others to define problems, think about choices, and share in recovery.[13] In the UK, the National Institute for Health Research (NIHR) has begun to target peer support for patients with psychosis, where patients report feelings of safety during treatment, and where trained and monitored support workers respond to their anxiety at discharge.[14]

Human rights

Global mental health and user involvement are closely aligned to the agenda of human rights. It is manifest through information sharing and training on the World Wide Web, through social networking, preventing social exclusion, and through the increasing expansion of research on service users as patient experts.[15,16] Good care is now deemed to constitute a basic human right, and no more so than in trauma, which frequently entails the violation of other rights. Testimony Therapy[17] and NET,[18] especially for the survivors of torture and war, (described below) provide examples of patients' reports as fundamental in alleviating PTSD symptoms. In conclusion, patients with PTSD have increasingly found a voice that matters both individually and collectively, and are shaping the expanding agenda of PTSD for users and clinicians at every level.

Psychological interventions and reported outcomes

Psychometric measures

In research and clinical practice, it is routine to include both clinician-rated and patient-rated measures of PTSD. The CAPS[19] is a structured interview designed to make a categorical PTSD diagnosis, and provide a numerical measure of PTSD symptom severity. It takes 30 to 60 minutes to administer, and training is required for reliable alignment to the *DSM-IV* PTSD criteria. The CAPS is considered to be the gold standard of clinician assessments of trauma,[20] but requires the patient to reply to highly specific questions on the nature of the trauma(s), the frequency and intensity of intrusive, avoidant, and hyperarousal symptoms, and the presence of other emotional and cognitive difficulties. It is for the clinician to judge the patient reports, devise a score, and then interpret its impact on social and occupational functioning.

Patients and research participants suffering from PTSD are also required to report themselves on the frequency and severity of their symptoms. Well-validated measures include the IES-R[21]; the PDS[22]; the Post Traumatic Stress Checklist[23] and the Hopkins Checklist.[24] These scales ask the patient to rate the existence of symptoms, their severity, frequency, and the impact they have on day-to-day functioning. They are not, with the exception of the PDS, routinely used for diagnostic purposes, but the form and content of the questionnaire is designed by clinicians to provide well-calibrated outcomes measures of PTSD before, during, and after treatment.

Patients with PTSD also report on associated psychiatric difficulties and concurrent diagnoses and other psychological problems, eg, depression with the Beck Depression Inventory (BDI),[25] or anxiety with the Beck Anxiety Inventory (BAI).[26] Patients with PTSD report feelings of shame and dissociative experiences.[27] Subjective quality of life (SQOL) scales feature widely in the literature[28] because PTSD patients have poorer SQOL than either medical student controls or psychiatric controls suffering depression, schizophrenia, or substance misuse[29] *(Table I)*. PTSD patients report less satisfaction with their living conditions, family relationships, leisure, social relationships, finances, personal safety, and "life in general." PTSD patients may have higher expectations of life than those with psychosis or depression, and perceive the diagnosis as less serious and feel that they should return to their everyday lives more easily. Pangioti et al[30] looked at 59 studies, 30 using standard patient questionnaires, and 20 using self-reports, and established a positive correlation between reported suicidality and PTSD, though the study cohort was heterogeneous, and that the fuller meaning of this relationship is not yet clear.

The reliability and validity of patient rating scales is high in the Western world, although doubts have been raised about their use in other cultures, and measures have been developed for specific purpose. In Africa, Bettancourt et al,[31] working in Northern Uganda with child soldiers, developed the Acholi Psychosocial Assessment Instrument (APAI). Shottelkorb et al[32] looked at PTSD in refugee children between 6 and 13 years old, settled in the US from 15 countries in conflict. They devised a 5-point rating scale—the UCLA PTSD Index—that could be used by the children, together with parents' reports on their children to identify and rate PTSD symptoms.

