

# Visions from the past: Reflecting on the history of epidemiological research in the refugee and post-conflict mental health field

Derrick Silove

## Abstract

Epidemiological research has made a major contribution to the knowledge-base in the field of refugee and post-conflict mental health in the last 30 years. There is a tendency however to question the cultural validity of study findings, or, alternatively, to argue that we have sufficient data to predict the mental health and psychosocial (MHPSS) needs of future populations exposed to mass conflict. This paper attempts to address both issues. Specifically, it is argued that, rather than an indicator of cultural inaccuracy in measurement, the large variation in symptom prevalence rates observed across studies may reflect a genuine difference given the unique profile of risk and protective factors that characterize refugee populations based on their individual histories of conflict and current conditions of resettlement. There are compelling reasons therefore, where feasible, to include epidemiological studies in the comprehensive approach of data gathering in assessing MHPSS needs - and to monitor changes over time - in current and future populations exposed to mass conflict.

Epidemiological research has played an instrumental role in establishing the knowledge base on which the modern field of refugee and post-conflict mental health field has been built. The last three decades has witnessed an

upsurge in research in the field coinciding closely in time with the lifespan of the Journal, a platform which has played a unique role in the dissemination of information to all actors in the field. It is fitting therefore to reflect on the history of epidemiological research in the field as a contribution to the celebration of the 30<sup>th</sup> anniversary of the Journal – a task I am honoured be able to undertake.

In offering this personal reflection, I am deliberately selective in the studies I cite – I do so simply to illustrate my comments, not to provide a comprehensive overview or review of the field. I rely heavily on some of the research of my group, no doubt revealing my biases in so doing; if some my assertions and conclusions are regarded as contentious and stimulate debate, all to the better; as Socrates taught, knowledge can only be advanced via a process of dialectical discourse.

By identifying some of the challenges and complexities that confront the field, my intent is not to discourage future researchers from entering the arena; to the contrary, my motivation is to provide some guidance in avoiding the pitfalls that I and my contemporaries faced over past decades. To those with the passion and commitment to enter the field, I offer unreserved encouragement; there is no other activity that I have experienced that is as intense, absorbing and challenging. If conducted appropriately, epidemiological research

in the field offers a unique opportunity for engagement with communities that have lived through the most egregious experiences – the process generates a platform for mutual learning that is beneficial to all, and ultimately contributes significantly to the knowledge base on which mental health and psychosocial services (MHPSS) are built.

Although there is no precise point in history that marks the commencement of the epidemiological enterprise in our field, the work conducted amongst survivors of concentration camps following WWII stands out as a sentinel milestone. The work and life of Leo Eitinger is an exemplar amongst leading researchers of the time. As is well known, Eitinger was a survivor of the concentration camps, returning to take up the position of Professor of Psychiatry at Oslo University after WWII where he devoted the remainder of his long career to studying the mental health of fellow concentration camp survivors (a tradition of research continued amongst refugees within the department ever since). There can be little doubt that Eitinger's personal experiences influenced his ideas and insights in the pursuit of his understanding of the psychiatric reactions and wider forms of adaptation exhibited by concentration camp survivors; it is noteworthy, however, how he managed to maintain a scientific perspective in his inquiries, regularly commenting on the methodological constraints he and his colleagues faced at the time (Eitinger, 1960).

During the epoch in which Eitinger worked, it was the custom to admit patients for relatively long periods of time to psychiatric wards, making it possible for him and his colleagues to conduct extensive observations of the extraordinary range and depth of psychiatric reactions and adaptive responses that survivors of human rights abuses exhibit (Eitinger, 1960; Eitinger, 1969). In his work can

be found descriptions of patterns of behaviour that were only “discovered” again much later in the field, including states of post-traumatic explosive anger and paranoid-like thinking, and extreme conditions of withdrawal, passivity, and social alienation (described as the “Musselman” syndrome).

Debates with colleagues during that epoch (Eitinger, 1965; Eitinger, 1969) are echoed in the literature in the field of modern traumatology, for example, surrounding the role that subtle brain changes and physical health play in shaping mental health presentations amongst survivors; whether there is a specific traumatic syndrome arising from exposure to gross human rights violations (then referred to as the concentration camp or KZ syndrome); the extent to which pre-existing constitutional factors influence patterns of long-term adaptation following exposure to extreme abuses; and the complex interactions that occur between past traumatic experiences and broader social conditions in the recovery environment in determining the capacity to function, for example, in employment.

