

IMPACT ASSESSMENT IN REHABILITATION OF TORTURE SURVIVORS

– a long-term research strategy
based on a global multi-centre study design.
Part I: Theoretical considerations¹

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Accumulated evidence that torture and other related human rights violation produces health-related consequences that require 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 work field of torture is therefore a work field with an applied clinical practice rooted in a health professional paradigm recognising, though, the importance and influence of the socio-political and legal dimension of torture as a trauma and in service provision.

In spite of a long history of rehabilitation of torture survivors, very few questions within service provision are answered. The implications of this shortcoming of knowledge are: 1) that effectiveness information on rehabilitation of torture survivors is not available, and 2) that no clear and scientifically valid recommendations on the organisation and functioning of rehabilitation services, and the intervention they offer in different socio-cultural contexts can be put forward.

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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.

The present article is a presentation of a long-term research strategy – The Impact Assessment Study – based on a global multi-centre study design and comprising 5 phases. The strategy 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 extend 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 guidelines« for the future clinical work.

Point of departure in the article will be an introduction to some of the theoretical considerations behind the research strategy, focusing on outcome assessment from a health professional perspective – what are we to measure? – and the nature of the existing knowledge-base within rehabilitation of torture survivors – the scientific state of the art.

1. Introduction

The issues around the quality of health care and provision of health care services have become a subject of increasing complexity and public interest. Practitioners in the mainstream of modern health care are committed to the advancement of »scientific practice« – a practice that is characterised by a theoretical framework that is rational and by the deployment, in such a framework, of knowledge derived from science, to ensure a continued quality development of the practice (Wennberg JE, 1993; Margison FR, 2000; Burgers JS, 2003).

Likewise, health care providers are being asked to provide evidence of the effectiveness of the treatment they propose to perform. To be responsive to these demands, it has become incumbent on health care providers to make available information supporting the effectiveness of their treatment and demonstrating that they achieve positive outcomes in their practices.

Effective dissemination of evidence of treatment outcome is also becoming crucial. Thus health care providers will need to give greater attention to a systematic description and evaluation of their own practices in the years to come (Fontana A, 1996; Eddy DM, 1998; Solomon SD, 2002).

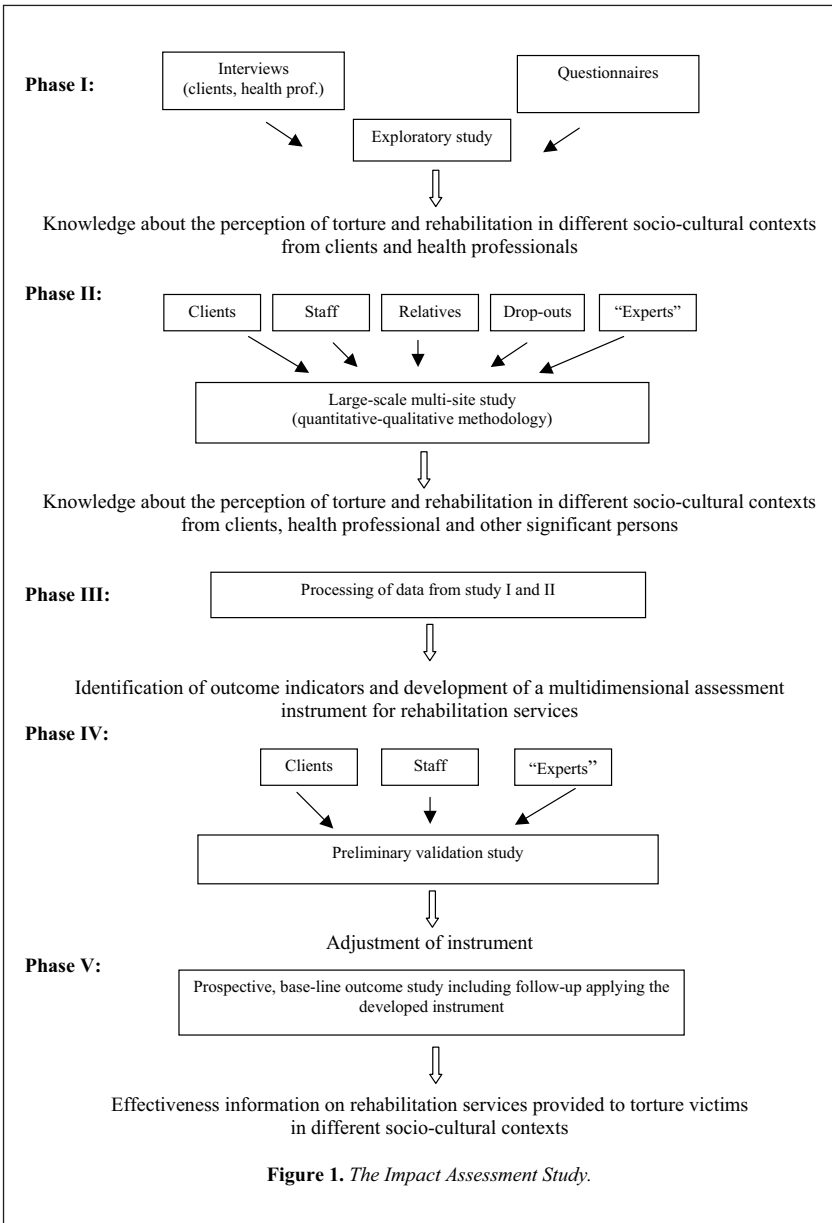
Accumulated evidence that torture and other related human rights violation produces health-related consequences that require health professional assistance, has been the point of departure for the development of a global association of rehabilitation centres specialised in rehabilitation of torture victims. The work field of torture is therefore a work field with an applied clinical practice rooted in a health professional paradigm recognising, though, the importance and influence of the socio-political and legal dimension of torture as a trauma and in service provision.