Patient ratings enable the clinician and the patient to recognize improvement within the patient's social and interpersonal contexts, and provide specific treatment programs. Contexts include gender, age, culture, concurrent diagnoses, years of education, type and source of trauma, and ongoing threat. There are, as yet, no universal core data for PTSD clinics. The United Kingdom Post Traumatic Stress Society (UKPTS) and the United Kingdom Trauma Group (UKTG) have made several attempts to implement this, but to date clinicians do not share an agreed data set.[33]

Psychological treatments

Narrative Exposure Therapy (NET)[18] is a treatment developed to treat the psychological sequelae of war, torture, and organized violence, based on the "testimony" method of treatment developed in Chile as a response to the political violence occurring there in the 1970s.[34] Testimony therapy involves *survivors telling their story* (our italics), which is transcribed, reviewed for editing, and given to the survivor as a written record. NET uses a similar method through integration and elaboration

Name of scale	**Who administers?**	**Number of items**	**Purpose**	**Authors/copyright status**
Clinician administered Post Traumatic Stress Disorder Scale (CAPS)	Clinician interview	20 open-ended questions rated by severity and impact on day-to-day functioning	Existence of PTSD diagnosis using *DSM-IV*	Blake et al, 1995. Available on request from www.ptsd.va.gov
Post-traumatic Diagnostic Scale (PDS)	Patient or clinician	49 items based on *DSM-IV* criteria. Items rated according to frequency	Diagnoses and measures severity of PTSD	Foa, 1995. Copyrighted with manual
Impact of Events Scale-revised (IES-R)	Patient or clinician	22 items Intrusion, Hyperarousal, & Avoidance subscales rated 0-4	PTSD symptom severity & clinical cut off of 1.5	Horowitz et al, 1979. Available on request from www.ptsd.va.gov
Hopkins Symptom Checklist (HSCL-37)	Clinician	37-item checklist plus LEC rated 0-4, never to always	Flexible tool; widely translated in many cultural settings for symptom severity	Parloff, 1950s. Updated by Bean et al, 2000
Dissociation Experiences Scale (DES)	Patient	28 items rated 0-100%	Screens for dissociative symptoms	Carlson & Putnam, 1986. Available via www.sidran.org
Post Traumatic Stress Checklist (PCL)	Patient	17 items rated on scale 1-5	Preclinical scale with civilian or military format	Weathers et al, 1994. Available via www.mirecc.va.gov
Life Events Checklist (LEC)	Clinician	17 categories of traumatic events rated from 'happened to me', 'witnessed' down to does 'not apply'	Identifies life events to augment patient reports and obtain a full trauma history	Gray et al, 2004. Downloadable in pdf from www.ptsd.va.gov
Beck Depression Inventory (BDI)	Patient - but interpreted by clinician	18 self-rating items scaled from 0-3 with severity score	Measures symptom severity of depression	Beck et al, 1996. Published by PsychCorp, San Antonio
Beck Anxiety Inventory (BAI)	Patient - but interpreted by clinician	21 self-rating items scaled from 0-3 with severity score	Measures symptom severity of anxiety	Beck et al, 1993. Published by PsychCorp, san Antonio
Manchester Short Assessment of Quality of Life MANSA	Patient or Clinician	13 domains rated 1-7 point scale	Measures overall satisfaction with quality of life	Priebe et al, 1999. Available via www.qmul.ac.uk

Table I. Common scales for PTSD patients in Western practice.

of the traumatic memory into a full autobiographical and contextual memory, often using a "lifeline." Habituation to feared memories occurs through repeated and updated accounts of the patient's whole life experiences—an approach that has produced a good evidence base.[18]

Refugees in the UK offered trauma-focused cognitive behavior therapy (TF-CBT) report greater improvement of PTSD symptoms than treatment as usual (TAU) controls, but not as much as treated non-refugees.[35] Their stories may be compromised by limited English, poor interpreter training, a power imbalance with participants wanting to please, and the additional impact of poor recall and concentration of many PTSD patients in describing past events. These factors are compounded by the perception of patients, clinicians, the judiciary, and the police, that patients who report events inaccurately are malingerers or liars. In fact, patients with inconsistent or incomplete accounts are more typical of traumatized survivors.[36]