In later decades following WWII there was a relative lull in epidemiological research in the field. As late as 1988, a review of contemporary studies on the mental health of torture survivors concluded that the database in this area was slender, in spite of the ubiquitous use of this form of abuse around the world (Goldfeld et al., 1988). There were some outstanding epidemiological studies undertaken in the more general field of Migration Mental Health, but these inquiries did not always distinguish clearly between the stressors of migration and refugee-specific traumatic events in determining mental health outcomes (Krupinski, Stoller & Wallace, 1973).

From the mid-1970s onwards, several factors converged to provide the impetus that

generate the “birth” of the modern field of refugee and post-conflict mental health as we know it. An important catalyst was the international movement to ban torture in which mental health professionals played a leading role, sensitizing them to the psychosocial needs of survivors who were refugees in western countries. Advocacy by these leaders led to the establishment of the first specialist rehabilitation services for torture survivors in Europe, and then around the globe. An added factor in the 1980s was the large outflow of persons fleeing the wars in countries of Southeast Asia (Vietnam, Cambodia and Laos), producing the largest movement of refugees the world had witnessed since WWII. Hundreds of thousands of refugees were confined for prolonged periods camps in the region prior to being re-settled in western countries. This influx prompted pioneers in the field to establish culturally-appropriate mental health services across North America, Europe and Australasia.

Around the same time, in the USA in particular, the discipline of Psychiatry was undergoing a major paradigm shift away from its previous adherence to psycho-analytic principles towards a more biological perspective which aligned the profession more closely with General Medicine. This new approach was reflected in the reformulation of diagnostic categories (referred to as a process of “operationalization”) in the third edition of the Diagnostic and Statistical Manual (DSM-III), published in 1980. DSM-III also took a major step in defining more clearly the category of posttraumatic stress disorder (PTSD), a development that led to an exponential growth in clinical work and research in the field of psycho-traumatology. These developments in turn had an important influence on the growing field of refugee and post-conflict mental health.

The adoption of what was considered to be the principles of logical positivism in Psychiatry provoked a spirited debate in the emerging refugee and postconflict mental health field (see for example, Summerfield, 1998). Critics asserted that constructs such as “trauma” and “PTSD” were reifications based on western epistemologies in Psychology and Psychiatry. Imposing these constructs on culturally diverse communities served only to “medicalize” normative responses to human rights violations, stigmatizing refugees as “patients” rather than recognizing that they were survivors. It was also asserted that applying western approaches of “trauma therapy” also resulted in weakening traditional recovery and healing mechanisms specific to the cultures of refugee groups.

Although the controversy that followed has largely abated, it left a residue of important lessons that persist, particularly about the central focus that needs to be given to culture in all activities in the field, including in epidemiology. This principle played a key role in the development of the first screening measures for PTSD, depression and anxiety developed specifically for the refugee and post-conflict mental health field. Cultural and linguistic adaptation was the first step in the development of these measures, only then followed by psychometric testing to assess indices of reliability and validity (Mollica et al., 1992). Other researchers adapted structured diagnostic interviews developed for general psychiatric epidemiological studies to a range of cultural groups (de Jong et al., 2003).

The large body of epidemiological studies that emerged over the following decades has done much to establish the knowledge base on which our field is grounded. Nevertheless, for the field to progress further, it is important to confront several areas of concern, primarily in the interpretation and use of data

from epidemiological studies. Measurement remains one of the most enduring challenges – and space does not allow a full exegesis of the complexities surrounding this issue. Most studies in the field have used self-report screening measures (which for many participants are completed with field worker assistance). These measures typically assess the severity and/or frequency of common mental health symptoms of PTSD, anxiety and depression, although the focus has expanded to include other categories such as Intermittent Explosive Disorder (IED), and less commonly, to cultural syndromes.

