

# Using the International Classification of Functioning, Disability and Health (ICF) to describe the functioning of traumatised refugees<sup>a</sup>

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## Abstract

The aim of this project was to use the International Classification of Functioning, Disability and Health (ICF) to develop an interdisciplinary instrument consisting of a Core Set, a number of codes selected from ICF, to describe the overall health condition of traumatised refugees. We intended to test 1) whether this tool could prove suitable for an overall description of the functional abilities of traumatised refugees before, during and after the intervention, and 2) whether the Core Set could be used to trace a significant change in the functional abilities of the traumatised refugees by comparing measurements before and after the intervention.

In 2007, eight rehabilitation centres for traumatised refugees in Denmark<sup>b</sup> agreed on a joint project to develop a tool for interdisciplinary documentation and monitoring, including physical, mental and social aspects of the person's health condition. ICF, developed and approved by WHO in 2001, was found suitable because it offers a common and standardised language and a corresponding frame of reference to describe health and associated conditions in terms of functioning rather than symptoms and diagnosis.

Traumatised refugees are in most cases severely affected mentally by the traumas they have been subjected to, physically by injuries suffered

during torture and war, psycho-somatically with pain, and socially by cultural uprooting, as well as by social difficulties in the exile community. The *rehabilitation perspective thus seems to be more meaningful than the traditional treatment perspective because it takes into account the very complex situation of this group.*

The aim of the project was to find out whether any functional changes could be monitored using the instrument. The aim was neither to study nor to describe the effect of rehabilitation approaches, such as conditions related to traumatised refugees' networks or environments that might affect the refugees' living conditions. It was also not the intention to discuss the cause of the potential changes of the functional abilities.

The project selected a Comprehensive Core Set of 106 codes among 1,464 possible codes<sup>1</sup> used by an interdisciplinary group of international and national experts in rehabilitation of trauma-

a) This article is based on the project report: ICF som dokumentation og monitoreringsredskab – anvendt til primært traumatiserede flygtninge [ICF as a documentation and monitoring tool applied on primary traumatised refugees]. Aarhus: MarselisborgCentret, 2009. The report is only available in Danish.

b) The eight rehabilitation centres were: Clinic for Traumatised Refugees, Vordingborg; Clinic for Traumatised Refugees, Aarhus; RCT, Fyn; RCF, Region North Jutland; RCT, Jutland; RCT, Copenhagen; OASIS and RIC, Horsens (RIC, Horsens, closed down before the start of the intervention phase). The pilot project ended up with seven centres.

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tised refugees. The Comprehensive Core Set was furthermore reduced to a Brief Core Set of 32 codes by the interdisciplinary team (key persons) at the centres included in the project. From each centre six clients were randomly selected from those who fulfilled the inclusion criteria. All were scored within a four week period after the start, before any intervention was initiated, and up to a month after the first scoring.

The results from this project led us to the conclusion that it is possible to develop an instrument based on the ICF classification. The instrument is useful for a general description of the total health condition (physical and mental functional ability as well as the environmental impact) of traumatized refugees. The tool helps describe changes in the functional abilities used in connection with the preparation of the plan of action. It can also be used to describe the refugees included in the study and their general condition.

The ICF Core Set for traumatised refugees has not yet been validated, but the results of the project provide a basis for further development.

*Key words:* refugees, torture, trauma, body function, rehabilitation centres

## Introduction

Among refugees in Denmark, 20 to 30% are traumatised because of torture, war, persecution and other kinds of organised violence or flight. It is estimated that approximately 50% of the Danish refugee population, equivalent to 55,000 refugees, are suffering from anxiety and depression. Of these, approximately 22,000 (20% of the entire population) fulfill the criteria for Posttraumatic Stress Disorder (PTSD).<sup>2</sup>

The group of traumatized refugees is a complex target group with very different backgrounds. The nature, the number, and the duration of the traumas have affected the refugees both mentally and physically with symptoms such as fear, depression, sleep problems, and pain. Furthermore, many exiled refugees are affected by the living condi-

tions in their new country, e.g., waiting times for political asylum or residence permits, and at the same time they have to adapt to a new culture, acquire a new language, and accept new norms. At the rehabilitation centres and clinics in Torture documentation inside detention centres in Denmark, refugees suffering from sequelae of the trauma of torture, war, flight, etc. are offered specialised rehabilitation and treatment. In order to be referred to the centres, the refugees must need an intervention beyond what the ordinary public social and health systems offer.

The intervention offered by the centres to the refugees is holistic based on the entire life situation, because not only the traumatic events, but also social factors, play a role in the range of symptoms and the prognosis.

This means that the intervention is interdisciplinary, including psychotherapy, physiotherapy, psychomotor treatment, examination and treatment by medical specialists, as well as social coordination and treatment. Some centres and clinics also offer educational rehabilitation.

The focus is on rehabilitation, defined as *“a goal-oriented, cooperative process involving a member of the public, his/her relatives, and professionals over a certain period of time. The aim of this process is to ensure that the person in question, who has, or is at risk of having, seriously diminished physical, mental and social functions, can achieve independence and a meaningful life. Rehabilitation takes into account the person's situation as a whole and the decisions he or she must make, and comprises coordinated, coherent, and knowledge based measures.”*<sup>3</sup>

Danish rehabilitation centres for traumatised refugees have for many years collaborated to find suitable tools to document the clients' distress and monitor the outcome of the efforts of rehabilitation. Many centres agreed on implementing the Harvard

Trauma Questionnaire Revised (HTQ-R), but the implementation was not coordinated. Some of the centres have used other tools and methods.

Studies of the effect of rehabilitation on refugees' health care have been very scarce. In a Health Technology Assessment (HTA) carried out by Region South of Denmark, existing studies up to 2008 were examined. Several outcome studies were conducted for treatment of PTSD. Few studies included populations with unspecified complex traumas (DESNOS).<sup>c</sup>

Only two studies in the report targeted traumatised refugees living in exile in Western countries. Birck<sup>4</sup> completed one study at BZFO in Berlin, while Carlsson et al.<sup>5</sup> completed another study at the Rehabilitation and Research Centre for Torture Victims (RCT) in Copenhagen. Both studies used symptom-related rating scales, but Carlsson's study also used a self-rating scale for quality of life. Neither study could prove any significant effect immediately after treatment, but Carlsson's study showed a significant improvement 23 months after treatment started.