In spite of a long history of rehabilitation of torture victims, very few questions within service provision are answered. The implications of this shortcoming of knowledge are: 1) that effectiveness information on rehabilitation of torture victims is not available, and 2) that no clear and scientifically valid recommendations on the organisation and functioning of rehabilitation services, and the interventions they offer in different environments can be put forward (Gurr R, 2001).

As in mainstream health care, new requirements to the work field of torture emphasis a change from the idealistic practice of the 1970s and 1980s to a knowledge-based, scientific and academic approach in the years to come. 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 a context of application and addresses problems identified through continual negotiation between actors from a variety of settings. Knowledge production as well as dissemination and implementation of knowledge should therefore not be driven by an isolated »research practice« seeking to transfer knowledge to the field of practice (Dreier O, 1993; Dreier O, 1996; Hanney SR, 2003).

The present article is a presentation of a long-term research strategy – *The Impact Assessment Study* – based on a global multi-centre study design (Fig.1). The strategy 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 victims.

Point of departure will be an introduction to some of the theoretical reflections and considerations behind the research strategy, focusing on outcome assessment from a health professional perspective – *what are we to measure?* – and the nature of the existing knowledge-base within rehabilitation of torture victims – *the scientific state of the art*.



2. Assessment of health and treatment outcome in general health care

Assessment of health and outcome of treatment are in general very complex and the scientific approach – the design of the study, the methodology, the choice of assessment instruments and outcome parameters – implicates a series of conceptual and methodological issues that need to be addressed (Barkham M, 1998; Eddy DM, 1998; Wells KB, 1999; Slade M, 1999; Gilbody S, 2002).

Assessment of health

In order to assess health outcome an assessment of health status is required, which in turn must be based on a concept of health.

Acceptable definitions of health have been changing throughout history. The past 150 years have led to a shift away from viewing health in terms of survival, through a phase of defining it in terms of absence from disease, onward to an emphasis on positive themes of happiness, social and emotional well-being and quality of life.

There is now broad agreement that the concept of positive health is more than mere absence of disease or disability and implies »completeness« and »full functioning« or »efficiency« of mind and body as well as social adjustment. Beyond this there is not one accepted definition (Bowling A, 2001).

Following this broad definition assessment of health status becomes a complex task. Health is to be seen as a construct, which cannot be measured directly. The overall concept of health or change in health status must therefore be assessed based on a number of indicators defined within the various domains of health.

Additionally there are multiple influences upon patient outcome, which also requires a broad model of health. The non-biological factors that can affect recovery and outcome include patient psychology, motivation and adherence to therapy, coping strategies, socio-economic status, availability of health care, social support networks and individual and cultural beliefs and behaviours.