Other patient reports are specific to the population under investigation. In a study of subjective distress in childbirth, Anderson et al[37] found that patients reporting loss of control, fear of labor, pain, perinatal dissociation and low sense of coherence, were associated with a higher risk PTSD risk. Germain et al[38] looked at treatments for sleep disturbance in combat-exposed US veterans suffering PTSD, using sleep diaries and nightmare measures. Bormann et al[39] carried out a trial with US veterans using a meditation-based Mantran Therapy. Patients' checklists, self-monitoring of their adherence to treatment, and satisfaction with the program, were all associated with better reduction of PTSD symptoms. The recommended psychological treatments for PTSD in the UK and USA[40,41] all involve direct processing of traumatic memories, but the uptake by patients is variable. The acceptability of PTSD diagnosis and the experience of TF-CBT have been investigated qualitatively with traumatized asylum seekers.[42] Participants reported diagnosis as stigmatic, as they thought others saw them as weak or having failed. All participants expressed ambivalence about engaging with treatment, but they wanted help with symptoms and a chance to build their future life. They wanted to be believed; they wanted a trusting relationship and an end to isolation. But they feared retraumatization, failure in treatment, and above all, repatriation and the resumption of traumatic events. Despite these fears, patients saw the therapeutic relationship as critical in the acceptability of treatment. Scepticism about talking therapies compared with pharmaceutical treatment meant that participants reported the need for strong persuasion increasing engagement, and raised levels of trust in clinicians and others in the host country. The authors recommend advocacy with asylum seekers, and a phased approach to treatment to increase the acceptability and efficacy of TF-CBT.

In an innovative study with patients who did not respond to TF-CBT,[43] group music therapy was found to significantly ameliorate PTSD symptoms. Participants reported music as less intrusive, less threatening, more enjoyable, and closer to their healthy identity than individual talking therapy. They also reported that music kept them calmer, allowed the expression of anger and loss in a safer, controlled setting, making engagement easier, and helping with avoidance and social functioning. Some participants eventually returned to TF-CBT and the authors again proposed a more phased approach.

Reported adverse effects

Adverse effects of PTSD treatment, as reported by patients, have received less attention. Bisson at al[44] examined 72 studies and found many gaps in patient reported outcomes in PTSD sufferers. Not a single study focused on adverse effects of treatment as reported by patients, and only eleven studies gave a full account of dropout in treatment trials. Thirty percent dropout of eligible participants in PTSD treatment trials is common.[45,46] Church et al[47] looked at Emotional Freedom Techniques in US veterans with PTSD, and excluded 90/149 from the study, of whom 74 were "not interested." Similarly, Germain et al[38] excluded 65% of those initially screened for treatment, participants mostly not attending or declaring they were "not interested," but again, with no further explanation.

One notable exception was Ehlers et al.[48] Their patient measures included PTSD symptoms, measures of disability, anxiety and depression, reports from dropout patients, reports on total symptom remission, speed of recovery, the competence of the therapist, and ratings of the therapeutic alliance. Felmingham and Bryant[49] found patients' reported confidence in treatment as critical in the maintenance of response to TF-CBT. Subjects who had been the victims of sexual assault, war, or who had a psychosis diagnosis were excluded from the study. However, Ford et al[50] established that patients' levels of hopefulness, self-efficacy, belief in treatment, and satisfaction with therapist and therapeutic alliance were all predictors of better therapy outcomes for teenage delinquent girls with PTSD symptoms.

In the study by Ford et al,[50] there were anecdotal accounts of participants not arriving for treatment, including their difficult timetables and logistical problems. Carr et al[43] found that traumatized asylum seekers facing legal, economic, and social upheaval, reported regular attendance (an essential factor in therapeutic success) for health care, competed with childcare, court appearances, compulsory registration and unreliable transport. Galovski et al[51] piloted a manualized therapy for PTSD and found that *tailoring* the length of therapy from 4 to 18 sessions (the convention is 12) created better outcome on self-report measures. Ehlers et al[48] similarly found that some patients with simple PTSD prefer an intensive seven day treatment, described as easier to concentrate on, easier to remember, harder to avoid, and providing a faster to return to normal life.

Two studies in Edinburgh suggested that patients who report sadness, fear, anger, or disgust have less favorable outcomes using exposure therapy than where anxiety predominates.[52] Similarly reported shame and guilt identified in traumatic memory "hotspots" has required a different conceptual model of PTSD intervention. Guilt and shame are more treatment resistant to TF-CBT than fear or anxiety.[53] Patients report that although they are not to blame for a traumatic event, they feel blamed by others, and suffer consequent shame. When challenged, patients report that they were "born bad," and are "different from everyone else."[54] Updating is completed by patients accessing a more helpful and compassionate perspective of their experience where they can "self-soothe" and accept themselves as victims not perpetrators.