Similar to the HTA report, another study carried out in relation to this project concluded that the most frequently used instruments assessed PTSD symptoms,<sup>5,37</sup> depression, and anxiety.<sup>5, 7, 10, 12-22, 25, 27, 28, 30-37</sup> Few studied quality of life as well,<sup>5, 7, 13, 14, 37, 38</sup> but none was related to the functional abilities of the clients. Not all instruments were validated with the refugee populations studied, which may have affected the results.

Generally speaking the results were few and sometimes negative. The studies were conducted using very different levels of evi-

dence, and the interpretation of data was complicated because of differences in population, samples, and assessment methods. The selected studies showed that the effect of rehabilitation on improving the health participants' conditions was limited.<sup>39</sup>

The limited number of studies and their poor outcomes speaks for developing both rehabilitation methods adapted to the complexity of traumatised refugees and a measuring instrument which has a broad focus on health and disease. This requires an instrument that can measure both mental and somatic symptoms and also clarify how context affects ability to function. The former is a subject for method development at centres based on thorough research, and this project addresses the latter.

### The population

The population for the Core Set developed by the project included *both* primary traumatised refugees *and* secondary traumatised refugees. Primary traumatised refugees are defined as: "Individuals who have been subjected to a traumatic experience in another country like a horror experience during war, civil war, political persecution, torture and other kinds of organised violence, which furthermore may have caused loss of closely related individuals, house and home, homeland, etc., which have led to serious mental, physical and social problems". Secondary traumatised refugees are defined as: "Individuals who are living together with a primary traumatised person, so that the relationship in itself is threatening the mental, physical and social integrity of the person."<sup>2</sup> *The population selected for inclusion in the project is primary traumatised refugees ages 18 to 65 years old, who have been assessed and recommended for interdisciplinary rehabilitation including physiotherapist/psychomotor therapist, social worker and psychologist,*

c) Disorder of Extreme Stress Not Otherwise Specified.

and for whom the interdisciplinary approach was planned to take place at least once a month with a social worker, and once a week with a psychologist and physiotherapist/psychomotor therapist.

### The method

ICF can be used as a classification where the functioning is scored (coded) by selecting certain domains or categories from the different components of the classification. Gradients can be added to measure the degree of functional impairment.

The main purpose of the project was to develop an ICF Core Set for traumatised refugees. According to WHO, a Core set is a number of codes that are sufficient to describe the overall health condition for a certain group of patients. Usually three to 18 codes are considered sufficient for this purpose at the second level. However, more codes may be necessary for groups of patients with very complex symptoms and for specifying results of rehabilitation.<sup>1</sup> The Core set should include as few categories as possible but be sufficient to provide a detailed, multidisciplinary description of the functioning and the patients' impairment of functions.

For this purpose the Delphi technique<sup>d</sup> was chosen. The Delphi technique is a structured communication process comprising four key characteristics: anonymity, repetition (including controlled feedback), statistical group response, and expert input. The

Delphi technique has been used to develop other Core Sets, especially for somatic diseases.<sup>40, 41</sup>

Twelve experts were selected based on criteria for having 1) extensive experience in the rehabilitation of traumatised refugees, 2) neutrality by having no occupational relationship to any of the participating centres, and 3) representation from multiple disciplines. Two of the experts were from Austria and ten from Denmark. Two experts were physicians, three were physiotherapists, two were psychologists, one was a psychotherapist and four were social workers.

The Comprehensive Core Set was constructed through three rounds of selection by the twelve experts.<sup>e</sup>

*Delphi-round 1:* The experts opted out codes at the second level (362 codes),<sup>f</sup> which they found irrelevant for the group of traumatised refugees. Codes opted out by all experts were subsequently removed from the set of codes.

*Delphi-round 2:* A form including the remaining codes was distributed to the experts. They were asked to answer yes or no whether the codes were relevant to the group of traumatised refugees. Their own answers from the first round were available for each of them as well as the answers from the other experts, but made anonymous. The share of experts who didn't opt out the single code from the first round was noted in percentage.

*Delphi-round 3:* For the third Delphi-

d) The Delphi technique is a partial element of the Delphi method.

e) However, in the second round only ten of the experts answered.

f) First level comprised eight chapters within the component of "Body Functions", eight chapters within the component of the anatomy of the body,

nine chapters within the component of "activities and participation" and five chapters within the component of "environmental factors", totaling 30 chapters. Each component was categorised in domains (chapters), which were practical and provided sets of connected physiological functions, anatomic structures, acts, tasks, and spheres of life (International Classification of Functioning, Disability and Health. WHO, 2001:215).

round, forms identical with those from the second round were distributed. The experts were again asked to answer yes or no as to whether they found the code relevant for the group of traumatised refugees. The experts could see their own answers as well as the answers from the other experts, but the answers were made anonymous. The share of experts who didn't opt out the single code from the second round was noted in percentage.

After each Delphi-round, there was a consensus calculation including all codes with at least 80% consensus among the experts. The number of codes included in the Comprehensive Core Set was 106.

The Comprehensive Core Set included too many codes for practical use. Therefore a continuing process to further reduce the number of codes and to select a Brief Core Set was initiated in two phases:

Three key persons from each project centre's interdisciplinary team selected codes, 80% or more included in the final brief Core Set of 32 codes.

To test the reliability of the scoring we planned to videotape clinical interviews with clients from the centres, each interdisciplinary team scoring clients with the Brief Core Set. However, for practical reasons this was not feasible. Instead, key persons acted as clients and, after intervention, scored the actors based on the role play video.

