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Zusammenfassung

Die ‚International Classification of Functioning, Disability and Health' (ICF) ist eine Klassifikation für Alltagsfunktionen und Gesundheit in der Rehabilitation und stellt außerdem einen gemeinsamen Bezugsrahmen für alle Gesundheitsberufe dar. Kürzlich wurde die ICF vom World Health Assembly verabschiedet. Damit sind alle Mitgliedstaaten der WHO aufgefordert, die ICF zu implementieren. Wenn ein bio-psycho-soziales Denk-Modell in der Rehabilitation zur Anwendung kommt, ist es notwendig die Perspektive der Patienten zu berücksichtigen. Das übergeordnete Ziel dieser Doktorarbeit war die Konzeptualisierung der Patientenperspektive im Bezug zur ICF. Diese Arbeit besteht aus drei wissenschaftlichen Artikeln, die hintereinander präsentiert werden.

Im ersten Artikel wurden klinische, tätigkeitsbezogene Instrumenten, die in der Ergotherapie im Bereich der Rheumatologie und Rehabilitation von Erwachsenen verwendet werden, zur ICF in Beziehung gesetzt. 7 Instrumente wurden in der Literatur identifiziert und analysiert. Nur ein Instrument, nämlich das Canadian Occupational Performance Measure (COPM), berücksichtigt die Perspektive der Patienten auf eine klienten-zentrierte Weise. Außerdem ergab die Analyse, dass alle 7 Instrumente nicht auf den Gesundheitszustand Bezug nehmen, sie sind also ethiologisch neutral.

Im zweiten Artikel wurden konzeptionelle Modelle aus der Ergotherapie zur ICF in Beziehung gesetzt. 3 konzeptionelle Modelle wurden in der Literatur identifiziert. Die Analyse ergab, dass zwei Konzepte aus den Modellen nicht in der ICF abgebildet werden: 'Erfahrung des Umgebungs-Raumes' und ‚Gewohnheit'. Das Konzept 'Ruhe' stellt in der ICF eine ‚Körperfunktion' dar und wird im Gegensatz dazu in den konzeptionellen Modellen als ‚aktive Entspannungstätigkeit' definiert.

Um die ICF in der klinischen Praxis umzusetzen, wurden ‚Comprehensive ICF Core Sets' für verschiedene Gesundheitszustände entwickelt, zum Beispiel für rheumatoide Arthritis (ICF RA Core Set). Das ICF RA Core Set soll alle ICF Kategorien beinhalten, die für die Alltagsfunktion von Patienten mit rheumatoider Arthritis wichtig sind. Es wurde von Experten in einem strukturierten Konsensusprozess entwickelt. Dabei entstand eine vorläufige Version des ICF RA Core Set, die jetzt validiert und weiterentwickelt werden soll. Das Ziel des dritten Artikels war es, das ICF RA Core Set aus der Patientenperspektive zu validieren. Ein qualitativer Forschungsansatz wurde verwendet. 63 (83%) der ICF Kategorien auf der zweiten Ebene aus dem ICF RA Core Set wurden auch in den Interviews gefunden. 25 zusätzliche ICF Kategorien, die nicht Teil der vorläufigen Version des ICF RA Core Set sind, wurden in der Analyse der Interviews identifiziert. Die Validität des ICF RA Core Set aus der Patientenperspektive ist gegeben, jedoch sollten die zusätzlich genannten Kategorien für die Weiterentwicklung berücksichtigt werden.

Abstract

The overall aim of the International Classification of Functioning, Disability and Health (ICF) is to provide a classification for functioning and health in rehabilitation and a common framework for all health professions. The ICF has recently been approved by the World Health Assembly. All member countries of WHO are therefore requested to implement the ICF. Especially within the bio-psycho-social model in rehabilitation, it is important for health professionals to consider the perspectives of patients. The objective of this thesis was therefore to conceptualise the patient perspective of the ICF. The thesis consists of the three articles presented in consecutive order.

The objective of the first article was to explore the relationship of clinical, occupation-based instruments which are used in occupational therapy in adult rheumatology and musculoskeletal rehabilitation to the ICF. 7 instruments were identified in a literature review and analysed. Only one instrument, the Canadian Occupational Performance Measure (COPM) addresses the patient perspective in a client-centred way. All 7 instruments were found to be etiologically neutral as they do not bridge to the health condition that causes the disability.

The objective of the second article was to explore the link of conceptual occupational therapy models to the ICF. 3 conceptual occupational therapy models were identified in the literature. The concepts ‘felt space’ and ‘habituation subsystem’ were found to be not covered by the ICF. ‘Rest’ was found to be a *body function* in the ICF, whereas ‘rest’ has an *activity* perspective in the conceptual occupational therapy models.