The majority of studies that have been conducted in the field rely on cross-sectional designs, providing a “snapshot” of the person’s level of psychosocial distress at one point in time. This approach has several inherent limitations for both the interpretation and use of the data. First, symptoms can fluctuate widely over short periods of time both within individual and across populations. This should come as no surprise given the rapidly changing conditions in which refugee and postconflict populations often find themselves (Silove et al., 2014). Second, in populations exposed to recurrent and ongoing traumatic events and stressors, it is particularly difficult to distinguish between transient states of distress and frank mental disorder based on a measure of symptoms at one point in time.

Efforts have been made to address this concern by using calibration techniques in which clinicians undertake structured clinical interviews which are compared with symptom checklists administered independently by field workers. A major concern that is not always addressed is that the symptom thresholds generated for a self-report measure in one culture and context may not apply in another – yet not all researchers undertake the process of re-calibrating measures, simply adopting the

“conventional” cut-off that has been reported in the previous literature (Silove et al., 2014).

In reality, however, there is no fail-safe procedure for achieving high levels of accuracy in assigning psychiatric diagnoses in large-scale epidemiological studies in the field. It simply is not feasible to duplicate a full clinical interview undertaken by trained and experienced mental health professionals in these population-wide settings. At best, therefore, the prevalence rates of “disorder” generated need to be regarded as estimates only, suggestive of “probable” or “possible” mental disorder.

This raises an important question whether it is ever justified to derive averaged prevalence rates of mental disorder from systematic reviews of the pooled body of epidemiological studies conducted in the field. These procedures have been conducted with increasing statistical sophistication at intervals over the past two decades (see for example, Fazel, Wheeler & Danesh, 2005; Steel et al., 2013; and Charlson et al., 2019). I will not dwell on the substantive findings of these studies here given that these details are not relevant to the points I wish to make – and can be readily accessed by the reader from the literature.

Perhaps the most important finding of all these reviews – and one that is often overlooked – is the heterogeneity in prevalence rates identified across studies, especially in rates of PTSD, depression and anxiety. This pattern of marked variation in prevalence across studies is true even when the exact same measures and sampling methodologies have been used across studies (de Jong et al., 2003). It is noteworthy that in the most recent review of the literature (Charlson et al., 2019), statistical adjustments were made to control for factors found to increase heterogeneity, such as differences in the sociodemographic characteristics of samples.

Yet this procedure appears to run counter to the core principles adopted by major ecological models in the field (Silove et al., 2017) currently applied in the refugee and post-conflict mental health field which emphasizes the unique aspects of each refugee and post-conflict population and its MHPSS needs. Although sharing many common experiences in the generic sense (such as exposure to pre-migration traumatic events and postmigration stressors), these populations vary enormously in the nature, extent and context in which these challenges occur. They also come from societies with unique histories, cultures, and the resources and capacity to adapt to adversity. For these reasons, heterogeneity in the prevalence of mental disorder in epidemiological studies should be anticipated and interpreted as an indication of the likely accuracy of the findings, rather than as a signal of inaccuracy in the method or a statistical “problem” that has to be controlled for in the analysis. Put simply, there are strong observational and theoretical reasons to raise questions about the pooling of epidemiological data in our field if the aim is to derive averaged prevalence rights at a global level in order to guide future service planning in new refugee situations – and presumably thereby to avert the need to undertake further population-specific epidemiological studies. I suggest that the contrary inference should be drawn, that is, that past findings of heterogeneity together with strong observational and theoretical reasons, argue strongly for the need to conduct further epidemiological studies in new refugee settings in order to obtain as accurate picture of the MHPSS needs in that specific context.

In that regard, there is a strong case to be made that longitudinal studies, although labour-intensive, offer a far more useful source of information than cross-sectional studies in that they indicate the patterns of change in a

community over time. In that sense, symptom change (and ideally measures of functioning) can provide an invaluable “barometer” not only of the broad MHPSS needs of the community at any one time, but how these needs change over time. By measuring potentially modifiable sources of stress in the community, planners can use longitudinal data to introduce accurately defined new programs to address these problems and to monitor the impact of these interventions over time.