Based on the above mentioned, it is increasingly recognised that assessment of »social health« and »quality of life« measures should be included when evaluating health care interventions.

The concept of »social health« in assessment of health

Donald et al. (1978) have called a broader view of health than the reporting of symptoms, illness and functional ability »social health« . They conceptualised social health both as a component of health-status outcomes

and, in terms of social support systems that might intervene and modify the effect of the environment and life stress events on physical and mental health. Assessment of social health focuses on the individual and is defined in terms of interpersonal interactions and social participation.

Other authors have also conceptualised social health as a separate component of health status, defining it in terms of the degree to which people function adequately as members of the community (Renne K, 1974; Greenblatt M, 1982).

Lerner (1973) noted that health status may be a function of non-health factors external to the individual, such as the environment, the community and significant social groups and recommended that social well-being measures focus on constructs such as role-related coping, family health and social participation. He hypothesised that socially healthy persons would be more able to cope successfully with day-to-day challenges arising from performance of major social roles; would live in families that are more stable, integrated and cohesive; would be more likely to participate in community activities; and would be more likely to conform to societal norms.

The concept of »quality of life« in assessment of health

Several theoretical frameworks can be applied in the definition and conceptualisation of quality of life.

Social science and the 'good life'. There are several meanings of the term 'quality of life' in social research ranging from individual fulfilment and satisfaction with life to the quality of the external environment.

Experiential social indicators research has focused on the importance of measuring subjective well-being. This research has increasingly indicated that, in contrast to subjective variables, objective, social background variables account for relatively little of the variance in happiness, life satisfaction and well-being, thus leading to more emphasis on the importance of subjective feelings of independence, control and autonomy as predictors of well-being (Bowling A, 2001).

In non-experiential social indicators research, quality of life encompasses all external, or objective, circumstances of life – e.g. housing, leisure activities, work, and the environment. Environmental research has focused on non-experiential objective background characteristics of communities, while also attempting to incorporate subjective public values and levels of satisfaction and preferences (Koukoulis S, 2002).

Needs satisfaction is the theoretical basis of many of life scales developed for use in mental health. This theory is a reminiscent of Maslow's hierarchy of need (physiological, safety and security, social and belonging, ego, status and self-esteem, and self-actualisation), and the argument

that once basic biological and survival needs have been met, emotional and social needs become more prominent (Maslow A, 1954).

Gap theorists argue that in the developed world perceptions of quality of life are less likely to be related to basic needs, where these are largely met, but more to one's expectations in life, and to social comparisons with past achievements, and also to comparisons with others (Michalos AC, 1986). Quality of life could be defined in terms of what one has lost, or lacks, rather than what one has. So quality of life is influenced by past experience, present circumstances and aspirations for the future.

Phenomenologists argue that quality of life is dependent on the interpretation, and perceptions of the individual and that perception and achievement of quality of life is dependent on an individual's preferences and priorities in life. The meaning of the concept of quality of life is thus arguable dependent on the user of the term, their understanding of it, and their position and agenda in the social and political structure (Edlund M, 1985).

Quality of life in relation to health is rarely explicitly defined in published studies, but often implicitly defined from a functionalist perspective of society, which relates to the ability to perform activities of daily living and fulfil role obligations necessary for the society as a whole.

From a health perspective, quality of life has been said to refer to the social, emotional and physical well-being of patients following treatment, and to the impact of disease and treatment on disability and daily functioning (Kaplan RM, 1985). It focuses on the impact of perceived health status on the ability to lead a fulfilling life. It is also a personal and dynamic concept for, as health status deteriorates, perspectives on life, roles, relationships and experience change.

The theoretical framework of health-related quality of life, then, is based on a multidimensional perspective of health as physical, psychological and social functioning and well-being.

Health-related quality of life could be defined as »optimum levels of mental, physical, role and social functioning, including relationships, and perception of health, fitness, life satisfaction and well-being.« It should also include some assessment of the patient's level of satisfaction with treatment outcome and health status and with future prospects. It is distinct from quality of life as a whole, which would also include adequacy of housing, income and perceptions of the immediate environment (Bowling A, 2001).