In order to apply the ICF in clinical practice, Comprehensive ICF Core Sets have been developed for various different health conditions. The Comprehensive ICF Core Set for rheumatoid arthritis (ICF RA Core Set) is one example. The ICF RA Core Set should include all relevant ICF categories for the functioning of people with rheumatoid arthritis. It was developed by experts in a formal decision-making and consensus process by integrating evidence gathered from preliminary studies. The consensus process revealed a current, preliminary version of the ICF RA Core Set which now needs to be validated and further developed. The objective of the third article was to validate the ICF RA Core Set from the patient perspective. A qualitative research approach was used. 63 (83%) of the 76 second-level categories from the ICF RA Core Set were also found in the interviews. 25 second-level categories which are not part of the current ICF RA Core Set were identified in the interviews. The validity of the ICF RA Core Set was supported by the perspective of individual patients. However, some additional issues raised in this study but not covered in the current ICF RA Core Set need to be investigated further.

Content

Introduction to the background and the objectives of the thesis

Introduction to the background

While the focus of the medical model is to treat a specific disease condition of an ill person, the bio-psycho-social model in health care aims at a holistic, multidimensional and multidisciplinary understanding of health and health related conditions. The bio-psycho-social model is increasingly applied in health care systems all over the world, especially in rehabilitation medicine. In a bio-psycho-social understanding of health, the ability of the individual to engage in activities and to participate in society determine the daily functioning of the individual, as well as a possible disability (1).

There have been two major conceptual frameworks in the field of functioning and disability: the international classification of impairment, disability and handicap (ICIDH) (2) and the 'functional limitation' or Nagi, framework (3). Contrary to the ICIDH, the Nagi framework was not accompanied by a classification. Contrary to both the ICIDH and the Nagi framework, the current framework of disability – the WHO International Classification of Functioning, Disability and Health (ICF) now focuses on function instead of impairment. The holistic, bio-psycho-social approach in rehabilitation medicine is addressed by the ICF. The ICF is being increasingly applied in clinical research and clinical practice in rehabilitation all over the world. The ICF has recently been approved by the World Health Assembly. All member countries of WHO are therefore requested to implement the ICF (4).

The overall aim of the ICF classification is to provide a unified and standard language for the description of health and health-related conditions in rehabilitation and a common framework for all health professions. The ICF has two parts, each containing separate components. Part 1 covers **functioning** and **disability** and includes the components: *body functions* (b) and *body structures* (s) and *activities and participation* (d). Part 2 covers **contextual factors** and includes the components: *environmental factors* (e) and *personal factors* (Figure 1) (4). The latter category is not "coded" but rather added to the category coding is a verbal description.

Each component consists of chapters which then consist of categories. Within the component *activities and participation*, *Chapter 5 Self-care* includes the categories *d510 Washing oneself* (second-level) and *d5100 Washing body parts* (third level) among many others (Figure 1).