To measure functioning and disability, WHO recommends a common generic scale for quantification. The degree to which a code is problematic has gradients followed by a percentage stating the degree of functional impairment: "no problem" 0-4%, "a little problem" 5-24%, "a moderate problem" 25-49%, "a serious problem" 50-95%, "a complete problem" 96-100%, "without specification" and "not relevant".<sup>1</sup>

However, the gradients make it very

difficult to clarify the degree of improvement or impairment. Client improvement in functioning from 51% to 49%, will change a serious problem to a moderate problem, but no change in evaluation will occur from 95-50%. In our project we therefore have chosen a Visual Analogue Scale (VAS) from 0-100% (from none to total impairment) to register client level of functioning.

The score was based on clinical assessment interviews of the clients by each professional within the teams. Each professional was responsible for focusing on a certain number of codes, but the final score was carried out within the interdisciplinary team, both by the first and the second score. There is always a risk of serious biases when a score is based on a clinical interview. However, this was our best choice since we didn't find any appropriate objective tools that could replace the clinical interview. Training to provide a common understanding for interpreting the codes minimized this bias.

## Implementation

The guidelines for implementation of the project were that:

- Each centre should initiate rehabilitation of six new clients within a three-month period from the start of implementation.
- The first scoring should take place no later than four weeks after the project start date, but before any intervention was initiated. Within this period all members of the team should have at least one session with the client to gather the necessary information about the client for assessment in order to arrive at the initial score. It was agreed in advance which codes each of the clinicians was responsible for, and treatment should not start during this period.
- The period of intervention was fixed to a

maximum of eight months after the first scoring of the client. Periods of vacation for the clinicians were added to the period of intervention, so that the effective rehabilitation period was eight months, but not exceeding 34 weeks in total.

- The second scoring should take place either by ordinary termination of the client within the period of intervention or eight months after the first scoring assuming the client was not terminated before that date.

There were no requirements for specific methods of intervention. Except for the above mentioned criteria, treatment as usual should be offered. Furthermore, there were no common guidelines for using measurement instruments nor restrictions on which instruments each clinician or centre could use for assessment of the client or in their clinical work with him/her.

## Results

### *The population*

Out of 42 planned courses of intervention (six clients from each centre), 39 clients from eleven nations were included in the project. The vast majority was from the Middle East, including eleven from Iraq (Table 1).

Among the registered clients were 23 men and 13 women: 14% had an unstable asylum status, 81% were married, 62% were referred from a GP, 27% from the municipality and 3% from a psychologist, a psychiatrist, a specialist MD or local psychiatry, while 68% needed an interpreter for treatment.

From Figure 1, 73% of the clients had been subjected to traumatic experiences directed towards themselves or towards themselves and others, while 13% were sub-

**Table 1.** *Clients distributed on nationalities.*

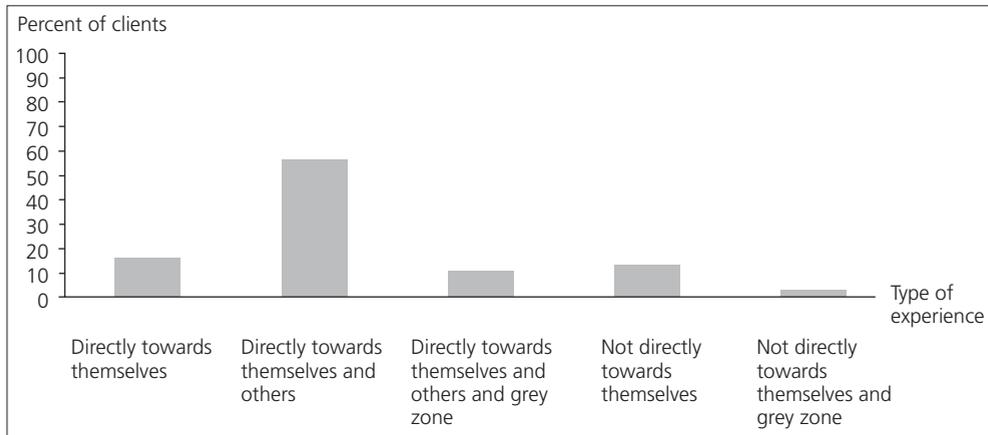
Nationality	Number
Iraqi	11
Iraq Kurds	3
Bosnian	1
Armenian	1
Lebanese	1
Palestinian	2
Afghani	1
Somali	1
Chad	1
Kosovar	2
Iranian	5
Other	2
No data	2

jected to traumatic experiences not directed towards themselves.

At the time of the first scoring, 68% had one or more well-known somatic diseases. Among the most common diseases were chronic back pain, whiplash, tinnitus, and pain after torture. In addition, diabetes, increased blood pressure, asthma, migraine, Mb cordis, arteriosclerosis, slipped disc, joint deviations, cirrhosis of the liver, gastritis, constipation, etc. Also at the first scoring, 84% had a well-known mental disease. Among the 31 clients who answered that they had a mental disease, 17 suffered from depression, 24 from PTSD, 10 from anxiety and 26 from other mental diseases. The vast majority thus had a somatic disease, a mental disease or both. No analysis was carried out to correlate the presence of traumatic experiences to somatic and mental diseases.

### *The Core Set*

The Comprehensive Core Set was based on codes selected by the expert group. The Del-

**Figure 1.** The type of traumatic experiences the clients were exposed to (informed by the key persons).**Table 2.** Allocation of codes of the five components in Core Sets.

Components:					
Number of codes	Body functions	Body anatomy	Activity and participation	Contextual factors	Total
Comprehensive Core Set	32	5	44	25	106
Brief Core Set	10	0	17	5	32

phi-technique consisted of three rounds with an interval of 14 to 21 days.

All the experts answered the questionnaires timely except in round two, where only ten experts answered before distribution to the third round. A consensus of 80% was considered equivalent to at least ten experts (out of 12) who were not opting out a certain code. Based on that calculation, the Comprehensive Core Set comprised 106 codes. The allocation of codes on the five ICF components appears in Table 2.

To prepare a Brief Core Set, an additional round was chosen and the seven interdisciplinary teams from the centres negotiated which codes they found most relevant. Based on that process, a new Brief Core Set was developed resulting in 32

codes. The allocation of codes on the five components appears in Table 2.

