# The ICD-10-Symptom-Rating (ISR)

# **Brief Description**

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# 1 Construction of the Questionnaire ICD-10-Symptom-Rating (ISR)

#### **1.1 Initial Considerations**

In medical science - and therefore also in psychosomatics and psychology - the assessment of symptoms is an essential aspect of the evaluation and diagnosis of psychological disorders (Uexküll & Wesiack, 2003). Symptoms can be considered as both a "subjective sign of illness, as stated by the person concerned" (Uexküll & Wesiack, 2003), as well as an "objective disorder as determined by an expert" (Stieglitz, 2008). However, symptoms may have different relevance for patients, their relatives, therapists and health care providers.

*Patients and their relatives*: The perception of symptoms is perceived as the first indicator of an illness and may lead to the utilization of medical and psychotherapeutic services (Tritt et al., 2010a). Furthermore, patients and relatives use subjectively perceived changes in symptoms as a foundation for the evaluation of the success of a specific treatment.

*Therapists*: The evaluation of symptoms is used by doctors and therapists as a basis for the classification of the syndrome. Syndromes are, according to Stedman (2005), an aggregate of symptoms and signs associated with any morbid process, together constituting the picture of the disease. These symptoms and signs are used for assessing psychopathology as well as for providing a diagnosis from a specific classification system (Stieglitz, 2008), like the ICD-10 (World Health Organization, 1992) or the DSM-IV (American Psychiatric Association, 2000). The evaluation of syndromes is also used to document any changes induced by the therapy and thus allows for the assessment of any medical or psychotherapeutic effects (Hill & Lambert, 2004).

Health care providers: In general, more credibility is ascribed to so-called Patient Reported Outcomes than to treatment evaluations from physicians. The patients' perception and their satisfaction regarding their treatment (including their treatment success) is an important factor for health care providers, especially when the health care providers are in competition with other providers. In general, the provision of indemnification by a health care provider is normally determined by a doctor or psychotherapist assigning an ICD-10-diagnosis (World Health Organisation, 1992). With the ICD-10, chapter V (for psychological disorders), a criteria oriented approach was taken as the foundation for ascribing diagnoses of mental disorders, based on simple observable and explorative psychopathological criteria pertaining to time and the course of illness. Most of these criteria are symptoms (Freyberger & Stieglitz, 1996). It has also be repeatedly demonstrated that psychological symptoms can influence the course of other somatic illnesses. Accordingly, the assessment of psychological symptoms can be relevant for health care providers, especially when mental disorders are covered by the specific insurance policy.

All these factors may be considered relevant reasons why symptom assessment plays such a central role in the diagnosis and evaluation of psychological disorders. Standardized surveys, based on psychometric ratings made by patients, are frequently used in routine care (von Heymann et al., 2003; Tritt et al., 2007). However, the use of extensive psychometric testing in research and clinical practice is highly time consuming and usually involves high license fees. This is especially true when comprehensive questionnaires, which assess a variety of disorders, and disorder-specific assessments are used at the same time (Herzog, Stein & Wirsching, 2000; Kazdin, 1994).

In order to address this, one approach may be to rate each disorder with a disorder-specific questionnaire, i.e. for eating disorder patients an instrument for the evaluation of eating disorder symptoms would be used. It certainly does not make any sense to use an anxiety or depresssion scale to evaluate changes in such symptoms. Circumstances become much more complicated in such cases where the goal is to evaluate all co-morbid psychological disorders, which – depending on interest and research topics – may hold a few advantages: Usually patients (especially inpatients) manifest more than one psychological diagnosis. For example, in a large psychosomatic consecutive sample (Tritt et al., 2003) patients exhibited on average 2.1 different ICD-10 mental diagnoses and in a larger psychiatric sample (Härter et al., 2004) the patients featured 2.24 ICD-diagnoses. In general, the more co-morbid Fdiagnoses the patient presents with, the longer and more intensive the therapy is (von Heymann et al., 2003). Focusing on the main psychological diagnosis is not always the solution, as the key aspect of the therapy may change during treatment and the increased consumption of resources due to the co-morbidity would then not be taken into account. Another problem is that the extent and scope of co-morbidity is often only fully realized some time after the therapy has started and a delayed assessment of symptoms (in comparison to an evaluation of the symptom-status at initial assessment) often has negative effects on the evaluation of the therapeutically induced changes, since patients often report a more or less quick reduction of symptoms quite early in therapy. Adding to this point is the fact that completing multiple questionnaires may overtax a patient with high co-morbidity and the administrative costs of creating a patient-specific package of questionnaires for each and every patient does not seem very practical. These may very well be the

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reasons why comprehensive questionnaires, such as the Symptom Check List -90-R (Derogatis, 1994), are favored.

