

Torture rehabilitation: Reflections on treatment outcome studies

Edith Montgomery, PhD*, Nimisha Patel, Clin.Psych.**

‘Evaluating the Services of Torture Rehabilitation Programmes: History and Recommendations’ by James Jaranson and José Quiroga is the third updated version of a desk study review of the scientific literature on rehabilitation of torture survivors world-wide¹. The first desk-study was published in *Torture Journal* in 2001² and the second updated and expanded version in 2005.³ This most recent, and timely, desk-study was presented at the IRCT scientific conference in December 2010: ‘25 years of torture healing. Are we ready to assess outcomes?’

The authors should be greatly commended for their persistent and meticulous endeavours in exploring and documenting the evidence base within this area. In this article we offer our own reflections, as presented during the conference firstly, on the evidence presented by Jaranson and Quiroga, and some gaps; and secondly, outlining what we consider to be some of the challenges we all face in developing the evidence base for the rehabilitation of torture survivors.

*) Rehabilitation and Research Centre for Torture Victims (RCT), Denmark, em@rct.dk

***) Medical Foundation for the Care of Victims of Torture England

The evidence

As Jaranson and Quiroga document and conclude in their review, the evidence for effects of torture rehabilitation world-wide is relatively scarce¹. As with all desk-studies, there are likely to be some omissions, partly influenced by the inclusion and exclusion criteria adopted, and some limitations. In this review, one limitation is the almost exclusive focus on mental health problems reported by adult survivors of torture and organized violence. This is poignant as many torture survivors have a multi-faceted presentation of somatic, psychological and social problems,⁴ as well as other difficulties impacting on their health and well-being. Jaranson and Quiroga’s review does consider one study specifically focused on somatic indicators, though other relevant studies are omitted.^{1,5-7} Similarly, there is consideration of one study of rehabilitation of refugee or asylum-seeking children, and many others omitted (for example, see Peltonen and Punamäki, for a review on interventions with children exposed to armed conflict).⁸

Whilst an exclusive focus on specific problems experienced by torture survivors risks being overly narrow and neglecting the full range of torture survivors’ health experiences, such studies can contribute to the evidence base. For example, in one systematic review of treatments for Post-Traumatic Stress Disorder (PTSD) among refugees and

asylum-seekers,⁹ 2010) ten randomized controlled trials (RCTs) of treatments for PTSD among refugees and asylum-seekers with altogether 528 participants were identified. The trials, however, were small, and allocation concealment and blinding were inadequate. No treatment was firmly supported, but there was evidence for Narrative Exposure Therapy (NET) and Cognitive-Behavioural Therapy (CBT). The authors suggest that future trials should evaluate interventions that are developed within the cultural context of refugees, based on a local understanding of trauma and psychological distress. In a recent (as yet unpublished) randomised study of testimonial therapy with Sri Lankan torture survivors¹⁰ such an approach showed promising results, although more studies are necessary with different groups.

In December 2008 an international conference “Rehabilitating Torture Survivors” was organized by RCT and the Centre for Transcultural Psychiatry in Copenhagen.⁴ In recognition of the limited numbers of randomized controlled trials of torture survivor rehabilitation, the general consensus at the conference was that trauma-focused cognitive-behavioural therapy or Eye Movement Desensitization and Reprocessing (EMDR), as well as interdisciplinary pain rehabilitation, should be components of rehabilitation programmes to address some of the common difficulties experienced by torture survivors. Furthermore, greater attention to contextual aspects, in which the facilitation of social integration and family relationships are crucial, was considered essential to positive health outcomes.

Why is evidence limited?

There are many reasons why evidence is limited in this field. As with all areas of health and well-being, the development of the evidence base is continual, and studies

continue to be refined in methodology and focus, with the pace of such development being dependent on many factors, not least theoretical, methodological, contextual, financial and other reasons. With respect to this field, it is important to bear in mind that torture rehabilitation evolved as a movement, arising within a particular political, legal and historical context, only commencing about 30 years ago and thus, compared to many other areas in medicine and psychology, this field is relatively young.