A further note of caution is warranted in relation to the use of epidemiological data to test theoretical models examining the pathways leading to adverse mental health outcomes, such as PTSD. Path models based on structural equation modelling (SEM) are now commonly used for this purpose given that they confer some key advantages over traditional regression methods in allowing the derivation of latent variables and the identification of direct and indirect pathways leading to symptom outcomes. Again, the majority of analyses are conducted on cross-sectional data and the chronology of events is therefore inferred by the ordering of variables within the model being tested. For example, pre-migration traumatic events invariably are located “earlier” in the model than postmigration living difficulties.

Although the constraints of cross-sectional design are regularly identified in scientific reports, the full extent of this limitation needs to be considered in some detail. For example, it is inevitable given the location of variables in the model (based on the inferred chronology of events) that some are more likely to show indirect pathways than others. This is particularly true in relation to traumatic events and postmigration stressors. In that regard, it is important to recognize that all the data included in the model are collected at one time point. There are many reasons,

therefore, that some experiences may be under-reported, and this is particularly true of traumatic events. The mechanisms involved are multifarious: memory decay over time, psychogenic amnesia, dissociation, active avoidance of events that provoked feelings of humiliation, shame, guilt and anger, and hesitancy in reporting these events to strangers. In some persons with PTSD, there may be a countervailing tendency to report memories of trauma that repeatedly intrude into the survivor's mind.

More generally, clinical experience teaches us that people living under conditions of extreme duress – which is commonly the case for refugees – tend to focus on their immediate living difficulties, an understandable, adaptive response. Clearly then, when asked, they will emphasize these immediate problems and downplay historical experiences, especially in a single interview. Expectations that the interview may result in further material or psychosocial assistance may accentuate this tendency.

Moreover, all theories of epistemology and development emphasize the cumulative nature of learning in which templates of knowledge are adjusted and reformulated based on the incorporation of serial experiences. Although we may distinguish in our measures between variables such as past traumatic events and current living difficulties, at the information processing level, the task is to integrate all experiences in a far more complex manner, a hermeneutic procedure that currently defies quantification. For that reason alone, it would be surprising if there were not epistemic connections between past traumatic events and current living difficulties reflected in indirect pathways exhibited in SEM models. Caution should therefore be exercised in drawing simple inferences from these findings, such as that current living difficulties have a more

“direct” impact on current mental disorder. As a practical example, it is commonplace in clinical practice to observe that seemingly low intensity stressors can trigger the first onset of PTSD; this does not mean that trauma was unimportant in the genesis of the disorder, but rather reflects the “final straw” phenomenon in which the cumulation of events has reached a threshold point where the person is no longer able to assimilate and respond adaptively to the entire history of threat and insecurity that they have endured.

These issues remind us that ultimately, research is an active human endeavour in which there is a constant need to re-evaluate methods, procedures, outputs and analyses, ideally undertaken amongst groups of informed individuals who bring their diverse views to engage in the dialectical process of making sense of the process. Statistical analysis, however sophisticated, is only one of the tools that may assist this process – but of course, the machine won't think for us.

Finally, it is worth reminding ourselves repeatedly about the basic principles that should be applied in research in the field. It is difficult to justify epidemiological research that is not primarily service focused. For this reason, it is essential that leaders in health and other sectors in humanitarian programs play an integral role in the planning and implementation of studies and in the use of data to maximise service developments.

Extensive consultation with all stakeholders is central to the preparatory process and indeed must be pursued throughout the study. Fortunately, there is a consensus that “parachute” research in which inadequate time and effort has been given to building these relationships with the community, should no longer occur. The aim is to encourage a genuine partnership in which communities participate at all levels, in planning, ownership, leadership

and use of the data. The parallel process of capacity building is a key activity, ideally extending beyond teaching core skills in the research process itself.

In the preparatory phase, it is essential to gather available sources of information via community consultations and informants and where available, reference should be made to the grey literature. In-depth qualitative and ethnographic studies are now essential, both because of the perspective and information they offer in their own right, but also to generate hypotheses that inform future epidemiological surveys.

It is often said that epidemiological surveys in our field are expensive, time-consuming, and slow to produce useful results, particularly in rapidly changing humanitarian settings. The field has reached the point where it is possible address these concerns. There is an ample body of knowledge – and researchers with experience who can be consulted – to advise on structured methods to expedite sampling, selection and adaptation of measures and training and monitoring of field workers. The recording of interview data on mobile electronic platforms allows the rapid transfer, organization, and processing of data so that there can be a quick turn-around of information for use by the community, services planners and wider stakeholder groups.