Patients who express fears about participating in TF-CBT frequently mention the risk of *re-traumatization*.[42,55,56] Patients are informed that talking about past traumas may leave them feeling sad or angry—but it is an important distinction to show that they will not be re-traumatized, especially during episodes of extreme dissociation. Young[55] proposes four stages to deal with this:

- addressing the basic need for safety
- processing traumatic memories within the biographical context
- challenging negative self-appraisals (eg, helplessness and fear of re-traumatization)
- increasing meaningful and pleasurable activity in the present.

Similarly, information about previous mental health interventions for PTSD symptoms is lacking. Delahanty et al[57] carried out a trial, and asked for a baseline measure self-report on any previous psychiatric therapy. Those with prior history of any description benefited least from treatment.

Exclusions

Many studies describe exclusions eg, those with psychosis,[58] sexual violence,[59] multiple traumas,[60] and suicidality.[61] Some studies with veterans have excluded women[59] and many have excluded those with a diagnosis of complex trauma. This may provide reliable data for a limited range of clinical problems, but clinicians and patients are aware that severe, repeated and enduring threat leads to multiple mental and physical health problems.[7]

The impact of terrorism on whole communities eg, the Madrid bombings, the Oklahoma bombings, and the September 11th attack on New York's Twin Towers, has been reviewed by Whalley and Brewin,[62] who concluded that as many as 20% of those directly traumatized would have PTSD symptoms 2 years after an attack. Survivors with no previous contact with mental health services were least likely to seek help, even after extensive public health messages. The authors conclude that more proactive mechanisms such as "Screen and Treat" would help identify need where people were not disclosing their distress.[62]

Sayer et al[63] found that US veterans who had served in Iraq and Afghanistan, would wait years for help, if at all. When asked why not, participants reported lack of education about PTSD, an invalidating culture, health service and disability barriers, and personal beliefs all conflicted with seeking help. Similarly Grey at al[64] looked at help-seeking behaviour in refugees experiencing PTSD symptoms in a number of studies. Refugees complain not just about cultural and linguistic barriers, but also social exclusion, separation from family and country, distrust of host country systems, racism and economic poverty. The authors propose a three-stage care pathway. *Table III* attempts to address the broader social, judicial, and political contexts that add meaning to the trauma reported experiences of refugees.

The needs of humanitarian aid workers

The voices of health and humanitarian aid workers, at risk of PTSD, have been neglected. Shah et al[65] found a significant prevalence of secondary traumatic stress in 76 aid workers in India. These workers were taking details or providing care to those directly exposed to trauma, were themselves overlooked, often working 6 or 7 days a week, with attention focussed only on direct victims, and where they said they could not expect support from their agencies. Turyahabwa et al[66] found an incidence of 14% PTSD in Liberian health workers during its civil war. When asked, workers disclosed both direct and indirect trauma, all of which had impacted on professional and personal functioning. Other workers involved with disasters, such as journalists[67] and military personnel, are exposed to direct and indirect trauma,[68] leading to post-traumatic disorders. These groups all request nonmandatory help *a priori* from clinicians within their professional group, or those sharing the values of the agencies employing them. Their PTSD symptoms can be mitigated by better screening for resilience,[69] preparation, and engagement with the host culture. In the aftermath of disaster, psychological debriefing includes creating safety, reassurance, and information exchange, and where the order of help is critical. Traumatized staff reported debriefing worked best with factual exchanges and updates from other staff who were present; "operational debriefing" rather than exploration of emotional experiences.[70] All these staff report specific preferences for help from those seen as sharing their values and occupational experiences.

Unique characteristics of PTSD survivors: a qualitative example

One study of PTSD patient-reported outcomes provides a good example of how different they are from clinicians or observers.[5] On July 7th 2005, Al Qaeda attacked the London Transport system with three bombs, killing 56 people, including four suicide bombers—an incident that became known as known as "7/7." A nation wide 'Screen and Treat' mental health program was implemented as part of the emergency response, with quantitative studies demonstrating the efficacy of TF-CBT for 125 patients treated.[71.72] This qualitative study sought to understand how survivors with PTSD uniquely experienced the London bombings. Eighteen of the 82 patients evaluated for the quantitative studies were interviewed in-depth.