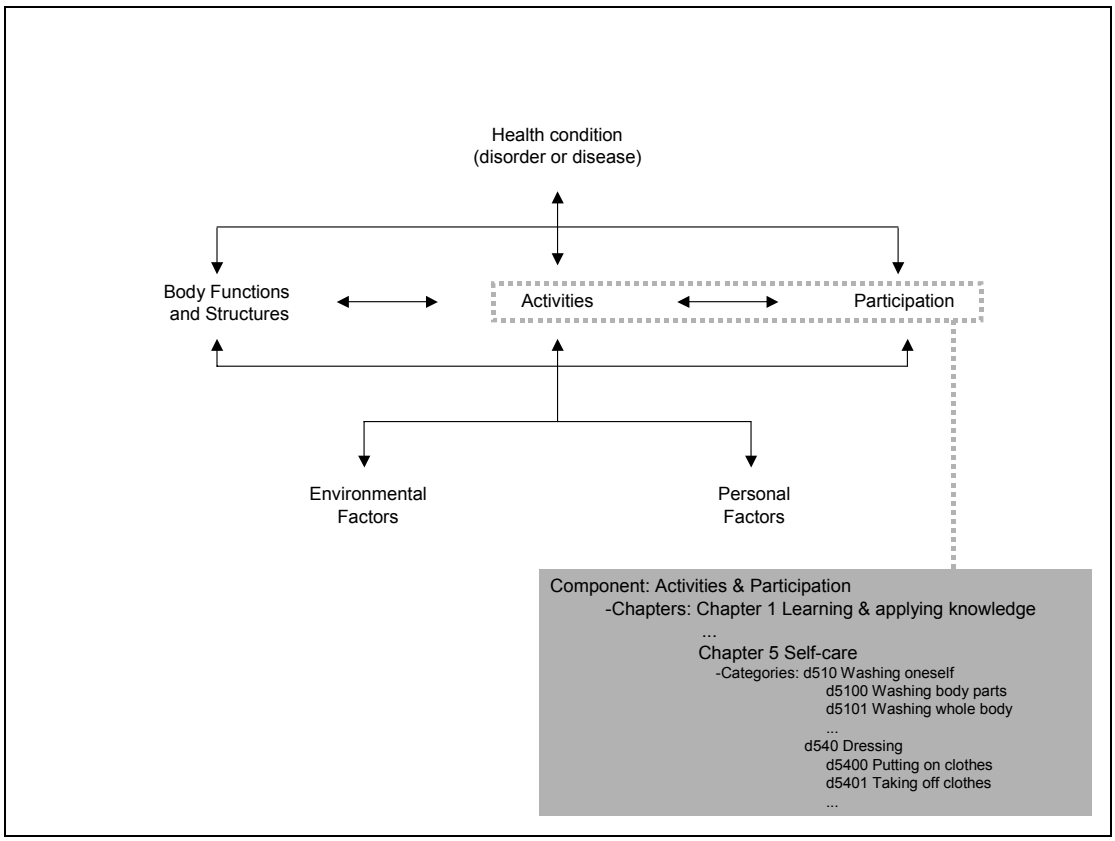

Figure 1. The model of the ICF.

‘Activity’ in the ICF is defined as the execution of a task or action by an individual, whereas ‘participation’ is the person’s involvement in a life situation (4). Activity and participation are core aspects of occupational therapy.

Occupational therapy is one discipline within rehabilitation medicine. Occupational therapists understand activity and participation from an occupational perspective: Occupational therapists consider meaningful occupations of individuals as a contribution to health and apply these meaningful occupations in their treatment. Occupation includes everything that a human being does, such as physical, mental, social and rest occupations, occupations for productivity, leisure and self-care. Occupations and activities which are used in therapy should be meaningful from the perspective of the patients (5-9).

The thesis consists of the three articles for publication of which the aims are described below. The articles are presented in consecutive order. In addition, two appendices are included. Both appendices refer to the third article. The first appendix shows the results of the linking of the concepts to the ICF in the qualitative study. The second appendix gives an example of one transcribed interview.

Introduction to the objective of article 1

Measurement of outcome is necessary to prove effectiveness of treatment. Cost-effectiveness is currently becoming one of the key-terms in health care systems all over the world. Outcome in rehabilitation is assessed differently by different professional groups. Standardized and widely accepted instruments exist to measure the outcome of rehabilitation from the perspective of each professional group.

In WHO member countries, all professions in rehabilitation medicine are requested to use the ICF. In order to use the ICF as common framework for classification of functioning, disability and health-related conditions and to implement it in clinical practice, the link between the ICF and the instruments which are used to measure outcome must be explored. It is important to know which ICF categories are addressed by each item of an instrument (10). If health professionals know which ICF categories are measured by which instrument, they are able to select an appropriate instrument to assess a specific category of functioning.

Furthermore, the link between the ICF and instruments which are used in practice could improve the communication and understanding between health professionals because the ICF is intended to be used as a unifying model and common language in all health professions. It could show the focus of some instruments which are specific to a certain professional group. It could also help to clarify the perspective of different health professionals working together in multidisciplinary teams. Understanding each others' focus and perspective could enhance the quality of multidisciplinary team care in rheumatology.

The objective of the first article was to explore the relationship of clinical, occupation-based instruments that are used in occupational therapy in adult rheumatology and musculoskeletal rehabilitation to the ICF.

Introduction to the objective of article 2

Multidisciplinary teams in rehabilitation consist of different health professionals which all together provide the necessary holistic perspective of the patient's functioning and health. These professionals are nurses, medical doctors, physiotherapists, psychologists, medical social workers, occupational therapists and others. Even if all apply the ICF as a common framework, they still have their own professionals

perspectives and underlying conceptual theories and models (5-9). Models are simplifications of complex theoretical relationships. The different professional groups need therefore to examine the content of their underlying conceptual theories and models and relate them to the ICF.

The objective of the second article was to explore the link of conceptual occupational therapy models to the ICF and to compare the content of these models based on the ICF and with the ICF.