Torture rehabilitation was initiated and carried out mainly by health professionals working in human rights organizations, and to date these services remain largely apart from mainstream healthcare provision. More recently, some countries in Europe, including Denmark, have made efforts to integrate such services into mainstream health services. The political and financial context in which many of these services exist is crucial to acknowledge, particularly the struggles they face for survival whilst simultaneously endeavouring to offer quality, highly complex, multidisciplinary and multi-component services to torture survivors facing a multitude of legal, social, welfare and health-related problems in a climate hostile to asylum seekers and refugees.

Many of the organisations offering rehabilitation services to torture survivors thus face a constant fight for resources and acknowledgement, with staff under immense pressure to focus on what many perceive as their core, if not primary, task – providing treatment and care. Hence, whilst outcome research is valued and recognised as crucial to the delivery of quality services, it is not seen as a priority. For some, research is viewed with deep suspicion, and dismissed, based on views that research can be harmful, that it diverts valuable, and scarce financial resources away from direct client care, and

that research on torture victims is generally unethical. Not surprisingly, research in this field has been difficult to implement, and together with methodological and theoretical complexities, and resource constraints, the development of the evidence base has been gradual and some would argue, slow.

The challenges

Despite these complexities, there is an increasing commitment by practitioners, researchers and service managers to developing research on treatment/rehabilitation outcomes, whilst also recognising that there remain some serious challenges. Some of these conceptual, context-related and methodological challenges to developing the evidence base for torture rehabilitation are outlined below.

Conceptual/theoretical challenges

In a field driven initially by the overwhelming need for services for torture survivors within human rights organizations, it is understandable that the development of theoretical models for rehabilitation programmes was not a priority. Whilst there have been many important theoretical contributions over the years, a lack of clarity persists, and consensus on how rehabilitation is conceptualized, what the intended outcomes of rehabilitation are and why, and which differences may be dependent on diverse country contexts (e.g. economic, political, cultural). Not surprisingly, many creative interventions have spontaneously arisen and evolved in different country settings, with many rehabilitation programmes combining multiple methods drawing on different disciplinary traditions, diverse activities, treatments, philosophies and theories. Some focus on adults only, others also on children, young people, families and communities affected by torture and organized violence. Rehabilitation activi-

ties have also included advocacy at individual and policy levels. In short, the diversity in rehabilitation approaches and programme components (as well as their particular mix and emphasis, notwithstanding the diversity in the nature and levels of competencies of practitioners) poses an important research challenge. The question is, can different programmes ever be comparable, and study results ever be generalisable, and how valid and relevant would such an approach to research be, given that there are enduring controversies in the field about what rehabilitation is and its theoretical underpinnings and what are desired outcomes, let alone which of them are measurable?

Context-related challenges

Where outcome research is carried out, it is often not only under enormous resource constraints, but also faced with the challenge of addressing the somewhat unique social, legal and cultural context in which torture survivors present for health and other related services and the complexity of the interventions (invariably involving multiple interventions offered simultaneously, specific to each client/family). Importantly, diversity in torture survivors and their experiences is a reality: torture survivors have varying cultural, ethnic, religious, political and linguistic backgrounds. Their experiences of torture and their specific context vary, as do their experiences subsequently – for many seeking asylum, common experiences include hostility, discrimination, homelessness, poverty and a hostile asylum determination process. For others, torture is followed by attempts at survival, and a search for justice, or access to justice, whilst still living in insecure conflict, post-conflict or transitional states. The complexity of this diversity poses a challenge to outcome research and it is to be considered sensitively and respectfully in research,

not to be treated as an inconvenience, or hindrance to be overlooked, or ignored or overly-simplified in research efforts.