From thematic analysis of the verbatim transcripts, there were *two distinct time frames* (our italics) described. The first four themes were clustered around the day of the bombs, "7/7"; the remaining three were post 7/7. The 7/7 themes included: shock, and disorientation (in the train or bus immediately after the blast), horror (at the carnage around them), getting out (of the tube train or bus), and reorientation and reconnection with the outside world (in the London streets, and in the journeys to hospital, work, college or home). The post-7/7 themes included post-traumatic stress and depression (by normal clinical criteria), feeling different from those who were not there (in ways that could not be understood by others), and recovery and resilience *(Table II)*.

Participants described multiple *shifts in the meaning* of their experiences. At first they had no idea that a bomb had exploded, simply that the train was collapsing. Once up at street level, survivors, some wounded, all filthy, were quickly led from the stations because they were told of the threat of further explosions. Another shift of meaning was that for some, life that day was meant to continue as usual (although it clearly did not).

Here is an example:

> 'I said "I don't need to get on a bus to go to hospital; I'm not injured. I'm not hurt. I don't need to go to hospital." And my daughter didn't want to either and so we [...]

Distinct time frames	Emergent themes	→	→	→
1. Day of the bombings; 7/7	Shock & disorientation	Horror	Getting away	Reconnection and reorientation
% identified	77	66	61	50
2. Post 7/7	PTSD and depression	Feel different from others		Recovery and resilience
% identified	100	61.1		50

Table II. Thematic analysis of the London bombings patients' responses (N=18).[5]

> walked back to the office [...] I didn't realise that of course we were covered in black and I said "don't worry we'll get back to the office and we'll just clean ourselves up and we'll just go to work [...] And then as we went into reception, there's a big reception area with a telly, [...] and my daughter just completely fell apart at that point and lost it, and I never forget trying to get her to sit down and she was screaming, to "just turn it off, turn it off, turn it off".' (P8, female, 50 years).[5]

Self-blame was prevalent, where the dead and the dying had to be abandoned by those who felt it was their duty to stay. Rescue workers ordered them to come up, and another shift of meaning was that *they were the victims* of the attack, not first aid workers. One first aid-trained survivor was distraught as she had been unable to help others. Another agonised about swigging from her water bottle before it was poured on the burns of a victim. They described a sense of *solidarity*, which continued through their attempts at joint escape, often hand in hand, hugging strangers in the blackened and dust-filled tunnels. There was a focus on survival, kindness, and heroism.

Post 7/7, participants spoke about their *disconnectedness and difference* from others. This led to isolation and alienation, where the world had changed forever, and where participants had not been able to share their experiences. Talking about others not involved one said: "There were times that I was [...] just wanting to move away from them, or ignore them, cut off from them." (P6, female, 51 years).[5]

Recovery was found in the *group sharing experience*, and in making other life changes:

> "I've grown up more, which I think has really helped and it made me see things differently and understand things more and it's been a real learning curve [...] it's made me see life in a kind of different way". (P7, female, 26 years).[5]

Separation was not part of becoming politically mobilized. Rather, it was one of increased personal *attunement to suffering*, both their own, and of others, providing clues to their own resilience and ultimately their rehabilitation. Here is one of their testimonies:

> "I don't get as scared or flustered or, you know, nervous as before. Um [...] I do get trepidation from time to time but er [...] when the thought comes to my mind I ... tell myself, "don't worry, it's not a terrorist, "(P5 male, 42 years).[5]

These narratives reveal a group whose lives changed forever in the moment of the blast, and who did not attribute the atrocity to Al Qaeda, in ways that politicians, the public, and the media did. Some felt pity for the perpetrators; others blamed the Government for taking the UK to war in Iraq. They did not seek retribution, but complained of delays in rescue. Self-blame, 'I should never have been on that train,' was more common. Wilson et al[5] conclude that, despite mortal danger, survivors detailed where they were in relation to the other passengers around them, recalling moments of togetherness, and joint escape. As individuals, each felt different and disconnected from the outside because experiences could not be shared. But as a collective, they could share this experience of numerous acts of heroism and kindness which needed to be incorporated into a more balanced narrative.