Introduction to the objective of article 3

In order to apply the ICF in clinical practice, Comprehensive ICF Core Sets have been developed for various different health conditions. The Comprehensive ICF Core Set for rheumatoid arthritis is one example. Rheumatoid arthritis is a chronic disabling disease (11) which is often associated with inability to conduct occupations, such as paid work and other daily activities, ultimatively leading to the experience of limitation in the patients' daily activities and restriction in societal participation (12-19). People with rheumatoid arthritis experience a decrease in overall functional ability and quality of life (12) and a greater loss of their life activities than people without rheumatoid arthritis (17). The Comprehensive ICF Core Set for rheumatoid arthritis should include all relevant ICF categories for functioning of people with rheumatoid arthritis by representing the typical spectrum in functioning of these patients.

The Comprehensive ICF Core Set for rheumatoid arthritis was developed by experts in a formal decision-making and consensus process integrating evidence gathered from preliminary studies. The experts consisted of rheumatology health professionals. Preliminary studies included a Delphi exercise, a systematic review,

and an empiric data collection (20). The consensus process revealed a current, preliminary version of the Comprehensive ICF Core Set for rheumatoid arthritis. The current, preliminary version of the Comprehensive ICF Core Set for rheumatoid arthritis now needs to be validated and further developed.

One aspect in this validation process is to explore the patient perspective. In order to explore the perspective of patients, a qualitative research approach was considered most appropriate. When measuring and assessing daily functioning in people with rheumatoid arthritis from a holistic bio-psycho-social perspective in rehabilitation, it is important to include the patient perspective because personal values for outcomes vary between and within patients and professionals (21, 22). Qualitative methodology provides the possibility to explore the perspective of those who experience the disease (the patient perspective) (23, 24).

Comprehensive ICF Core Sets have been developed for other chronic diseases apart from rheumatoid arthritis and preliminary versions have been established. The next step is the validation. The Comprehensive ICF Core Set for rheumatoid arthritis is the first to undergo validation. Therefore, the present study is also considered to be a methodological pilot study for the validation and development of other Comprehensive ICF Core Sets for other diseases and health conditions.

The objective of the third article therefore was to validate the current version of the Comprehensive ICF Core Set for rheumatoid arthritis from the patient perspective using a qualitative approach.

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Content comparison of occupation-based instruments in adult rheumatology and musculoskeletal rehabilitation based on the International Classification of Functioning, Disability and Health (ICF)

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Abstract

Objective: To compare the content of clinical, occupation-based instruments that are used in adult rheumatology and musculoskeletal rehabilitation in occupational therapy based on the International Classification of Functioning, Disability and Health (ICF).

Methods: Clinical instruments of occupational performance and occupation in adult rehabilitation and rheumatology were identified in a literature search. All items of these instruments were linked to the ICF categories according to 10 linking rules. On the basis of the linking, the content of these instruments was compared and the relationship between the capacity and performance component explored.

Results: The following 7 instruments were identified: The Canadian Occupational Performance Measure, the Assessment of Motor and Process Skills, the Sequential Occupational Dexterity Assessment, the Jebson Taylor Hand Function Test, the Moberg Picking Up Test, the Button Test and the Functional Dexterity Test. The items of the 7 instruments were linked to 53 different ICF categories. 5 items could not be linked to the ICF. The areas covered by the 7 occupation-based instruments differ importantly: The main focus of all 7 instruments is on the ICF component *activities and participation*. *Body functions* are covered by 2 instruments. 2 instruments were linked to 1 single ICF category only.

Conclusion: Clinicians and researchers who need to select an occupation-based instrument must be aware of the areas that are covered by this instrument and the potential areas that are not covered at all.

Introduction

While the focus of the medical model is to treat a specific disease condition of an ill person, the bio-psycho-social model in health care aims at a holistic, multidimensional and multidisciplinary understanding of health and health related conditions. The bio-psycho-social model is increasingly applied in health care systems all over the world, especially in rehabilitation medicine (1). In a bio-psycho-social understanding of health, the ability of the individual to engage in activities and to participate in society determine the daily functioning of the individual, as well as a possible disability.

There have been two major conceptual frameworks in the field of functioning and disability: the international classification of impairment, disability and handicap (ICIDH) (2) and the 'functional limitation' or Nagi, framework (3). Contrary to the ICIDH, the Nagi framework was not accompanied by a classification. Contrary to both the ICIDH and the Nagi framework, the current framework of disability – the WHO International Classification of Functioning, Disability and Health (ICF) now focuses on function instead of impairment. The holistic, bio-psycho-social approach in rehabilitation medicine is addressed by the ICF (4). The ICF is being increasingly applied in clinical research and clinical practice in rehabilitation all over the world (1). The overall aim of the ICF classification is to provide a unified and standard language for the description of health and health-related conditions in rehabilitation and a common framework for all health professions (4). The ICF has two parts, each containing separate components. Part 1 covers **functioning** and **disability** and includes the components: *body functions* (b) and *body structures* (s) and *activities and participation* (d). Part 2 covers **contextual factors** and includes the components: *environmental factors* (e) and *personal factors* (Figure 1). The latter category is not

“coded” but rather added to the category coding is a verbal description. ‘Activity’ is defined as the execution of a task or action by an individual in the ICF, whereas ‘participation’ is the person’s involvement in a life situation (4).