Initially we aimed at developing a license fee, extensive, far-reaching tool for the overall rating of symptoms by the patients, hence saving valuable resources and being suited for the comprehensive, multi-center application in the framework of Quality Assurance, in accordance with the requirements of the IQP-Project (Tritt et al., 2007). Ideally, we hoped that the test would use one screening item per syndrome. When a certain amount of symptomatic impairment was documented with an item, additional items could then be used in an adaptive testing mode in order to evaluate the syndrome. However, we encountered several obstacles: To execute such an approach, screening items with the required sensitivity and specificity must be available. Further considerations and empirical assessments proved that this path was not viable within the set parameters and desired quality (Zacharias, 2006). Furthermore it must be noted that not all relevant syndromes or symptoms (e.g. delusions, alcohol abuse or cognitive impairment) lend themselves to self-rating by the patient, which constitutes an additional problem. Taking these limitations into account, we endeavored to create a high quality, practical, and economic self-rating tool for the evaluation of symptoms limited to those psychological syndromes suitable for self-evaluation.

An additional idea during the conceptual phase of this project was the subject of the often mentioned doubts concerning the quality of research based on clinically diagnosed patients. The use of standardized diagnostic instruments, like the Structured Clinical Interview for DSM (SCID; First, Benjamin, Williams & Spitzer, 1997; First, Spitzer, Gibbon & Williams, 1997) or the World Mental Health Composite International Diagnostic Interview (CIDI; World Health Organisation, 1990), is a

solution to this problem, but these interviews have been viewed as involving a high consumption of resources, especially when used in routine care.

#### 1.2 Goals

The development of the ICD-10-Symptome Rating (ISR) also aims at bridging the gap between a comprehensive, symptomatic evaluation of psychological disorders and a valid, standardized ICD-diagnosis. It is planed to use the ISR-results as a foundation to be optionally supplemented with a computer program offering efficient standardized ICDdiagnoses. The ISR represents the first step in this dual tiered project. The goal for the overall project<sup>1</sup> had to be taken into account while formulating the items of the ISR. The primary goal of the questionnaire is the evaluation of the momentary state and changes occurring over time pertaining to psychological symptoms based on self-rating by the patient. Additionally, the ISR performs a screening function for the second tier of the project, which seeks to improve the quality of ICD-10-diagnoses given in routine care and in research. Based on the results of the different ISR modules (subscales), additional items can be offered within the framework of adaptive testing, which will be used to direct the patient and diagnostician through the specific ICD diagnostic algorithms, resulting in standardized ICD-10 diagnoses. While the ISR is available as an independent questionnaire in diverse forms (paper/pencil - version, electronic versions with automated ratings) the second tier of the ICD-10diagnostic will only be available electronically.

<sup>&</sup>lt;sup>1</sup> For additional information on test design and goals please view Tritt et al, 2008

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#### 1.3 Questionnaire design

In compliance with the aforementioned ideas, the ISR is suitable for use with adults and juveniles within the framework of out-patient and inpatient routine care, mental health service research, quality assurance and general research. It is the intention to cover as broad a spectrum of psychological symptoms as possible. The design of the ISR is based on chapter V (F) of the ICD-10 (World Health Organisation, 1992), which has established a worldwide consensus concerning the relevance of specific symptoms for the evaluation of psychological disorders and their diagnostics. During the first phase of the development, the diagnoses stated in the ICD-10 were summarized as syndromes by a panel of five experts. Subsequently, each of these syndromes was rated by these experts to see whether the majority of symptoms, belonging to the specific syndrome, were suitable for reliable, valid and honest selfratings by patients. The experts could assess the suitability of each syndrome with "yes", "undecided" or "no". The results of the expert panel may be viewed in appendix I of the test manual. The syndromes with less than five consistent evaluations by the experts were discussed. With three exceptions all syndromes with a minimum of four "yes" votes were formulated as items for the tool. All three exceptions "nonorganic sleep disorders syndrome" (ICD-10 F51), "Mental and behavioural disorders associated with the puerperium, not elsewhere classified" (ICD-10 F53) and "psychological and behavioural factors associated with disorders or diseases classified elsewhere" (ICD-10 F 54) were deemed to be nonefficient as individual syndromes in the ISR due to symptomatic overlap with other syndromes or the level of medical knowledge required to allow for adequate differentiation with other disorders. The decision was taken to cover these syndromes in the second tier of the overall project, aiming at standardized ICD-diagnostics. Obviously some of the ISR items may