The Brief Core Set comprises the following codes:

#### BODY FUNCTIONS

b130 Energy and drive functions  
General mental functions of physiological and psychological mechanisms that cause the individual to move towards satisfying specific needs and general goals in a persistent manner.

*Inclusions:* functions of energy level, motivation, appetite, craving (including craving for substances that can be abused), and impulse control.

b134 Sleep functions  
General mental functions of periodic, re-

versible and selective physical and mental disengagement from one's immediate environment accompanied by characteristic physiological changes.

*Inclusions:* functions of amount of sleeping, and onset, maintenance and quality of sleep; functions involving the sleep cycle, such as in insomnia, hypersomnia and narcolepsy.

#### b140 Attention functions

Specific mental functions of focusing on an external stimulus or internal experience for the required period of time.

*Inclusions:* functions of sustaining attention, shifting attention, dividing attention, sharing attention; concentration; distractibility.

#### b144 Memory functions

Specific mental functions of registering and storing information and retrieving it as needed.

*Inclusions:* functions of short-term and long-term memory, immediate, recent and remote memory; memory span; retrieval of memory; remembering; functions used in recalling and learning, such as in nominal, selective and dissociative amnesia.

#### b152 Emotional functions

Specific mental functions related to the feeling and affective components of the processes of the mind.

*Inclusions:* functions of appropriateness of emotion, regulation and range of emotion; affect; sadness, happiness, love, fear, anger, hate, tension, anxiety, joy, sorrow; lability of emotion; flattening of affect.

#### b180 Experience of self and time functions

Specific mental functions related to the awareness of one's identity, one's body, one's position in the reality of one's environment and of time.

*Inclusions:* functions of experience of self, body image and time.

#### b280 Sensation of pain

Sensation of unpleasant feeling indicating potential or actual damage to some body structure.

*Inclusions:* sensations of generalized or localized pain in one or more body part, pain in a dermatome, stabbing pain, burning pain, dull pain, aching pain; impairments such as myalgia, analgesia and hyperalgesia.

#### b715 Stability of joint functions

Functions of the maintenance of structural integrity of the joints.

*Inclusions:* functions of the stability of a single joint, several joints, and joints generalized; impairments such as in unstable shoulder joint, dislocation of a joint, dislocation of shoulder and hip.

#### b730 Muscle power functions

Functions related to the force generated by the contraction of a muscle or muscle groups.

*Inclusions:* functions associated with the power of specific muscles and muscle groups, muscles of one limb, one side of the body, the lower half of the body, all limbs, the trunk and the body as a whole; impairments such as weakness of small muscles in feet and hands, muscle paresis, muscle paralysis, monoplegia, hemiplegia, paraplegia, quadriplegia and akinetic mutism.

#### b735 Muscle tone functions

Functions related to the tension present in the resting muscles and the resistance offered when trying to move the muscles passively.

*Inclusions:* functions associated with the tension of isolated muscles and muscle groups, muscles of one limb, one side of the

body and the lower half of the body, muscles of all limbs, muscles of the trunk, and all muscles of the body; impairments such as hypotonia, hypertonia and muscle spasticity.

#### ACTIVITIES AND PARTICIPATION

##### d175 Solving problems

Finding solutions to questions or situations by identifying and analysing issues, developing options and solutions, evaluating potential effects of solutions, and executing a chosen solution, such as in resolving a dispute between two people.

*Inclusions:* solving simple and complex problems.

##### d230 Carrying out daily routine

Carrying out simple or complex and coordinated actions in order to plan, manage and complete the requirements of day-to-day procedures or duties, such as budgeting time and making plans for separate activities throughout the day.

*Inclusions:* managing and completing the daily routine; managing one's own activity level.

##### d240 Handling stress

and other psychological demands

Carrying out simple or complex and coordinated actions to manage and control the psychological demands required to carry out tasks demanding significant responsibilities and involving stress, distraction, or crises, such as driving a vehicle during heavy traffic or taking care of many children.

*Inclusions:* handling responsibilities; handling stress and crisis.

##### d350 Conversation

Starting, sustaining and ending an interchange of thoughts and ideas, carried out by means of spoken, written, sign or other forms of language, with one or more people

one knows or who are strangers, in formal or casual settings.

*Inclusions:* starting, sustaining and ending a conversation; conversing with one or many people.

##### d470 Using transportation

Using transportation to move around as a passenger, such as being driven in a car or on a bus, rickshaw, jitney, animal-powered vehicle, or private or public taxi, bus, train, tram, subway, boat or aircraft.

*Inclusions:* using human-powered transportation; using private motorized or public transportation.

##### d570 Looking after one's health

Ensuring physical comfort, health and physical and mental well-being, such as by maintaining a balanced diet, and an appropriate level of physical activity, keeping warm or cool, avoiding harms to health, following safe sex practices, including using condoms, getting immunizations and regular physical examinations.

*Inclusions:* ensuring one's physical comfort; managing diet and fitness; maintaining one's health.

##### d620 Acquisition of goods and services

Selecting, procuring and transporting all goods and services required for daily living, such as selecting, procuring, transporting and storing food, drink, clothing, cleaning materials, fuel, household items, utensils, cooking ware, domestic appliances and tools; procuring utilities and other household services.

*Inclusions:* shopping and gathering daily necessities.

##### d630 Preparing meals

Planning, organizing, cooking and serving simple and complex meals for oneself and others, such as by making a menu, selecting

edible food and drink, getting together ingredients for preparing meals, cooking with heat and preparing cold foods and drinks, and serving the food.

*Inclusions:* preparing simple and complex meals.

#### d640 Doing housework

Managing a household by cleaning the house, washing clothes, using household appliances, storing food and disposing of garbage, such as by sweeping, mopping, washing counters, walls and other surfaces; collecting and disposing of household garbage; tidying rooms, closets and drawers; collecting, washing, drying, folding and ironing clothes; cleaning footwear; using brooms, brushes and vacuum cleaners; using washing machines, driers and irons.

*Inclusions:* washing and drying clothes and garments; cleaning cooking area and utensils; cleaning living area; using household appliances, storing daily necessities and disposing of garbage.