The changing agenda

This paper has shown that the definition of PTSD now includes a greater number of traumas within an expanding range of cultures and contexts. PTSD patients include individuals, couples, families, and whole communities, with varying prevalence and prognosis. The *DSM-5* criteria now refer to chronic and repeated traumas over much longer periods of time, where personal records may not exist, where there are no reliable witnesses, or where false or absent memories prevail.[6]

Victim statements

Patients' accounts of trauma are consequently more complicated. There are useful guidelines on memory and trauma, particularly when giving testimony in legal contexts, as well as the impact of trauma and stress on the memory of children, older adults and other vulnerable groups.[73] We now know that patient reports of traumatic events are subject to distortion, reconstruction, and omission. This is the starting premise for CBT, where revisiting the traumatic memory in a safe setting, allows the patient to insert corrections and update the story.[74] Wright et al[75] provide a useful overview of recovered and false memories but conclude that it is not yet possible to distinguish recovered or false memories from objective reality. Clinicians still need to establish external corroboration for historical traumatic events to validate the experience for patients,[76] which may then allow them to pursue other forms of redress for example, through legal processes. Advances in forensic science and information technology are able to enhance the credibility of victim statements. Clinicians who work with traumatized patients can now access the past with much greater accuracy and speed through the Internet to verify historical accounts, (ideally with the patient) as part of trauma-focused therapy. The greatest barrier to victim statements being made however are the attitudes and prejudices of clinicians, other professionals and the organizations which they represent.[77] Smith and Heke[77] highlight the importance of educating professionals and the public about the more complete nature of PTSD and its crippling effect on patients' capacity to communicate accurately their trauma stories. Victim statements have also helped clinicians to identify risk factors and thereby reduce further revictimization and self-harm.[78] Key predictors include: any past or present psychiatric diagnosis, women more than men, older age, and lower educational status.[79] Consequently the risk agenda is not just about making sense of the past, but also helping patients to improve their future.

Children

Children are a particularly complex case for subjective reports. The *DSM-5*[6] description of preschool PTSD states:

> The criterion that the children's reactions at the time of the traumatic events showed extreme distress has been deleted. If children were too young to verbalize their acute reactions to traumatic experiences, and there were no adults present to witness their reactions, there was no feasible way to know about these reactions.

The BPS[73] guidelines recommend that only children of 9 upwards recall traumatic events in a form akin to that of adults. Children have a much more plastic and changeable cognitive framework for reporting their trauma, and are more likely to be influenced by adults into making the story more acceptable to them. Yule[80] recommends that small children who have been traumatically bereaved be given comfort, security, and for their basic needs to be addressed, and where advice given to carers as early as possible. Assessment and management of their trauma requires specific expertise in child mental health, and readers are advised to refer to Bauer.[81] Psychological therapy for traumatized young children has an emerging evidence base but is not yet incorporated into a universally accepted approach. Current practitioners adapt CBT,[82] EMDR,[83] child-centered play therapy,[32] Children's Accelerated Trauma Therapy (CATT[84]) and Kid's Narrative Exposure Therapy (KIDNET[85]).

Acceptability of treatments to patients

Patient reports tell us something important about the acceptability and credibility of trauma-focused treatments. It has already been shown that about a third of participants in research trials decline this effective treatment. In clinical practice, there may remain many nonattenders or those who fail to complete treatment,[86] and the changing trauma agenda needs to address *why patients fail to engage*. Refugee studies[42,55] suggest that TF-CBT presents as fearful, complex, time-consuming, and untrustworthy. The essential dichotomy remains; traumatized patients want clinicians to help them to forget traumatic events, in order to move on with their lives. Clinicians who offer trauma-focused treatments encourage patients to re-visit the past, repeatedly and in detail, as a means of processing the traumatic event(s) as a verbally accessible memory.[86]

One way forward for engaging with this counterintuitive approach is by educating and preparing traumatized patients. Services can now provide online access, as well as up-to-date, and more professional educational materials for new patients, and whole populations at risk. Written materials can be translated, using culturally appropriate figures of speech including metaphors for minority groups.[87,88] Service users can be consulted about materials that they have found comprehensible and motivationally helpful. All these approaches would assist in overcoming patients' doubts about the trauma-focused model.

