

THE WORK FIELD OF TORTURE AND NGOs – THE REALITY AND IMPACT

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Accumulated evidence that torture and other related human rights violation produce health-related consequences that requires health professional assistance, has been the point of departure for the development of a global association of rehabilitation centres specialised in rehabilitation of torture survivors. The majority of these survivors lives in third world countries where locally funded rehabilitation services are minimal or non-existent, and most of the specialised rehabilitation centres for torture victims are non-governmental organisations (NGOs) who are totally dependent on foreign donors

After a quarter of a century and impressive expansion of rehabilitation efforts worldwide, there is still no consensus about the efficacy of treatment interventions for torture survivors.

There is little literature about treatment outcome, design models and structure of rehabilitation services, cost-effectiveness, or sustainability of services.

General principles of assessment and treatment remain unchanged and controversies over Posttraumatic Stress Disorder (PTSD) applicability for torture survivors persist.

Since systematic knowledge and scientific evidence is lacking in many areas within the work field, it has not been possible to recommend or reach consensus on »best practice guidelines« and on the organisation and functioning of rehabilitation services they offer in different socio-cultural contexts.

The current paper is intended as a critical overview of NGOs – viewed from the perspective of the reality and impact of what they achieve at the work field of torture.

1. Background

Accumulated evidence that torture and other related human rights violation produce health-related consequences that requires health professional assistance, has been the point of departure for the development of a global association of rehabilitation centres specialised in rehabilitation of torture survivors. The majority of these survivors lives in third world countries

where locally funded rehabilitation services are minimal or non-existent, and most of the specialised rehabilitation centres for torture victims are non-governmental organisations (NGOs) who are totally dependent on foreign donors (van Willigen LHM, 1992).

Most rehabilitation centres and programmes have adopted multidisciplinary approaches, linking traditional rehabilitation of individuals and interventions provided at the community level, to the legal and political aspects of torture and are additionally engaged in medico-legal documentation, prevention and advocacy activities. The professional staffing at centres may include physicians, psychiatrists, psychologists, counsellors, physiotherapists, social workers, occupational therapists, nurses and lawyers.

Through the years many intervention approaches have been applied, varying from centre to centre and from health professional to health professional and without concordance in problem understanding, and priority and goal setting in treatment (Amris, K & Arenas J, 2003).

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2. Level of knowledge – »scientific state of the art«.

Two critical studies

A desk study and a literature review

On behalf of DANIDA Gurr R, & Quiroga J. conducted a comprehensive desk study in 2001: »*Approaches to Torture rehabilitation – a desk study covering effects, cost-effectiveness, participation, and sustainability*«, based on material collected in 1997-98 (Guur, R. & Quiroga, J., 2001. Out of more than 400 scanned refereed journals, other journals, books, and unpublished articles, 250 were selected for review and included in the study.

In the introduction, the authors state: »...*having done a thorough review of the literature, we are disappointed by how few questions in service provision*

are answered. In some areas of interest there are virtually nothing available.»

In their conclusion Gurr R, & Quiroga J, (2001) pointed out that knowledge is missing in several areas, and put forward the following recommendations for future research:

- Studies of the effectiveness of different models of organisation of torture rehabilitation services
- Studies of the efficacy of different treatment approaches
- Studies of the criteria for successful outcomes in treatment and the duration of achieving these outcomes
- Studies of the cost-effectiveness of the different treatment approaches
- Studies of the cultural influences on the response to trauma
- Studies on how the majority of people, in different cultures, who never receive treatment, copes with their trauma
- Studies on intervention strategies for the prevention of the onset, the reduction of the severity or prevention of the recurrence of mental health sequelae in torture survivors
- Studies on specific high-risk groups among victims of organised violence, such as women, rape victims, children, orphans, family members, ex-soldiers, etc.
- Studies to separate the medical and psychological sequelae of torture from the sequelae of refugee trauma
- Studies of resilience factors and an elucidation of why not all exposed to severe trauma develop long-lasting conditions
- »Westernised« approaches, i.e. what are the respective advantages and disadvantages of the different approaches
- Studies on the coping strategies of the second generation of torture survivors, and on integrative problems to elucidate how the impact of trauma is transmitted to the next generation

A field-based research

Based on a global multi-centre study design a long-term research programme – *The Impact Assessment Study The Impact Assessment Study (I-V): A long-term research programme based on a global multi-centre study design* has been drafted in 2002 (Amris K, & Arenas J, 2003, 2004a, 2004b, 2005a, 2005 b). The research programme comprises 5 phases and has been developed with the aim of conducting a systematic »mapping « of the work field of torture, and the clinical practice applied in multidisciplinary rehabilitation of torture survivors.