Methodological challenges

There are also many methodological challenges to developing the evidence base, only some of which are highlighted here. The first challenge is to understand the discrepancy between the clinical impression (e.g. that therapy is beneficial, clients do seem to improve in various ways) and the often rather limited improvements that can be identified in scientific studies.¹¹ This discrepancy can present a barrier to outcome research in the absence of co-operation and sustained dialogue between clinicians and researchers within the area.

The second challenge is that there remain conflicting views on the question of how to approach the issue of randomisation, highly relevant to particular types of studies (e.g. RCTs) and particular research methodologies. Is it unethical to randomise traumatized refugees to different types of treatment or even to no treatment, or is it rather un-ethical not to conduct effect studies since the evidence is lacking or unclear?

The third challenge relates to the selection of appropriate outcome indicators. Most studies commonly use symptoms and diagnoses. A specific problem related to this is what can be termed the 'ceiling effect'. If the symptom level reported by a client is so high that it reaches the maximum level of symptom severity, for example when completing a specific measure, it would be difficult to measure improvement. The client might report that they felt better, or improved after therapy, but their reporting might still reach the maximum level of symptom severity on the outcome measures. A more appropriate approach could be to use functioning, rather than symptom level in studies of torture

victims.¹² Both functioning and quality of life, could be not only more relevant but essential to explore among people with multiple problems of long duration, as is the case with many torture survivors.

The last challenge that deserves attention is the question of whether or not the health effects of exposure to torture are chronic. If the health effects are chronic, how do we measure improvement? Studies using the same interventions show different results, so a related question is whether torture effects can be chronic in some contexts and not in others. And since the effects of torture are multiple, we would need to know which effects are possible to ameliorate, under which conditions, and which are unlikely to show change despite any health interventions.

The future

In reflecting on a way forward there are many questions which arise for us, perhaps possible avenues for future joint efforts. For example:

- Can there ever be a shared conceptualisation of what rehabilitation for torture survivors is, and what it aims to change?
- Is there a possibility that we can arrive at a minimum set of shared desired outcomes in this field?
- Must there be only one approach to outcome evaluation, drawing on only particular epistemologies and research methods from natural sciences, or can we encourage and value a range of epistemologies and methodologies (including mixed methods), and therefore what we value as 'evidence'?

Jaranson and Quiroga wisely warn us not to be deterred by the complexities and challenges in conducting outcome research with torture survivors, and suggest that: "Perhaps

most important, centres must start collecting data. Even if only descriptive or demographic data is available, this data should be collected. Eventually program evaluation can develop into outcome of treatment efficacy and, finally, the impact of the program". In this sense, at the very least, we should all aim to start somewhere, and this may mean working with what we have, and what we are able to do in our unique country settings, and with the available resources and skills. Pooling together our efforts, wherever possible, would enhance our work, facilitate mutual learning and provide support to practitioners and researchers across centres or services for torture survivors. However, starting somewhere may also require that there be a shift in organizational culture to enable data collection and research, including outcome evaluation, so that traditional divisions and suspicions can be minimized, and there can be shared ownership within and across organizations/centres in seeing research as essential to developing context-relevant, culturally-appropriate and effective rehabilitation services.

In addressing their own question 'how can it be possible to do research that is scientifically excellent?', Jaranson and Quiroga quote Voltaire: "The best is the enemy of the good", as encouragement to conduct more research, and not to be deterred by the various challenges. Whilst this is a sentiment we sympathise with, we would advocate that this should not be an excuse for conducting less than rigorous research. Research in this field should aim to be relevant to the very complex social, cultural, political and legal context in which torture survivors live, access and utilize healthcare and other rehabilitation services, and it should be ethical and genuinely respectful towards those whose lives we hope to help improve. In this regard, we must not lose sight of the

primary reason why we are striving for a better evidence base – to ensure that we provide access to the highest quality of care and rehabilitation to torture survivors, which is their right, not a privilege.

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