Treatment from the patients' perspective in measurement of health

Analysis of the patient perspective – patient experiences and patient evaluations – can be incorporated in measurements of health care services and is inarguably important in understanding patients' perception of, and sat-

isfaction with, their health outcome following treatment (Druss B, 1999; Fisher D, 1999; Lelliott P, 2001; Simpson EL, 2002).

Different types of measurements can be applied:

- Assessment of behaviours and attitudes, which illustrates the patients' health and disease behaviour including compliance, norms, values, expectations and experiences
- Assessment of patient satisfaction and degree of fulfilment of expectations of the treatment
- Assessment of patients' preferences for treatment in relation to the likely effect on their health and health-related outcome

There is considerable evidence that patients' assessment of care have important consequences for their health and for the health care they receive. Patients who are dissatisfied with their health care are more likely to engage in activities, which disrupt their medical care, and could compromise their health outcome (Kaplan SH, 1989).

In this way patients' assessments become not only an evaluation, but also a predictor of health outcome.

Applied study designs in treatment outcome research

Various research designs are available in outcome research, but most often outcome studies are conducted using:

- Randomised controlled trials (*efficacy studies*) where the target experimental therapy is implemented by the researcher under rigid control and the patient randomly allocated to either experimental therapy or to a control group, or
- Quasi-experimental study designs assessing treatment as it is applied in the field (*effectiveness studies*).

The advantages of randomised controlled trials are that the research outcome, with a high degree of possibility, can be attributed to the application of treatment.

Disadvantages are that interventions are provided under tightly controlled and largely artificial experimental conditions, while patients, clinicians and other decision-makers need to know how treatments work in the real world and whether they are cost-effective under routine conditions. Important questions relating to the organisation and delivery of services are additionally rarely addressed in randomised trials (Gilbody SM, 2002).

Research related to effectiveness rather than efficacy provides therefore a series of advantages, but also disadvantages. The study design involves less manipulation. It is therefore more feasible and provides clinical rel-

evant feedback to treatment providers (Wells KB, 1999; Scott RS, 2003).

The outcome of the treatment a person receives is however determined by a number of factors. In uncontrolled studies it can therefore be difficult to attribute any difference in outcome to the treatment itself. Improvement may e.g. be explained as spontaneous recovery or related to external events. This threat to the validity of the research outcome can be ruled out by applying a relevant comparison group.

3. Assessment of health and treatment outcome in torture rehabilitation

Level of knowledge – »scientific state of the art«

In 2001 Gurr & Quiroga published a comprehensive desk study –»Approaches to Torture Rehabilitation« – based on material collected in 1997-98. 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 states: *»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.«*

Most of the published literature on the health related consequences of torture and rehabilitation of torture victims is descriptive. Only few clinical outcome studies exist and these studies have limitations due to the lack of: control groups; definition of diagnostic criteria; theoretical framework for problem identification and understanding, goal setting in therapy and provided interventions; validation of assessment instruments and identification of relevant outcome indicators.

In their conclusion Gurr & Quiroga (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, cope 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 on 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.

The implications of this lack of knowledge and the resulting lack of scientific evidence within the work field are, that no clear and scientifically valid recommendations on the organisation and functioning of rehabilitation services and the interventions they offer in different environments can be put forward. The complexity of contributing factors and the lack of controlled studies mean, that clinical decisions have to be made based on simpler evaluation methods and professional judgement.

The problem of torture

Torture, as currently understood in international law, involves several elements: the infliction of *severe pain* (whether physical or psychological) by a *perpetrator* who acts *purposefully* and *on behalf of the state*.

There are several purposes, which torture can serve, but the broad objective includes the maintenance of social control, the defence of ruling values and the suppression and prosecution of political opponents and criminals. Where torture has become institutionalised or where police can act with complete impunity, the threshold at which torture is seen as an appropriate tool can decrease.

Torture and other forms of violence can be perpetrated to assist »ethnic cleansing« – the expulsion of one or more ethnic groups – or more generally to induce in a population a sense of terror.

The targets of torture are a mix of those who have long been recognised as potential victims – foremost, political or military opponents of the ruling power – as well as others who are under-recognised as targets of torture: alleged criminals, the poor and socially marginalised, and ethnic minorities (Welsh J, 2002).

Torture practised today is either state policy – the deliberate use of torture with the silent or open support of the government – or it can arise out

of ineffective control of law enforcement personnel, including impunity for those who carries out the atrocities, or is practised in conflict zones including members of armed opposition groups.