#### d660 Assisting others

Assisting household members and others with their learning, communicating, self-care, movement, within the house or outside; being concerned about the well-being of household members and others.

*Inclusions:* assisting others with self-care, movement, communication, interpersonal relations, nutrition and health maintenance.

#### d710 Basic interpersonal interactions

Interacting with people in a contextually and socially appropriate manner, such as by showing consideration and esteem when appropriate, or responding to the feelings of others.

*Inclusions:* showing respect, warmth, appreciation, and tolerance in relationships; responding to criticism and social cues in relationships; and using appropriate physical contact in relationships.

#### d740 Formal relationships

Creating and maintaining specific relationships in formal settings, such as with employers, professionals or service providers.

*Inclusions:* relating with persons in authority, with subordinates and with equals.

#### d750 Informal social relationships

Entering into relationships with others, such as casual relationships with people living in the same community or residence, or with co-workers, students, playmates or people with similar backgrounds or professions.

*Inclusions:* informal relationships with friends, neighbours, acquaintances, co-inhabitants and peers.

#### d760 Family relationships

Creating and maintaining kinship relationships, such as with members of the nuclear family, extended family, foster and adopted family and step-relationships, more distant relationships such as second cousins, or legal guardians.

*Inclusions:* parent-child and child-parent relationships, sibling and extended family relationships.

#### d820 School education

Gaining admission to school, engaging in all school-related responsibilities and privileges, and learning the course material, subjects and other curriculum requirements in a primary or secondary education programme, including attending school regularly, working cooperatively with other students, taking direction from teachers, organizing, studying and completing assigned tasks and projects, and advancing to other stages of education.

#### d860 Basic economic transactions

Engaging in any form of simple economic transaction, such as using money to pur-

chase food or bartering, exchanging goods or services; or saving money.

#### d870 Economic self-sufficiency

Having command over economic resources, from private or public sources, in order to ensure economic security for present and future needs.

*Inclusions:* personal economic resources and public economic entitlements.

#### ENVIRONMENTAL FACTORS

##### e310 Immediate family

Individuals related by birth, marriage or other relationship recognized by the culture as immediate family, such as spouses, partners, parents, siblings, children, foster parents, adoptive parents and grandparents.

*Exclusions:* extended family (e315); personal care providers and personal assistants (e340).

##### e320 Friends

Individuals who are close and ongoing participants in relationships characterized by trust and mutual support.

*Exclusions:* immediate family (e310); extended family (e315); friends (e320); general social support services (e5750); health professionals (e355).

##### e355 Health professionals

All service providers working within the context of the health system, such as doctors, nurses, physiotherapists, occupational therapists, speech therapists, audiologists, orthotist-prosthetists, medical social workers.

*Exclusion:* other professionals (e360).

##### e460 Societal attitudes

General or specific opinions and beliefs generally held by people of a culture, society, subcultural or other social group about other individuals or about other social, political

and economic issues, that influence group or individual behaviour and actions.

##### e590 Labour and employment services, systems and policies

Services, systems and policies related to finding suitable work for persons who are unemployed or looking for different work, or to support individuals already employed who are seeking promotion.

*Exclusion:* economic services, systems and policies (e565).

#### Implementation

It was not feasible for all the centres to include enough clients within the inclusion period. Consequently, the period was extended another two weeks up to three and a half months. For several reasons it was not possible to maintain the frequency of four sessions per week with psychologists and physiotherapists/psychomotor therapists. It was not necessary to complete all the planned sessions, e.g., they had finished treatment with one of the specialists but continued with the others because all clients had different problems and therefore different needs for treatment. Nonetheless, we decided to retain them in the project to avoid an increased bias when comparing the first with the second scoring and to maintain a large number of clients in the project.

After the second scoring, 46% of the clients were considered recovered, 30% were still in treatment, 19% were excluded from the project, and 5% were unknown. In a few cases the second scoring was carried out by another person than the one who was responsible for assessment and the treatment. In these cases the scoring was exclusively based on the file.

By the second scoring, the key persons noted that, for 57% of the clients codes were redundant and for 47% codes were missing

within the Brief Core Set. Furthermore, the key-persons found that the Brief Core Set was too comprehensive and time-consuming.

#### *Results of the scoring*

For an instrument to be valuable for documenting and monitoring the rehabilitation of traumatised refugees, it must 1) include the range of problems most common for traumatised refugees and 2) measure changes in the functioning and health conditions addressed in the course of rehabilitation. In the following figures, the first score on each code is compared with the second score. Figure 2 illustrates the first response and second score regarding body functions for a single client. Code b144 has been scored like a disability after intervention, perhaps because there was no problem at the first scoring, which therefore scored 0%. The reason was not known in this case. Neither the duration of rehabilitation nor the status of

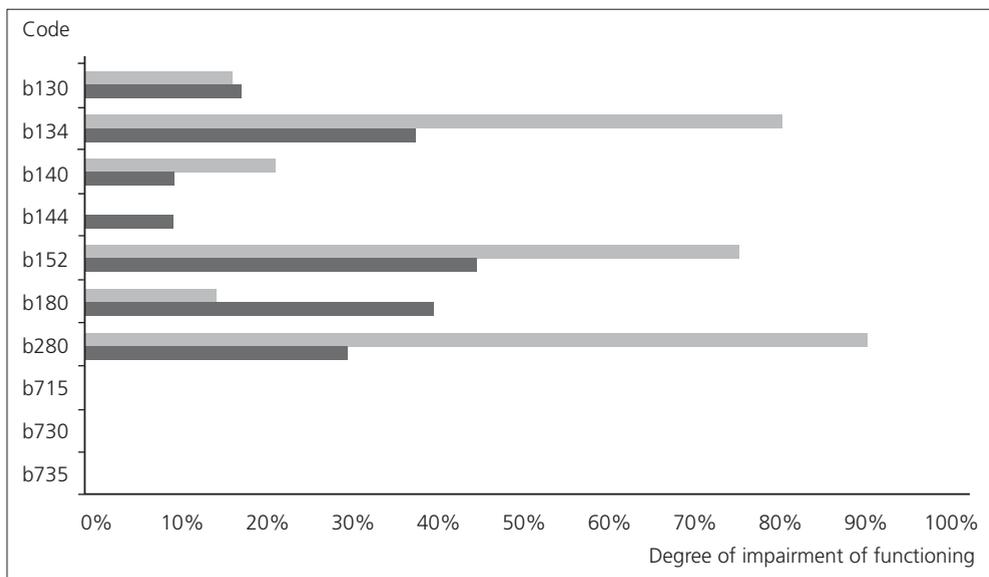
completion of rehabilitation was indicated. The percentage indicates the interdisciplinary assessment of the impairment of functioning within each of the codes, with 0% equal to no impairment and 100% equal to total impairment.