be viewed as first indicators for these three exceptions, i.e. the question concerning a "sleeping disorder" may point to a depression but also to a "nonorganic sleep disorder"; on another line the items for somatoform disorders may be seen as a first indicator for "psychological and behavioural factors associated with disorders or diseases classified elsewhere".

The syndromes, derived in this manner, are noted with their related ICD-10 diagnosis (in parentheses). The syndromes which were deemed suitable according to the criteria mentioned above are marked with "\*\*":

- Organic, including symptomatic, mental disorders syndrome (F0)
- Mental and behavioural disorders due to psychoactive substance use syndrome (F1)
- Schizophrenic, schizotypal and delusional disorders syndrome (F2)
- Manic disorders syndrome (F30)
- Bipolar disorders syndrome (F31)
- \*\*Depressive disorders syndrome (F32-F39)
- \*\*Anxiety disorders syndrome (F40-F41)
- \*\*Compulsive-obsessive disorders syndrome (F42)
- \*\*Severe stress disorder syndrome (F43.0 & F43.1)
- \*\*Adjustment disorders syndrome (F43.2)
- Dissociative disorders syndrome (F44)
- \*\*Somatoform disorders syndrome (F45)

- \*\*Neurasthenia syndrome(F48)
- \*\*Depersonalization syndrome (F48.1)
- \*\*Eating disorders syndrome (F50)
- \*\*Nonorganic sleep disorders syndrome (F51)
- \*\*Sexual dysfunction, not caused by organic disorder or disease syndrome (F52)
- \*\*Mental and hevavioural disorders associated with the puerperium, not elsewhere classified syndrome (F53)
- \*\* Psychological and behavioural factors associated with disorders and diseases classified elsewhere syndrome (F54)
- Abuse of non-dependence-producing substances syndrome (F55)
- Personality disorders syndrome (F60-F61)
- \*\*Enduring Personality changes syndrome (F62)
- Habit and Impulse disorders syndrome (F63)
- \*\*Gender identity disorders, disorders of sexual preferences and psychological and behaviorual disorders associated with sexual development and orientation syndrome (F64-F66)
- Factitious disorders syndrome (F68)
- Mental retardation syndrome (F7)

In the next step, we formulated items for each of the suitable syndromes in accordance with the ICD-10. Like the criteria used for the syndrome ratings, items were formulated only for such symptoms deemed suitable for reliable, valid and honest self-ratings by patients. In order to construct a relatively short instrument, only those items were to be included in the questionnaire, which were frequently specified by those patients experiencing the syndromes in question or which corresponded to the comprehensive diagnostic criteria of a syndrome. This approach also aimed at preventing a leveling of the scale scores, which would occur through inclusion of infrequently experienced symptoms.

The ISR pilot version 1.0 (Zacharias, 2006) included 36 items, consisting of six subscales: 1) depressive syndrome 2) anxiety syndrome, 3) compulsive-obsessive syndrome, 4) somatoform syndrome, 5) eating disorder syndrome and 6) the supplementary items, consisting of a variety of single items having a "screening" function for some further syndromes. One should note that the supplementary items do not represent a singular construct and therefore should not be construed as a scale per se. However, a mean of these items is used in the calculation of the ISR total score, which assess the overall severity of the patient's impairment.