In conclusion, it is noteworthy that in some of the most recent humanitarian crises, the absence of systematic epidemiological data has been considered to be a major gap in planning population-wide MHPSS services on a rational basis (Tay et al., 2019). Whether the failure to initiate such studies is attributable to resource constraints or to a growing skepticism about the value of epidemiological studies field can only be speculative. If the principles of good practice and careful interpretation of data are followed, future researchers in epi-

miology can make an invaluable contribution to the generation of knowledge in the field in a manner that will enhance both the quality and effectiveness of MHPSS programming for refugees and post-conflict populations. In a world in which there is every reason to fear an escalation of humanitarian disasters, we should make use of all the resources we have to ensure that we enhance the knowledge base in order to provide the best MHPSS outcomes for the survivor populations we serve.

### References

- Charlson, F., van Ommeren, M., Flaxman, A., Cornett, J., Whiteford, H., Saxena, S. (2019). New WHO prevalence estimates of mental disorders in conflict settings: a systematic review and meta-analysis. *The Lancet*, 394, 240-248.
- Chen, W., Hall, B. J., Ling, L., Renzaho, A. (2017). Pre-migration and post-migration factors associated with mental health in humanitarian migrants in Australia and the moderation effect of post-migration stressors: findings from the first wave data of the BNLA cohort study. *The Lancet Psychiatry*, 4, 218-229.
- De Jong, J. T., Komproe, I. H., Van Ommeren, M. (2003). Common mental disorders in postconflict settings. *The Lancet*, 361, 2128-2130.
- Eitinger, L. (1960). The symptomatology of mental disease among refugees in Norway. *Journal of Mental Science*, 106, 947-966.
- Eitinger, L. (1965). Concentration camp survivors. *American Journal of Psychiatry*, 121, 1030-1030.
- Eitinger, L. (1969). Rehabilitation of Concentration Camp Survivors:(Following Concentration Camp Trauma). *Psychotherapy and Psychosomatics*, 42-49.
- Fazel, M., Wheeler, J., & Danesh, J. (2005). Prevalence of serious mental disorder in 7000 refugees resettled in western countries: a systematic review. *The Lancet*, 365, 1309-1314.
- Goldfeld, A. E., Mollica, R. F., Pesavento, B. H., & Faraone, S. V. (1988). The physical and psychological sequelae of torture: symptomatology and diagnosis. *JAMA*, 259, 2725-2729.
- Krupinski, J., Stoller, A., & Wallace, L. (1973). Psychiatric disorders in East European refugees now in Australia. *Social Science & Medicine* (1967), 7(1), 31-49.

- Mollica, R. F., Caspi-Yavin, Y., Bollini, P., Truong, T., Tor, S., Lavelle, J. (1992). The Harvard Trauma Questionnaire: Validating a cross-cultural instrument for measuring torture, trauma, and posttraumatic stress disorder in Indochinese refugees. *Journal of Nervous and Mental Disease*, 180, 111–116.
- Silove, D., Liddell, B., Rees, S., Chey, T., Nickerson, A., Tam, N., Zwi A., Brook, R., Lelan Sila, L., Steel, Z. (2014). Effects of recurrent violence on post-traumatic stress disorder and severe distress in conflict-affected Timor-Leste: a 6-year longitudinal study. *The Lancet Global Health*, 2(5), e293–e300.
- Silove, D., Ventevogel, P., & Rees, S. (2017). The contemporary refugee crisis: an overview of mental health challenges. *World psychiatry*, 16(2), 130–139.
- Summerfield, D. (1999). A critique of seven assumptions behind psychological trauma programmes in war-affected areas. *Social Science & Medicine*, 48, 1449–1462.
- Tay, A., Riley, A., Islam, R., Welton-Mitchell, C., Duchesne, B., Waters, V., Varner, A., Moussa, B., Alam, A., Elshazly, M., Silove, D. (2019). The culture, mental health and psychosocial wellbeing of Rohingya refugees: a systematic review. *Epidemiology and Psychiatric Sciences*. 28, 489–94.