Health-related consequences of torture

Research suggests that the consequences of torture occur in the context of personal attribution of meaning, personality development, and social, political and cultural factors (Allden K, 2001; Basoglu M, 2001). For this reason one cannot assume that torture have the same outcome in different individuals and in different socio-cultural and political contexts.

The health-related consequences of torture are therefore likely to be influenced by many interrelated internal and external factors, including:

- age and developmental phase of the victim at the time of torture
- pre-existing personality, genetic and biological vulnerability of the victim
- prior history of trauma
- circumstances, severity and duration of torture
- preparedness for, perception and interpretation of torture by the victim
- cultural meaning of torture and cultural meaning of symptoms
- the social context before, during and after torture
- community values and attitudes
- political factors.

At the level of the community break down of social, political and economical networks are recognised as being consequences of torture and organised violence, afflicting dynamic relationships between individuals and the community impeding trauma recovery (Harvey MR, 1996; Pedersen D, 2002).

Consequently there are complementary approaches applied by professionals in understanding the impact of torture on the overall concept of health.

The clinical approach utilises a medical and psychological paradigm and relies on clinical history, physical examination, and mental status examination of the individual.

The community approach involves assessment of traumatised groups or populations and focuses on the impact of torture and violence on inter-relationships and the »psychosocial health« of the community (Cullen M, 2001; Blow AJ, 2002; Boyce W, 2002; Baum FE, 2003).

It is scientifically well documented that individual torture victims who are referred to treatment have a broad range of physical, psychological, social and legal problems. Most of the knowledge about the health-related

consequences of torture is, however, based on symptom description and established in western settings focusing on refugee populations (Basoglu M, 2001; Gurr R, 2001).

Research related to other dimensions of health than the reporting of symptoms and illness is missing and e.g. systematic information on health-related quality of life including physical and mental functional ability in torture victims is not available.

Physically torture survivors present a variety of symptoms from different body systems, which have been reviewed in several publications. Most of these articles have a listing of symptoms, but no diagnoses. Frequent and typical complaints that are reported even years after torture, are chronic pain related to the musculo-skeletal system, neurological symptoms and irritative symptoms from organ systems (Amris K, 2000; Gurr R, 2001).

The psychological sequelae of torture are likewise described in terms of listing of symptoms or clusters of symptoms. Despite the variability due to personal, cultural, social and political factors similarities in the psychological symptoms that emerge are described, with the main constellation of symptoms corresponding to those collected into the syndrome labelled as Post-Traumatic-Stress Disorder (PTSD). However, the utility of this diagnosis in non-western cultural groups has not been clearly established, although evidence suggests that there are high rates of PTSD and depression symptoms among traumatised refugee populations (Basoglu M, 2001; Allden K, 2002; Schnurr PP, 2002).

Further, cross-cultural research has revealed that phenomenological or descriptive methods are the most rational approaches to use when attempting to evaluate psychological or psychiatric reactions and disorders. What is considered disordered behaviour, a disease, in one culture may not be viewed as pathological in another. Likewise, while some symptoms may be present across different cultures, they may not be the symptoms that concern the individual the most. Therefore, the assessment has to include the individuals' beliefs about their symptoms, as well as an evaluation of the presence or absence of symptoms (Canino G, 1997; Loue S, 1999; Basoglu M, 2001; Allden K, 2002).

Relatively little is known about the social and economical consequences of torture. Social effects of torture are described in the literature at the level of the individual, the family, the community and the society.

The impact of torture on the »social health« of individuals and within families is described in terms of impairment of role-model coping, interpersonal interactions, and social participation leading to social isolation and stigmatisation, poverty, and family- and marital problems (Gurr R, 2001).

Flight into exile, displacement and settlement in a new country are additional events that aggravate the social and economic consequences of torture (Arenas J, 1987; 1994; 1997).

Organisation of treatment

Developments in the understanding of torture and its consequences, in rehabilitation approaches and in the relation between rehabilitation and prevention have led to a significant broadening of the efforts, skills and methodologies needed for what is now increasingly labelled *reparation* of torture victims. The concept of reparation includes medical and psychosocial rehabilitation of the individual, including rehabilitation as societal and political actor. It also includes public recognition of the criminal atrocity committed – and, eventually, punishment of the perpetrators.