The main objective of the overall study is to assess *if, how and to what extent* rehabilitation at specialised centres provided in different socio-cultural contexts improves the well-being of torture survivors, and based

on the achieved knowledge to establish empirically founded ‘best practice guideline’ for the future clinical work.

The expected output of the overall Impact Assessment Study is to be able to provide the work field of torture with:

1. Relevant and operational outcome indicators, which can be used in outcome monitoring at centres world-wide.
2. Knowledge on empirically validated rehabilitation of torture survivors, which can be used in the establishment of ‘best practice guidelines’ and in quality development of the clinical practise.
3. Effectiveness information regarding the organisation and functioning of rehabilitation services of torture survivors in different socio-cultural contexts.
4. Assessment instruments, which can be used in intercultural outcome research.

(Amris K. & Arenas J, 2005a, 2005b)

Phase I – an exploratory study – of The Impact Assessment Study *The Outcome of Torture Rehabilitation at Specialised Centres seen from the Clients’ and the Health Professionals’ Perspective* has been conducted as collaboration between the International Rehabilitation Council for Torture Victims (IRCT) in Copenhagen and IRCT affiliated rehabilitation centres in Indonesia, Bosnia, Kenya and Guatemala in the year 2002-3 (Amris K, & Arenas J, 2003, 2004a, 2004b, 2005a, 2005b; Pedersen T, 2003, 2005).

Data were collected using standardised questionnaires, semi-structured individual interviews and focus group interviews. At each of the 4 centres semi-structured individual interviews and focus group interviews were conducted within a sample of 5 health professionals and 5 torture survivors. Purposeful sampling was applied in the selection and inclusion of informants.

The most important findings from Phase I were:

- 1) The objective of rehabilitation – the problem identification and problem understanding – depends on the professional background and the composition of the staff at centres, as well as the socio-cultural context the individual centres are placed in.
- 2) The theoretical knowledge and practical experience available at centres often determine the way individual centres prioritize, to organise their clinical practice, but that this practice also is influenced by concrete possibilities and limitations within service provision.
- 3) A broad spectrum of theories, methods and treatment approaches are applied, and that no explicit method and procedure is used to elucidate,

uncover and define the multitude of clinical problems presented by the clients.

- 4) It seems difficult – within rehabilitation as it is practised – to clearly delineate professional tasks, professional competencies and qualifications, and that this diversity of positions and perspectives might influence mutual goal setting in and planning of treatment, and the coordination of overall rehabilitation courses.
- 5) Across the centres the interviewed clients expressed a *through-going satisfaction* with the support, treatment and rehabilitation they were provided. This satisfaction was placed in different dimensions – the psychological, the physical, and/or the social dimension – but represented in general an achievement of self-efficacy.

(Amris K. & Arenas J, 2005a, 2005b)

Phase II of the Impact Assessment Study *The qualitative processes of change associated with a successful outcome of rehabilitation of torture survivors* has been conducted as a collaboration between the Rehabilitation and Research Centre for Torture Victims (RCT) in Copenhagen and an RCT affiliated rehabilitation centre in Gaza, Palestine, in the year 2005.

The aim of the study was to increase knowledge and generate hypotheses about *the qualitative processes of change* associated with a successful outcome of rehabilitation of torture survivors, and how these processes of change are influenced by a number of interrelated internal and external factors, including:

1. The biography of the torture survivor
2. Contextual factors at the individual and at the societal level
3. Therapist characteristics
4. The applied clinical practice and organisation of service delivery

(Amris K, & Arenas J, 2005a, 2005b; Arenas J, unpublished).