Figure 2 shows how the functioning was evaluated, based on recording each code within the body functioning component before and after intervention. As an example, code b134 for sleep before intervention was estimated at 80% functional impairment, and after intervention it was reduced to 38%.

We also calculated the score for the total sample of clients. However, because the sample is small and does not constitute a normal distribution, we based our calculation on a median value of the impairment of functioning in order to provide an overall status for the clients' health conditions.

The results (Figure 3) show that the impairment of functioning for most codes was

**Figure 2.** An example of scoring a client response 1st (before intervention) and 2nd (after intervention) scoring for body functions.



**Figure 3.** Median values for each code calculated for the entire sample of clients by response 1st (upper) and 2nd (lower) scoring.

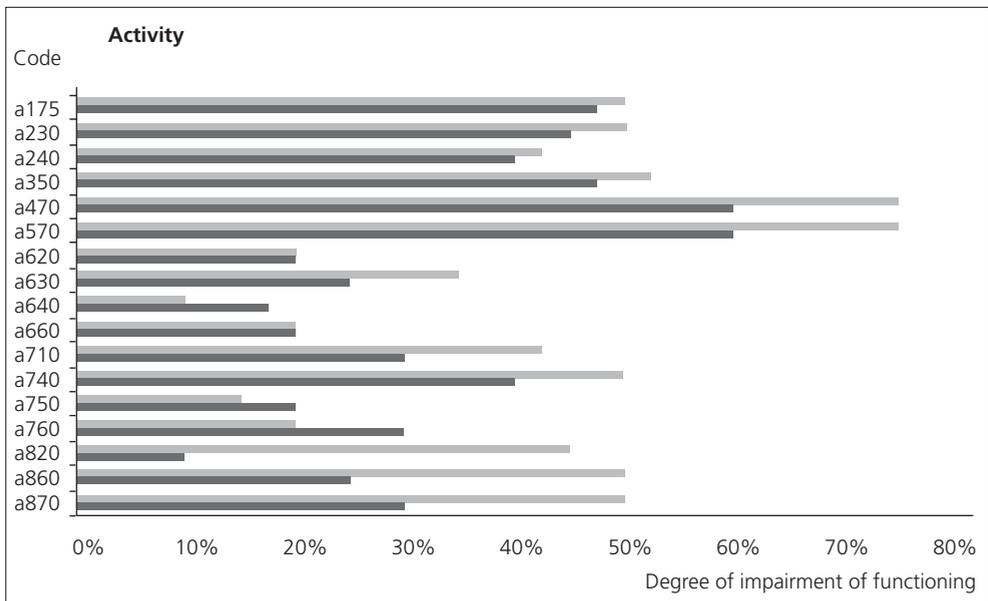
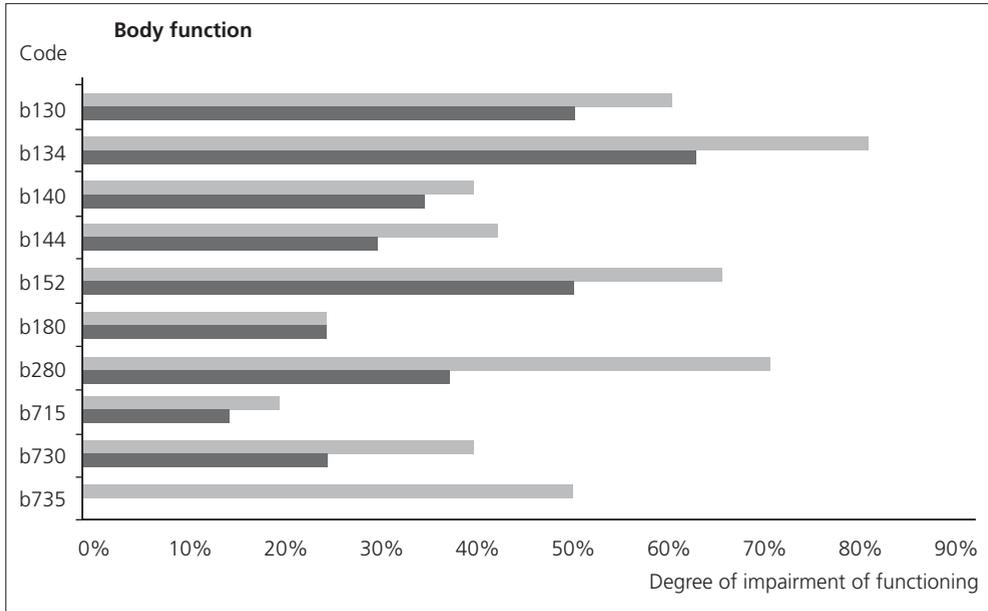
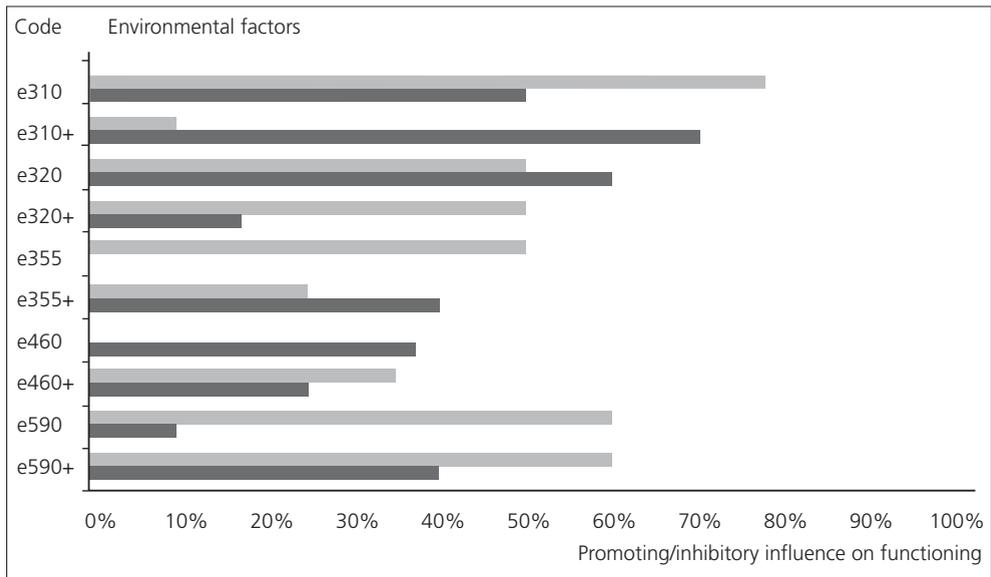
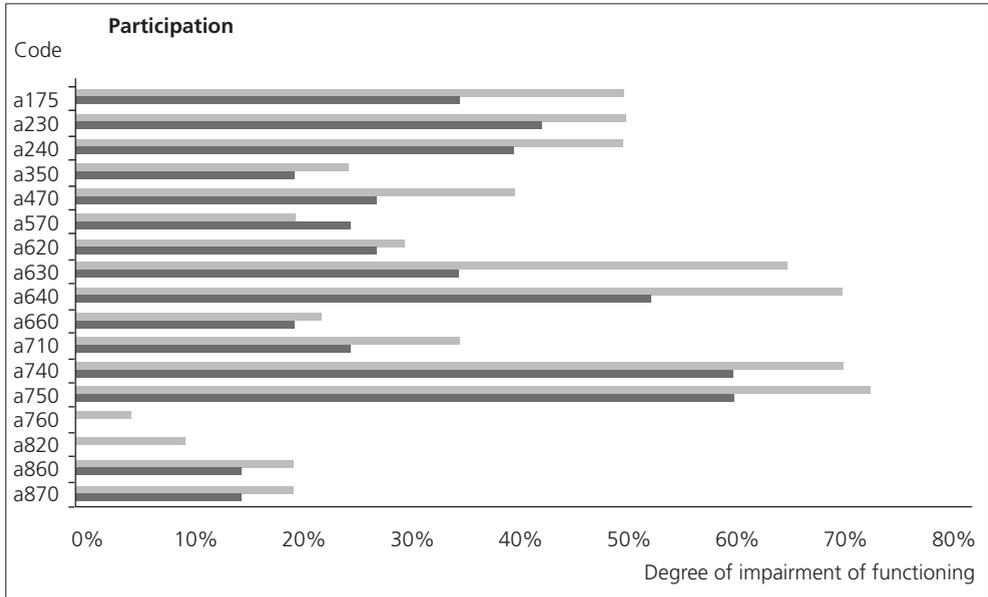