Most rehabilitation centres and programmes have therefore 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.

Several models of service structure have developed within the work field:

- integrated centres, where rehabilitation services are provided by a multidisciplinary team at the centre supplemented at some centres by co-ordinated referral to external experts
- core centres, supporting and co-ordinating referral of clients to external experts and networks
- networks of volunteers or part time staff offering services to torture victims without core support function
- community based intervention, where services are provided in the field.

Not only the organisation of service delivery, but also the clinical practise varies to a great extent between centres, countries and regions of the world. Some centres apply a medical approach in assessment and treatment prioritising medical and physical aspects in rehabilitation, other centres are more oriented towards psychosocial needs and treatment models. Some centres focus on rehabilitation of individual torture victims, others provide family- and group therapy, some centres offer a combination of individual, family- and group therapy and finally some centres work entirely community based (Gurr R, 2001; Amris & Arenas, 2003).

Given the different social and political contextual settings world-wide the target group also varies between centres. Some centres mainly receive clients from socially marginalised groups or ethnic minorities where torture and violence are randomly targeting whole populations, other centres work with victims of torture targeting selected individuals and in some

countries of resettlement rehabilitation centres work strictly with refugee populations.

Since systematic knowledge and scientific evidence is lacking in many areas, it has not been possible to recommend or reach consensus on »best practise guidelines« within rehabilitation of torture victims or within the individual health professional disciplines that contribute in the rehabilitation process. Throughout 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 & Arenas, 2003).

Furthermore the »work field of torture« has utilised knowledge and methods developed in other areas e.g. mainstream mental health services and assumed that they would be equally effective in the care of torture survivors (Gurr R, 2001; Amris & Arenas, 2003).

Establishment of theoretical frameworks based on research, and linkage of clinical practise with theory within rehabilitation of torture victims is therefore needed as well as operational definitions of e.g. torture as a trauma (problem identification and understanding), goal setting in therapy, successful treatment processes, and successful outcome of treatment and trauma recovery.

Implications for assessment of health and treatment outcome in torture populations

The complexity of the health-related consequences of torture necessitating a multidisciplinary approach in treatment, and the diversity of interventions provided in different models of service structure make outcome research a difficult task.

There is a desire within the health professional work field and by all funding agencies for indicators of individual improvement, service quality and utilisation efficiency. Literature – recognising the inadequacy – suggests that the indicators, which can be used are symptom reduction, improvements in functionality, achievements of negotiated treatment goals and consumer satisfaction (Rosenheck R, 2000; Gurr R, 2001).

However a prerequisite for developing operational and valid outcome indicators, which can be used in monitoring of rehabilitation services based on the above mentioned, is increased knowledge in several areas:

- Better understanding and definition of the health-related problems caused by torture – the objective of rehabilitation – seen from the torture victims' as well as the health professionals' perspectives.
- Increased knowledge about individual responses to the physical, mental and social effects of the health-related consequences of torture on ac-

tivities of daily living – functionality – and other quality of life parameters.

- Increased knowledge about the multiple internal and external modifying factors influencing mental and physical health status and treatment outcome.
- Increased knowledge about the influence of torture and health-related consequences of torture on social support systems within the family and within the community.
- Increased knowledge about the process of rehabilitation – the clinical practice and applied theories, goal setting and expectations from the clients’ as well as the health professionals’ perspective.
- Increased knowledge about the clients’ preferences, perception of and satisfaction with their health outcome following treatment.

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

4. The Impact Assessment Study

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 problems, which needs to be solved and the use of combined research methodologies applied in several steps in order to ensure validity of the results (Howard KI, 1996; Hollifield M, 2002; Horowitz AV, 2002).

Qualitative research methodology needs to be applied in order to obtain a better understanding of phenomena such as the objective of rehabilitation (problem identification and problem understanding), the process of rehabilitation, mutual goal setting in and expectations to rehabilitation, and criterions defining a successful outcome.

Qualitative research methodology will likewise be a prerequisite to identify meaningful outcome indicators and in order to develop instruments to be used in successive quantitative outcome research including effectiveness studies of different rehabilitation models, efficacy studies of different treatment approaches and in cost-effectiveness studies.