The study was an observational and analytical study involving an interdisciplinary problem/thematic oriented rather than discipline oriented approach, and a combined qualitative-quantitative research methodology with data collection from several complementary data sources.

Data were collected using standardised questionnaires, structured interviews, registration formats, semi-structured individual interviews, focus group interviews and observations made in the field.

At the centre semi-structured individual interviews and focus group interviews were conducted within a sample of 20 torture survivors (12 cases with a highly *positive outcome* and 8 cases with a *negative outcome* of rehabilitation provided by the centre), 20 carers (1 carer of each torture survivors) and 15 health professionals.

Purposeful sampling of information rich cases was applied in the selection and inclusion of informants.

The preliminary findings from the introductory study to Phase II were:

1. The way the problems are presented and described by the clients often reflects some *desperation* and the immediate response among some of them is to fight back – to blame the surrounding. It is not their problem, but the society – the problem and responsibility.
2. In some cases, the clients are not aware of the health professionals' goals, plans, means and methods of treatment. Neither are they aware of, what possibilities and limitations there are in service delivery within the given frame of the centre.
3. The health professionals identify as typical causes for a *negative outcome* of rehabilitation if the clients are not ready for therapy, when there is not understanding from the governmental organisations, when there is extreme poverty, when the clients have unrealistic expectations, and/or are not ready for therapy, when the treatment is very long, when the clients do not want to take medicine, and when the client lacks family support.
4. It is difficult for the health professionals to register *positive outcome* and changes in the client's personal use of life circumstances and it is particular difficult to attribute such changes to an applied health professional intervention. Possible positive outcome and changes must therefore be ascribed the event of rehabilitation combined with other contributing and interrelated life events.
5. Each health professional has his/her own practices, experience and therapeutic approach. The centre does not apply an explicit theoretical framework, an explicit approach or methodology in the rehabilitation of the torture victims.

(Arenas J, unpublished)

3. Rehabilitation, Clinical Practice and Research at the work field of torture

The relationship between rehabilitation, clinical practice and research is a complex subject and a problem at the work field of torture. This complexity leads implicitly – among other things – to discussions of practice development, practice reflection and research in general.

The majority of the health professionals at the centers refers that they need to develop their own skills and professionalism in order to manage their tasks within the work field. They also express the necessity for the development of norms and working standards in order to systematise, describe

and understand their clinical practice and based on this be able to implement theoretical framework that do not contradict the clinical needs.

They recognise that research and analysis should be part of the clinical practice and a basic activity at centres (Amris K, & Arenas J, 2005a, 2005b; Arenas J, unpublished).

Most rehabilitation centres and programmes' message today is to develop an »evidence based« rehabilitation, to create a »research environment« and to produce »a substantial professional input«. The institutions should »create an international position by producing and transferring quality and knowledge«.

It seems that the demands for change and new thinking at the centres do not include a clear view of, *what*, *why* and *how* the actual contents are, that one wishes »to develop« – and neither, *how* they could be carried out in practice with reference to the professional possibilities and limits. The *human resources* and the *professional content* of these demands and new challenges seem to be an enigma, a mystery.

Insufficient or non existent overall theoretical framework

The impression is that the centres' insufficient or non existent overall theoretical framework functions as 'strategy' among the health professionals.

Statements from the interviews and observations (Amris K, & Arenas J, 2005a, 2005b; Arenas J, unpublished) show that, among the practitioners exist a great professional distance and disagreement. The existence of these professional differences has the consequence, that it becomes *difficult to supervise* the health professionals at the centres, as the different questions, proposals and considerations often build on a theoretical *incompatible* understanding framework.

The collection and generalisation of the individual psychotherapists' practice will at the best be »eclectic« and theoretically inconsistent – that is to say, there will be a risk that these theories will consist of concepts, that contradict each other and not describe or be inadequate for the psychotherapists' *common* practice.

For the same reason, it is not possible for the centres to conduct *valid* studies and research based on the present practice.