Figure 3 continues on the next page.



less at the second scoring than at the first scoring.

The environmental factors can be considered promoting as well as inhibitory. Factors marked with a + are considered as promoting

and factors without a + are considered as inhibitory. For example, code e310 considers the influence of the family background: The family background can be both a promoting factor for the person's health condition *and*

an inhibitory factor. By the first scoring the background family is considered to be a 78% inhibiting factor, but by the second scoring this factor was reduced to 50%. On the other hand, the family background was only considered as a 10% promoting factor by the first scoring, but 70% by the second scoring. This means that the negative factors of the family background on the functioning of the clients were reduced, while the positive factors increased.

Based on median values it is not possible to draw any conclusive explanation for the results because we have no information about specific interventions and external events which may impact the health conditions, and we don't know how the single codes influence each other, e.g., how changes in the sleep function influence the perception of pain.

The objective of this project has mainly been to examine the applicability of ICF as an instrument for traumatised refugees, including the ability of the instrument to grasp relevant differences of functioning. It was not the purpose of this project to perform an effect study using ICF as an instrument. To do so a randomized control group should be selected and compared with the project group. The application of ICF as an instrument for monitoring only indicated whether a difference before and after intervention can be registered. Whether the difference is due to the intervention or to a general tendency to improve over time is not examined.

#### *The reliability*

Several biases have made it difficult to evaluate the reliability of the tool: 1) uncertainty in interpretation and evaluation of the codes, due to inconsistency in the participation of the project days when trial scoring took place and 2) changes of key persons within the project period.

However, the average difference between the highest and lowest scores (a summary average of all codes) decreased from 40% to 20% from the first to the second scoring. This indicated that increased knowledge of the tool improved the consensus among the teams scoring the clients and thus the reliability.

## **Discussion**

### *Development of ICF Core Set*

The steering group of the project selected the expert group from the criteria that each expert should have years of experience in the rehabilitation of traumatised refugees and that the group should be multidisciplinary. Presumably this was the best possible way to select a Comprehensive Core Set with the resources available for the project. However, we might have achieved a more reliable result had all processes included in the Delphi method been used. The selection of codes may have been altered if the experts had received prior training or had worked with the ICF. Objective criteria for expertise in the rehabilitation of traumatised refugees, e.g. specific training skills, titles, requirements of relevant publications, years of practice, could also have been considered. For future international use of the Core Set, an expert group consisting of international representatives might have been an advantage. Our expert group only included two international experts. However, within the western world it is not likely that the health conditions of traumatised refugees differ in any decisive way, considering that refugees in general come from the same countries. What may vary are the conditions of exile from country to country, and this will especially influence the environmental factors.

The consensus percentage has been discussed in the literature of ICF. The higher the percentage, the more reliable the Core

Set will be for the single codes. However, the more limited the Core Set, the greater the risk that some important codes will be missing to provide an overall description of the health condition of the target group. A consensus percentage of 80% seems to be reasonable even though we arrived at an extensive Comprehensive Core Set.