A long-term research strategy – *The Impact Assessment Study* – has been drafted, based on a global multi-centre study design. The research strategy comprises 5 phases as illustrated in Fig.1, which are to be conducted within a time framework of 5 to 6 years.

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 victims of torture, and based on the achieved knowledge to establish empirically founded »best practice guidelines« for the future clinical work.

Phase I

The first phase – a combined qualitative-quantitative, *exploratory study* – 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.

The first phase had two main purposes:

One was to identify and to describe – based on a phenomenological and ethnographic approach – the outcome of torture rehabilitation as provided at specialised centres and in different socio-cultural contexts seen from the clients' and the health professionals' perspectives

The other was to use the obtained knowledge in generating hypotheses to be elucidated by subsequent qualitative and quantitative research projects.

A representative sample of clients and health professionals were interviewed at each centre in order to obtain an increased and intercultural understanding of:

- The objective of rehabilitation – problem identification and problem understanding
- The process of rehabilitation – the clinical practice and applied theories, goal setting and expectations from the clients' as well as the health professionals' perspectives
- The clients' preferences, perception of and satisfaction with their health outcome following treatment.

A report »the Outcome of Torture Rehabilitation at Specialised Centres seen from the Clients' and the Health Professionals' perspective« has been elaborated based on the results of the study (Amris & Arenas, 2002) and will be accounted for in a separate article in this journal.

Additionally, the results from phase I will be used to further adjust the protocol and research methodology in phase II. When a research area is relatively new and little is known about it, and when the topics are highly complex, it requires careful conceptualisation of the findings ensuring precise definitions and descriptions of key issues.

Phase II

The objective of the second phase will be to further complement and increase the knowledge obtained in the first phase. Hypotheses generated in the first phase are thought further elucidated by broadening the perspective on torture victims and rehabilitation. This will be done by: 1) inclusion of more rehabilitation centres, 2) inclusion of other significant informants e.g. family members, »experts« with a professional relation to the work field e.g. lawyers, extreme cases e.g. treatment drop-outs, and torture victims never referred to treatment and, 3) by adjustment and development of applied instruments.

The second phase is planned as a multi-site study including 10-12 rehabilitation centres from different regions of the world. This design has been selected in order to heighten representativeness and in order to describe study findings across different socio-cultural contexts.

The applied research methodology will – as in the first phase – be a combined quantitative-qualitative approach based on questionnaires, and semi-structured individual and focus group interviews. The interviews will be elaborated in close collaboration with the participating actors and within the theoretical framework offered by *Participatory Action Research* (PAR) (Roche C, 1999; Pratt B, 1992).

A series of focus areas related to centres, clients, health professionals and other significant informants have been identified based on the results from phase I, including e.g.:

- The clients' perception of the rehabilitation course and outcome of rehabilitation in relation to other significant life events and the social context.
- The health professionals' expectations to and perception of the rehabilitation process and outcome of rehabilitation in relation to other significant events in the lives of the clients and their social context.
- The health professionals working methods and clinical experience within the work field applied in clinical reasoning and as a framework of provided interventions.
- Coping-strategies in relation to torture and other significant life events adopted by torture victims never referred to treatment.

Findings from the exploratory study – phase I – have emphasised the importance of the socio-cultural, ethno-cultural, and anthropological dimension. These dimensions should be further integrated and studied by the means of e.g. descriptive anthropology, anthropological medicine, and clinical ethnography. The method and strategy should be based on ethnography/participant observation.

With the intention of capturing the multiple dimensions and the complexity of the work field, and to ensure validity of the study findings, a

number of triangulations will be applied (Denzin NK, 1978; Janesick VJ, 1994):

- Data triangulation: the use of a variety of data sources
- Investigator triangulation: the use of several different researchers and evaluators
- Interdisciplinary triangulation: the use of several disciplines (medical, psychological, anthropological, and social scientists) to inform the research process and to broaden the understanding of method and content
- Methodological triangulation: the use of multiple methods to study a single problem
- Theory triangulation: the use of multiple perspectives to interpret a single set of data.

Criteria for assessing validity in the study will be applied in order to maximise construct and descriptive-contextual validity and to ensure generalisability to other cases and other socio-cultural contexts. Point of departure will be to place the researcher, the topic, and the sense-making process in interaction, emphasising (Athens L, 1984; Dingwall R, 1992; Maxwell J, 1992):

- The relationship between what is observed and the larger socio-cultural context within which the observations are made.
- The relationships among the observer, the observed and the context.
- The issue of perspective evaluating and interpreting data.
- The issue of representational reporting of study findings.