During the first pilot study of the ISR some questions that had been raised during the conceptual phase and item formulation of the questionnaire were examined empirically with N = 109 psychosomatic inpatients from four institutions (Zacharias, 2006). For instance, the symptoms used in the ICD-10 to diagnose a depressive disorder were evaluated as to how often they were actually present in the patients of this sample. Furthermore the possibility of a simultaneous evaluation of ICD-10 diagnostic criteria consisting of two components (e.g. "I lack self-

esteem and self-confidence") was investigated (Bühner, 2011): The two components were combined as one item and also examined individually as two separate items so that all three answers could be correlated with each other.

Within this pilot study the linguistic and contextual comprehensibility of the item formulation (cognitive debriefing) and viability were also checked and improved. In addition, this data was used for a first cross validation with the SCL-90-R (Franke, 20029 and the PHQ-D (Loewe et al., 2002). On the basis of the results of the first pilot study, the tool was refined in a 2.0 version consisting of 29 items. Some scales were slightly modified: For instance the question concerning suicidal tendencies was answered by 88.6 % of the patients diagnosed with a depressive disorder with "does not apply" or "applies a little"; as this item for obvious reasons is deemed too critical from a clinical point of view to do without, it was relocated as a supplementary item. In the meantime, norms have been established for the ISR version 2.0 (Tritt et al., 2010b) based on a comparison of a larger inpatient sample (N = 12,265) from 18 German clinics with a representative sample of adults from the Germany (N = 2,512).

## 2 Description and assessment of the ISR

This chapter describes the ISR. The items of the individual ISR modules, the supplementary items, and the possible responses to the items are presented first. Details regarding the computation of the ISR test scores are then described. As already stated, the supplementary items do not represent an individual construct. They include items, which a) can be ascribed to several syndromes, or b) screening items, which can be used as first indicators generating a more comprehensive search for impairment in other syndromes. Attribution of these items to the ICD-10 code of F-diagnosis can be found in parentheses before each supplementary item.

## 2.1 Description of Items and Scale Classification

The individual items of the ISR are presented sequentially below. Since the ISR results may be used subsequently as the foundation for providing an optional standardized ICD diagnosis, all items of a scale are presented together instead of randomly. As shown below, scale classification of the items is clarified by stating the name of each scale before presenting the corresponding ISR items. Obviously these scale names and therefore the item classifications are not mentioned on the ISR questionnaire.

#### Depressive Syndrome – 4 Items:

(Depression item 01) I feel down and depressed.

(Depression item 02) I no longer enjoy doing things I used to enjoy.

(Depression item 03) When I want to do something I lack energy and get tired quickly.

(Depression item 04) I lack self-esteem and no self-confidence.

#### Anxiety Syndrome – 4 Items:

(Anxiety item 01) I suffer from inexplicable anxiety attacks or fear situations that seem harmless to others.

(Anxiety item 02) Feeling intense anxiety in such harmless situations, I suffer physically from problems, such as rapid heartbeat, shortness of breath, dizziness, chest pains, choking sensations, trembling, inner restlessness, or tension.

(Anxiety item 03) I try to avoid these harmless frightening situations.

(Anxiety item 04) Just thinking about a possible anxiety attack scares me.

#### Compulsive-obsessive Syndrome – 3 Items:

(Compulsive-obsessive item 01) I suffer from recurring, seemingly senseless thoughts or actions which I cannot stop (such as excessive hand washing).

(Compulsive-obsessive item 02) I try to resist recurring, seemingly senseless thoughts and actions, but often don't succeed.

(Compulsive-obsessive item 03) I suffer from upsetting, seemingly pointless thoughts and actions which interfere with my everyday life.

#### Somatoform Syndrome – 3 Items:

(Somatoform item 01) I feed the need to see a doctor about inexplicable physical problems.

(Somatoform item 02) I constantly worry about having a serious physical illness.

(Somatoform item 03) Several doctors have assured me that I'm not seriously ill, but I have a hard time believing them.

#### Eating disorder Syndrome – 3 Items:

(Eating disorder item 01) I control my weight with low-calorie foods, by vomiting, with drugs (such as laxatives), or through extensive exercise.

(Eating disorder item 02) I think a lot about food and worry constantly about gaining weight.

(Eating disorder item 03) I spend a lot of time thinking of ways to lose weight.

#### Supplementary Items – 12 Items:

(Supplementary item 01- Indication for depression or organic, including symptomatic, mental disorders (ICD-10 F0) and others) I have a difficult time concentrating.