The method used for constructing the Brief Core Set did not strictly follow the rules of the Delphi method.<sup>40, 41</sup> However, we found the process described above useful and necessary to ensure a balance by considering the variable mental, physical and social aspects selected by different professional groups and the overall interdisciplinary view of the health condition of traumatised refugees. Compromises were made, and selected codes which were considered important by some professional groups but not others were excluded. For example, the physiotherapists/psychomotor therapists missed a code describing respiration (b499), which was considered a very important code. On the other hand, the Brief Core Set ended up with too many codes when considering that ICF must not be too complicated and time consuming for clinicians to use. From that perspective, the Brief Core Set needs to be re-considered.

The key persons had difficulty agreeing on how to understand and interpret each code. To increase both the validity and reliability of the scoring, help-descriptions for many of the codes should be prepared, explaining how the code should be interpreted and indicating how to examine the code with the client.

#### *Scoring the Codes*

The procedure for examining the level of functioning of the clients was not very clear. Some centres used alternative tools or tests to examine the clients, and some did not.

Furthermore, there were no clear instructions for interviewing the client in order to gather valid information corresponding with the codes. No clear distribution of responsibility among professionals within the interdisciplinary team was determined for gathering information about each code prior to the second scoring. To ensure a valid and consistent result, defining responsibility is crucial, and tools, checklists, and guidelines for the scoring need to be further developed.

ICF has been considered a professional assessment instrument, based on a consistent knowledge and theory regarding functioning and health as well as on information from the client. This assessment forms the basis for description of functioning in order to set priorities for rehabilitation efforts and goals. Thus ICF is not appropriate as a self-rating tool, and there is no direct link from certain answers stated by the clients to a certain score. In our view, the clinical assessment can not be avoided despite the application of so-called objective assessment tools. Assessment tools can supplement ICF but not replace clinical assessments.

In clinical research, scoring should not be carried out by the same person(s) also responsible for treatment or rehabilitation. This avoids bias deriving from the clinician-sconscious or unconscious wish to find a positive result. However, since no objective tools corresponding with the single codes have been developed, for practical as well as ethical reasons it is not feasible to completely avoid this bias. However, the bias can be minimised by more precise use of tools, check-lists and guidelines for the scoring process. The reliability of the scoring can also be increased by proper training of the clinicians to score the codes.

The results of the scoring can be useful for planning which aspects of the client's problems should be addressed and where to

discover the client's resources. However, ICF is not appropriate for determining any average of functioning for a client because each code cannot be equally weighted with the other codes.

By the second scoring, the key persons noted that for 57% of the clients codes were redundant and for 47% codes were missing within the Brief Core Set. Considering that traumatised refugees are a very complex group, with a variety of symptoms and distress, these figures seem quite modest. If the correlation is high between the codes that are redundant with respect to those missing, revising the Brief Core should be considered but, if not, expected variation within the group would be an explanation.

Evaluating the results from the first and second scoring showed that the Brief Core Set clearly identified relevant aspects of functional impairment for the clients. Only code no. p760 (family relationships) and p820 (school education) were lower than 20% impairment on average for both first and second scorings, and only related to participation. This indicates that the instrument is valid for providing information to focus on important aspects of the health conditions of the clients. In addition, the vast majority of the codes revealed a difference between the first and second scores, with the second score showing a decrease in functional impairment of the clients. A few codes showed an increase in functional impairment: (code no. a640 (doing house work); a750 (caring for household objects); e310d (immediate family); e320 (friends); and e355 (health professionals). The impairment of functioning of these aspects, which focuses on close relationships and dependency on professionals, can be explained by the fact that functioning improved on some more external aspects.

We didn't determine whether the de-

crease in functional impairment was significant or not because of the small number of clients included in the project and because this was not an objective for the project, though it could be an objective for further studies. Scoring a control group could also be considered, but this raises some ethical problems.

### Conclusion

On basis of the results, it seems fair to conclude that ICF is a suitable instrument to document and monitor achievements of the rehabilitation of traumatised refugees. By focusing on five very important components of functioning, Body Functions, Body Anatomy, Activity and Participation, Environmental Factors and Personal Factors, ICF offers an overall view of the human aspects of functioning. Considering the very complex situation of traumatised refugees, this perspective seems crucial since traumatising of refugees impacts the mental, physical, and social functioning. This advocates for an interdisciplinary approach emphasizing rehabilitation, which includes treatment, as a part of the effort. ICF seems to be an appropriate instrument to describe the overall health condition of a patient or client and to document and monitor rehabilitation. ICF focuses on functioning rather than symptoms and diagnosis. It takes into account impairment as well as resources of the person, which creates a good basis for an assessment of all aspects of the person's health conditions.

We successfully developed a Comprehensive Core Set with 106 codes describing common and important aspects of traumatized refugees' health conditions. The result might have been a little different if the procedure had been carried out by international experts selected by certain criteria, but probably not in any decisive way.

The key persons on the project selected a reduced number of codes to make the scoring practical within the framework of a rehabilitation centre. However, this Brief Core Set still includes too many codes to be practical, and a future analysis should reveal whether some codes are missing or redundant. For future implementation, the Brief Core Set should be revised.

The ICF provides a common language and understanding among different professional groups and a basis for common planning of the course of rehabilitation. However, common procedures, tools, and tests should be developed to increase the reliability of the instrument.

Based on this project, we cannot draw any conclusion about the effectiveness of the rehabilitation efforts at the seven participating centres. The changes in the level of functioning from the first to the second scoring can be due to treatment and rehabilitation, but can also be due to external factors such as changes in the situation of the client's homeland or in the legislation regulating the social situation of the refugees.

Finally, the ICF as an instrument for documentation and monitoring is not fully developed, but may be the best available common and interdisciplinary instrument for documentation and monitoring traumatised refugees.

For future projects, revising the Brief Core Set based on analysis of the data from this project should identify the most relevant codes for an overall description of the health condition of traumatised refugees and reduce the Brief Core Set to a practical number of codes. The instrument should also be validated in order to make it applicable for outcome studies.

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