Phase III

Operational, measurable outcome indicators with a relevant conceptual basis for multidisciplinary torture rehabilitation will be developed in the third phase. Based on processing of the data collected in the first and in the second phase it will be decided, what is to be measured and the agreed concepts will be defined and translated into an observable form. Additionally each indicator will be analysed for intercultural applicability.

The outcome indicators will be defined and developed according to a broad concept of health and change in health status encompassing the various domains of health, health-related quality of life, and »social health« including occupational and social role functioning, and maintenance of social relationships and activities (Barkham M, 1998; Goodman LA, 1998; Evans C, 2000).

Clients' satisfaction and degree of fulfilment of expectations of treatment will likewise be analysed as potential outcome measures.

With the aim of evaluating intervention, a multidimensional outcome assessment instrument will be developed based on a combination of instruments with different properties including the identified and operationalised outcome indicators (Marsella AJ, 1989; Mollica RF, 1992; Bracken PJ, 1995; Jaranson JM, 1995). Key characteristics that will be prioritised in constructing the instrument will be:

- A relevant conceptual basis for multidisciplinary torture rehabilitation
- High responsiveness reflecting clinical significant change in health status
- High quality of psychometric properties
- Intercultural applicability

Phase IV

The objective of the fourth phase will be to validate and test the acceptability of the developed multidimensional assessment instrument across cultures and to adjust the instrument if needed.

Psychometric equivalence among instruments in different cultures is satisfied when the psychometric properties of two or more cultural groups are essentially the same. Key issues are comparable reliability, validity and responsiveness (Marsella AJ, 1989; Marsella AJ, 1993; Friedman M, 1994; Orley J, 1994; Mollica R, 1996). The following will be considered validating the developed outcome assessment instrument across the participating centres:

- Content equivalence
- Criterion equivalence
- Conceptual equivalence
- Semantic equivalence

The outcome of a defined number of rehabilitation courses will be assessed applying the developed instrument. Following this the participating clients will be exposed to blinded in-depth interviews assessing treatment outcome as a reference.

Phase V

The objective of the study in the fifth phase will be to establish effectiveness information, conducting a prospective, baseline outcome study including a one-year follow-up applying the developed instrument.

A quasi-experimental study design (effectiveness design) is at present considered to be the most feasible. Since it is not possible, for ethical reasons, to randomise torture victims into non-treatment groups, a suitable

non-randomised comparison group will be identified from the background population to control for internal validity confounding.

Expected output of the overall study

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

- Effectiveness information regarding the rehabilitation of torture survivors in different socio-cultural contexts.
- 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.
- Relevant and operational outcome indicators, which can be used in outcome monitoring at centres world-wide.
- Assessment instruments, which can be used in intercultural outcome research.

5. Conclusion

The work field of torture needs to take responsibility for a knowledge-based development of the applied practices within rehabilitation of torture victims, and for making available information supporting the effectiveness of multidisciplinary rehabilitation.

A mutual and coordinated research effort, as outlined, will provide the work field of torture with:

- A systematic monitoring of the knowledge-base and identification of gaps in available knowledge.
- A coordinated and relevant knowledge production based on identified and prioritised needs.
- Dissemination and implementation of knowledge ensuring a knowledge-based development and targeted capacity building of the work field.

The cost to society of not providing therapy to victims of torture and other related human rights violation is not insignificant both on the individual and the societal level. Torture treatment contributes to the development of countries where torture has occurred or is still occurring.

As stated in the Jakarta Declaration on Health Promotion (WHO 1997): »Perquisites for health are peace, shelter, education, social security, social relations, food, income, empowerment of women, a stable eco-system, sustainable resource use, social justice, respect for human rights and equity.« Rehabilitation centres for torture victims are clearly contributing to

many of these factors in their society and funding of survivor services are therefore contributing to advocacy for human rights and the prevention of torture.

Production and transfer of systematic knowledge should be the point of departure for communication and dialogue with the wide range of constituencies out-side the work field and will be a sine qua non for a sustainable funding of the future anti-torture work.

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