The quality of the therapeutic alliance and the trustworthiness of the therapist depend on adherence to manualized protocols and the competence of the therapist.[46] Improving Access to Psychological therapies (IAPT) is a UK-wide CBT program aimed at providing services for patients who self-refer.[87,88] It provides session-by-session outcomes, which are shared with the patient, improving collaboration and CBT treatment fidelity.[89,90] Traumatologists can learn how to improve their public perception from such innovative programs, and trial such approaches in trauma clinics.

PTSD research in wider social contexts has shown that patients and their communities still understand little about PTSD and its trajectory. Clinicians can promote education through public health programs, mainstream schooling, voluntary sector outreach, and emergency services. A larger framework for addressing the more complex nature of PTSD includes adapting therapy to individual and local cultural needs and presentations.

The work of the International Society for Traumatic Stress Studies (ISTSS)[91] addresses the challenges of complex trauma by using a "phase-based" approach.[92] This includes the need for *stabilization* prior to trauma-focused work and *reintegration* on its completion. Stabilisation includes: psycho-education, regular communication, affect regulation, grounding patients in the present (to respond to dissociative episodes) and challenging belief systems about the world, self and others. Reintegration includes: assisting the patient to return to meaningful activity, including education, employment recreation and social activity; strengthening social networks and enhancing intimate and family relationships *(Table III)*.

Help-seeking behavior is limited by many barriers, often determined at an individual or cultural level. The emergence of better PTSD outcomes from EMDR and NET, including trials held in the developed and developing world, all indicate that patients are able and willing to face their past. But they may need to approach it, and tell their stories in different ways.[18,93] One distinctive difference in NET is that past events are not revisited as frequently. Emphasis is placed on the whole biography, allowing the patient to see a world that existed before and after the trauma in a tangible story. Similarly, narrative approaches permit the patient to direct the story and disclose trauma more gradually and in culturally acceptable ways. Creative arts therapies, allow access to memory when language fails, or when it is seen as too painfully intrusive.[43]

Greater attention to nonresponders to TF-CBT, both at research and clinical levels has to become a priority. Patients have told clinicians that their interpersonal contexts all affect the meaning of trauma and the changes needed for recovery. A minimum data set established either nationally or internationally would allow clinicians treating PTSD to identify associated risk, protective and resilience factors in sub-populations, and help patients with engagement and compliance.

The deployment of peer support workers trained to help fellow patients cope with the challenge of discharge needs to be trialled with PTSD patients. Peer support studies in the USA, Australia and Scotland have all responded to patient requests for direct input at their most vulnerable times, and may prove to be an important resource to increase trust, engagement and credibility for trauma survivors.

Conclusions

Patients have much to tell us about their experience of trauma, and how they interpret it, and have increasingly found a voice in mental health care, which can be used to better understand PTSD. Patients with PTSD read about their symptoms, share information, seek support from other patients, and expect good care as a human right. They now tell us how they see the clinician's competence, the therapeutic relationship, and their hopes for recovery and rehabilitation. Traumatized groups may prefer to share experiences with those subjected to the same suffering. For example, people subjected to extreme shame after rape are more likely to disclose to those similarly affected.[94] The London bombings study shows that survivors see themselves as uniquely transformed, and cannot be understood, even by close relatives. Some patients have reported that even the diagnosis of PTSD is stigmatic in communities or occupations that penalise failure or weakness.[88]

Stage of care pathway	Clinical applications		
1. Addressing sense of safety	Engagement depends on a sense of safety	Cultural and gender sensitivity of clinicians	Education about PTSD. Training in grounding and relaxation
2. Alleviation of symptoms	More phased, idiosyncratic measures	Regular, subjective assessment, eg, subjective units of distress	Feedback progress before each treatment session and reassess
3. Reintegration	Focus on community and deal with social exclusion	Identify and address wider separations and losses	

Table III. A three-stage model of PTSD for refugees.[64]

Engagement

Central to understanding patients' experience of being treated psychologically for PTSD is why some engage and others do not. Patients report many barriers to help-seeking, yet have high expectations of care and quality of life. Mental health trauma services may be seen as part of an establishment that has little in common with trauma survivors, and which may be monocultural and racist in its ethos. Information gathering may be inconsistent, inflexible, repetitive, or omit key factors that aggravate PTSD, eg, the presence of ongoing threat or traumatic grief. Services have been seen as agents of the State, and issues of confidentiality, security, and privacy need to be addressed proactively and consistently.