Validity can not be reached without a *categorization system*, which ensures, that it is possible to capture and understand the problems, which should be studied, with the methods, concepts and theories that are used for this purpose.

This difficulty means, that a possible evaluation of the psychotherapeutic practice at the centres cannot be carried out.

The reasons for this are as follows:

1. Generally, there does not exist an explicit method and procedure which can illuminate the specific clinical problems, changing processes and results of the psychotherapeutic practice for torture victims.
2. There are no case-descriptions, which in detail account for the method used. Intervention usually appears as a »mix« of different psychotherapeutic elements (eclecticism), and is not based on a solid and coherent theory.
3. There does not exist any controlled evaluation and follow up of the treatment results (monitoring and outcome indicators), which makes it difficult to assess the meaning of »non specific«, outer factors. Spontaneous improvement and positive results are often ascribed to the psychotherapeutic intervention alone.
4. The psychotherapists/health professionals have neither an explicit definition and understanding of the problems caused by torture or a theoretical framework and working methods.
5. There is no agreement amongst the psychotherapists/health professionals about how one should understand the torture victims' problems, or what to do with them. They have different theoretical frameworks: psychodynamic, cognition therapy, counselling, psycho-education, psychiatric categories, »eclecticism«, and so on.
6. The members of the psychotherapist/health professional group are often not aware of own and others resources, in relation to the multidisciplinary collaboration. They have not a dynamic and interaction pattern, which is known by all and accepted in relation to rehabilitation.

4. Knowledge production at the work field of torture

Since systematic knowledge and scientific evidence is lacking in many areas, it has not been possible to recommend or reach consensus on 'best practice guidelines' within rehabilitation of torture victims or within the individual health professional disciplines that contribute in the rehabilitation process.

Given the uniqueness of torture as a trauma, the complexity of the health-related consequences with numerous contributing and modifying factors, and the diversity of provided rehabilitation services to torture survivors, outcome research in this area is complex. The scientific approach implicates a series of methodological challenges and the use of combined research methodologies applied in several steps in order to ensure validity of the results.

Research qualified of producing such knowledge will demand a *shift* from the traditional discipline-centred mode of knowledge production towards a broader conception of knowledge production, where knowledge is

generated in the context of application and addresses problems identified through continual dialogue between *actors* from a variety of settings.

Qualitative research conducted with the aim to conceptualise and establish operational definitions of e.g. torture as trauma (problem identification and problem understanding), successful processes of change and thereby successful outcome of treatment and trauma recovery from the perspective of the health professionals and of the torture survivors will be *et sine qua non* for the identification of meaningful outcome indicators and a necessary step in developing instruments to be used in successive quantitative outcome research. This will include effectiveness studies of different rehabilitation models, efficacy studies of different treatment approaches and in cost-effectiveness studies (Amris K, & Arenas J, 2004, 2005; Hollifield M, 2002; Horwitz AV, 2002 ; Howard KI, 1996).

'Practice Portrait'

The work field of torture is a work field with an applied practice, which involves several parties with different positions and perspectives, different goals and means, and different opinions about working standards and desired changes. Knowledge production aiming at a systematic description, evaluation, and development of this practice should therefore be *collaborative* and *participatory* based on the knowledge and experiences of local practitioners and *relevant*, focusing on existing problems and possibilities related to the practice (Dreier O, 1996).

All these aspects are pivotal in participatory action/practice-oriented research, which aims at creating knowledge and building competencies allowing for *the participants/actors* themselves to develop their own practice.

To conduct participatory action research/practice research within the work field of torture is a demanding and complex assignment, the task being to »portrait« the applied practice through description, analysis, and conceptualisation (Amris K, & Arenas J, 2005a; 2005b).

'Practice portrait' (Dreier O, 1993, 1996; Markard M, 1994) is one possible method – an instrument – by means of which, a given practice can be analysed when conducting participatory action research/practice research. It is also to be seen as a method – a framework for reflections about specific *condition-meaning constructions* existing within the practice under study.

Consequently, practice portrait can delineate important focus areas analysing a given institutional practice:

1. *The organisational frame* – its development and change identity and values, visions and strategies, the internal structure, and the interrelation with other institutions.