(Supplementary item 02 – Indication for depression) I think about committing suicide.

(Supplementary item 03 – Indication for depression and non-organic sleep disorders (ICD10 F51) I have problems sleeping.

(Supplementary item 04 – Indication for depression and others) My appetite is diminished.

(Supplementary item 05 – Indication for organic, including symptomatic, mental disorders (ICD-10 F0) as well as stress) I keep forgetting things.

(Supplementary item 06 – Indication for ICD-10 F43.1) I suffer from recurring dreams or flashbacks of horrible events.

(Supplementary item 07 – Indication for ICD-10 F43.2) I have mental difficulties due to intense everyday stress (such as being seriously ill, losing my job, or separating from my partner).

(Supplementary item 08 – Indication for ICD-10 F48.1) I no longer perceive my feelings and experiences as my own.

(Supplementary item 09 – Indication for ICD-10 F48.1) The people and environment around me suddenly appear unreal, distant, and lifeless to me.

(Supplementary item 10 – Indication for ICD-10 F52) I have difficulties engaging in sexual activities.

(Supplementary item 11 – Indication for ICD-10 F62) I've changed significantly over the past years after having experienced an extremely stressful event (such as a head injury, a wartime experience, or abuse).

(Supplementary item 12 – Indication for ICD-10 F65/F66) I have a problem with my sexual preferences.

#### 2.2 Possible Responses to the Items

The symptoms rated by the ISR are not assessed in a binary fashion (like in the ICD-10: symptom present vs. not present) but by severity:

0 = does not apply

- 1 = applies a little
- 2 = applies quite a bit
- 3 = applies to a great extent

4 = applies extremely.

#### 2.3 Computation of the scale scores

To calculate the scores of the individual scales, the values ascribed to each item response (note "Possible Responses to the items, § 2.2) are added to generate a sum score . This sum score is then divided by the summands (number of items of this scale), resulting in a mean value of the items.

#### Example:

Depression score = (Depression item 1 + Depression item 2 + Depression item 3 + Depression item 4) / 4

To calculate the ISR total score, first the scores of the individual syndrome scales are again summed up. In addition to this, a mean of the supplementary items is calculated. Due to the large number of supplementary items and the relevance of psychological co-morbidity, the mean of the supplementary items is multiplied by the factor 2 and added to the sum of the ISR syndrome scales. This sum score is then divided by the amount of summands, leading to the ISR total score. The loading of the supplementary items was discussed critically by the ISR task force<sup>2</sup>. The possibilities of load factors ranging from one to three were looked at and viable arguments found in favor of each of the solutions. However, the task force decided in favor of the load factor two as a compromise. As

<sup>&</sup>lt;sup>22</sup> Members of the ISR Task Force: Prof. Dr. Markus Bühner (Munich), Dr. Friederich von Heymann (Munich), Prof. Dr. Burghard Klapp (Berlin), Prof. Dr. Thomas Loew (Regensburg), Dipl.-Psych. Thomas Probst (Regensburg), Prof. Dr. Wolfgang Söllner (Nuremberg), Prof. Dr. Karin Tritt (Munich/Regensburg), Prof. Dr. Michael Zaudig (Munich).

each syndrome scale was deemed to have the same value and as there were no convincing arguments available why a syndrome should be loaded heavier than others (as for instance in the SCL-90-R) all individual syndrome scales are calculated with the load factor of one in the ISR total score.

Total score = (mean value depression scale + mean value anxiety scale + mean value compulsive-obsessive scale + mean value somatoform syndrome scale + mean value eating disorder scale + mean value supplementary items + mean value supplementary items) / 7

## 2.4 Handling missing values

If an item of a <u>syndrome scale</u> is not answered (i.e. depression, anxiety-, compulsive-obsessive, somatoform or eating disorder scale) 25% to 33 % of the total information is missing. It is therefore deemed imperative that all items of the syndrome scales must be answered, if the syndrome scales are to be viewed and interpreted as independent modules.

Calculation of the total score is described above (view § 2.3). <u>Mean</u> <u>scores</u> are generated even if an item of a syndrome scale is missing, but <u>no more than one item per syndrome scale may be missing and the</u> <u>maximum permissible total of missing items is two</u>, including the supplementary items).

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