Clinicians' lack of awareness of the social, legal and logistical demands of victims in the aftermath of violence leads to high levels of attrition in assessment and treatment. Similarly, patients have insufficient understanding of PTSD. Educational materials, direct and online, treatments in flexible time slots, or in intensive packages, with culturally appropriate materials tailored to the individual needs of the patient or patient group, with better trained interpreters or advocates, all offer promising directions for care and research.[95]

Trauma-focused work is itself stressful and there remain many accompanying negative emotions and comorbidities that need to be addressed for successful outcome. NET and other narrative approaches, EMDR and creative arts therapies have all produced evidence that patients may prefer to tell their stories in a graded, guided way that places the traumatic memory into a full lifeline. Patients have reported that remembering the whole story allows them to update and consolidate the past and move to the present and the future.

The new PTSD agenda is now beginning to address these issues in open-ended clinical interviews, in qualitative research, and in a more careful appraisal of everyone initially included in trials, including those who fail to engage. Clinicians can give value to the subjective as well as the objective outcomes of PTSD treatment and learn much more from patient reports. ❑

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Resultados percibidos por el paciente en el trastorno por estrés postraumático
Parte 1: Foco en el tratamiento psicológico

Desde el año 2000, la información de los pacientes ha contribuido de manera significativa a la ampliación de los criterios diagnósticos para el trastorno por estrés postraumático, especialmente con la inclusión de la amenaza compleja, repetida e indirecta para las personas que desarrollan los síntomas. Este artículo describe y explica por qué la información del paciente es importante, a través de los movimientos de usuarios de salud mental en todo el mundo y del movimiento de derechos humanos. Se consideran 46 estudios recientes sobre resultados percibidos por el paciente de tratamientos psicológicos preferidos en la investigación y práctica clínica, y se los compara con resultados informados por el clínico, utilizando escalas de evaluación que diagnostican y miden beneficios terapéuticos. Se centra la atención en un estudio cualitativo de supervivientes de los bombardeos de Londres como un ejemplo de experiencia traumática personal de los pacientes. La comprensión de las consideraciones de los pacientes y sus limitaciones puede ayudar a incrementar el éxito en los resultados de la terapia focalizada en el trauma, especialmente cuando los pacientes no se comprometen con el tratamiento o no lo concluyen, cuando dudan de la validez de él, o no lo consideran como culturalmente apropiado, o cuando temen re-exponerse al pasado. Se dan recomendaciones específicas para un enfoque más cooperativo con los pacientes en cuidados psiquiátricos y comunitarios, y en investigación clínica.

Résultats rapportés par les patients dans l'état de stress post-traumatique.
1ère partie : traitement psychologique

Depuis l'année 2000, les critères diagnostiques de l'état de stress post-traumatique ont été significativement élargis grâce aux données des patients, en particulier avec l'inclusion d'une menace complexe, répétée et indirecte des individus symptomatiques. Cet article décrit et explique pourquoi les patients rapportent les faits, au travers des mouvements mondiaux d'utilisateurs de la santé mentale et les mouvements des droits de l'homme. Il s'intéresse à 46 résultats récents, déclarés par les patients, de traitements psychologiques favoris en recherche et en pratique cliniques et les compare aux résultats déclarés par les médecins, par des échelles de cotation de diagnostic et de mesure des bénéfices thérapeutiques. Une étude qualitative sur les survivants du bombardement de Londres est prise comme exemple d'une expérience de traumatisme personnel. Comprendre le point de vue des patients et leurs limites augmente les chances de succès d'un traitement centré sur le traumatisme, surtout lorsque les patients ne prennent pas ou ne terminent pas le traitement, lorsqu'ils doutent de sa validité ou le pensent inadapté à leur culture ou bien ont peur de revisiter le passé. Une meilleure collaboration entre les patients psychiatriques, les soins de proximité et la recherche clinique fait l'objet de recommandations spécifiques.

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