2. *The professional content* – human resources, theoretical frameworks, working methods, modes of intervention, and organisation of service delivery, relation between practice and research.
3. *Situational aspects* – possibilities for planning of tasks, conflict constellations, and specific approaches in the management of the practice.
4. *Communicational aspects* – internal as well as external communication and the relation between practice and research.

When applying practice portrait as the framework of analysis one can assess existing relations in the field of practice – *what* is the rationale behind clinical decision-making and mode of intervention and *how* is this influenced by the organisational structure at the centres.

5. The work field of torture and the NGOs partnerships relations – ‘practising impact assessment’

Bilateral development aid has had its critics for many years, but during the past decade we have also seen a growing number of critiques of NGOs (Smillie 1995; de Waal 1996; Sogge 1996; Roche 1999). These critiques describe a ‘vicious circle’ which the NGO sector, particularly in the North, faces and which it has helped to create.

This vicious circle has five main elements:

1. Increased pressure on NGOs to demonstrate results and the impact of their work
2. Increased competition between NGOs
3. Growing need for profile for fundraising and advocacy work
4. Poor institutional learning and accountability mechanisms
5. Lack of professional norms and working standards

These elements in combination produce a *growing gap* between the rhetoric of NGOs and the reality and impact of what they achieve.

An important conclusion from the literature review about the NGO’s is that monitoring, evaluation systems and impact assessment have tended to be ‘top-down and bureaucratic’ and that a ‘frequent way to impose authority has been to introduce sophisticated jargon’ which now needs demystifying (Hopkings 1995).

»North« and »South«, »Donor« and »Recipient« partnerships relation

There is a growing scepticism about the value of aid, and less trust between and inside ‘the partnerships relation’. Some argue that agreements and partnerships based on shared values have been replaced by bureaucratic

trust based on plans, strategies, budgets, and accounts. Others argue that the elements of this vicious circle perpetuate the tired old image of aid going from ‘donor’ (north) to ‘recipient’ (south) – a view of »development« as something that is done to other people, »far away« (Roche 1999; Oakley 1999; Pratt & Loizos 1992).

The above mentioned Impact Assessment Study gives an empirical base to affirm that:

1. The true impact of the »North«-»South« partnerships relation, work and collaboration remain *unclear* and there is little ‘consensus’ on which tools and methods are the most appropriate to examine the efficiency, effectiveness, consistency and impact of the interventions (monitoring, indicators, working standards, quality development, ICF, etc).
2. There is an inadequacy to promote *institutional learning*, *impact assessment* and *accountability mechanisms* – accountability to those who the partnerships work seek support, as well as to those who fund this work.
3. In the long term, the »North«-»South« partnerships relation, work and collaboration can only be sustained by more effective assessment and demonstration of its impact, by laying open the mistakes and uncertainties that are inherent in the partnerships relation and development work, by an honest assessment (‘soul searching’) of the comparative effectiveness of the respective work *vis-à-vis* changes in policy and practice of both organisations.

7. Conclusion

Since systematic knowledge and scientific evidence are lacking in many areas, it has not been possible to recommend or reach consensus on »best practice guidelines« within rehabilitation of torture survivors or within the health professional disciplines that contribute to this process.

The complexity of the health-related consequences of torture and the diversity of interventions provided in different models of service structure and in diverse socio-cultural contexts makes outcome research a difficult task.

There is a necessity within the health professionals and by all funding agencies for indicators of individual improvement, service quality and utilisation efficiency in the rehabilitation of torture survivors.

A prerequisite for developing operational and valid outcome indicators, which can be used in monitoring of rehabilitation services, is increased knowledge in several areas within the work field of torture.

Development of intercultural, validated assessment instruments will also be a prerequisite for implementation of outcome research establishing efficacy, effectiveness and cost-effectiveness information.

Consequently there is a large need for field-based research conducted in west and non-western contexts, which allows for a systematic description of the applied clinical practices and for an assessment of the impact of rehabilitation provides for specialised centres in the live of the survivors

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