Activity and participation are core aspects of occupational therapy. Occupational therapists understand activity and participation from an occupational perspective: Occupational therapists consider meaningful occupations of individuals as a contribution to health and apply these meaningful occupations in their treatment (5) (6-8). Occupation includes everything that a human being does, such as physical, mental, social and rest occupations, occupations for productivity, leisure and self-care. Nelson (9) describes occupation as the relationship between occupational form (the environmental-physical and socio-cultural dimension) and occupational performance (the active doing of the individual). Occupational form is related to meaning and occupational performance is linked to purpose.

All health professionals are under increasing pressure to evaluate their treatment and to produce studies about evidence and efficacy in order to justify their interventions. To explore the relationship between existing occupation-based instruments and the ICF is of utmost importance for occupational therapists and other health professionals in adult rheumatology and rehabilitation when they search for an outcome measure for an occupation- or activity-based intervention. If the ICF is used as a common framework and classification for rehabilitation intervention and care in the future, health professionals must know how they can assess the categories in the ICF which they target in their intervention. If clinicians search for instruments for assessing specific ICF categories, they must know which ICF categories are covered by which instrument. By linking instruments to the ICF, further information about the

instruments is generated which could be used to for further development. In adult rheumatology and musculoskeletal rehabilitation, the relationship between occupation-based instruments and the ICF has not been explored so far.

The link between instruments which are used in practice and the ICF could improve the communication and understanding between health professionals as the ICF is intended to be used as a unifying model and common language in all health professions. It could show the specific focus of some instruments which are used by certain professional groups. It could also help to clarify the focus and perspective of different health professionals working together in multidisciplinary teams. It is important that different health professionals are familiar with each other's focus and perspective. Understanding each others' focus and perspective could enhance the quality of multidisciplinary team care in rheumatology.

The objective of this paper was to explore the relationship of clinical, occupation-based instruments that are used in adult rheumatology and musculoskeletal rehabilitation in occupational therapy to the International Classification of Functioning, Disability and Health (ICF). The specific aims were to examine the content of these instruments by linking them to the ICF, to explore which concepts of the instruments were covered by the ICF, to compare the content of these instruments based on the ICF and to evaluate the differences between these instruments.

Methods

Search strategy

A structured literature search was undertaken. The following databases were used for the literature search: CINAHL R (database) (1982-1998 and 1999-2003), AMED (1985-2003), Medline (1967-2003), OTD-Base (www.otdbase.org) and the literature register of the Vienna University ALEPH. The following key words were used in combinations: instrument, measure, assessment, functional assessment, outcome, occupational therapy, occupational performance, occupation, activity, muscoloskeletal care, rehabilitation and rheumatology. If an instrument was found in the literature, specific articles on validity and reliability of the instrument were searched. If the instrument was not validated, the instrument was not included.

The criteria for inclusion of the instruments were as follows: [1] clinical instruments that assess occupation or occupational performance or functional performance, [2] established validity, [3] commonly used in adult rheumatology and/ or musculoskeletal rehabilitation by occupational therapists, [4] publication in a peer-reviewed journal, [5] existence of an English version of the instrument.

Whether an instrument was valid or not was judged according to whether validity of the instrument was established in the literature. Every instrument had to be validated in rheumatology and/ or musculoskeletal rehabilitation. Instruments that intend to measure functional performance only (as described by the authors of the measurement) were also included, if they relate to a task because they are commonly used in occupational therapy in adult rheumatology and/ or musculoskeletal rehabilitation in practice. Whether the instruments were used commonly in rheumatology and musculoskeletal rehabilitation was judged according

to the opinion of three expert occupational therapists and two expert rheumatologists who work in different settings in Europe.

We chose to include not only measures of occupational performance but also measures of functional performance since they provide important information regarding limitations in occupational performance. According to Townsend (8) occupational performance can be defined as the result of the dynamic relationship between the person, the environment and the occupation. It refers to the ability to choose and satisfactorily perform meaningful occupations that are culturally defined, and appropriate for looking after one's self, enjoying life, and contributing to the social and economic fabric in the community. Occupations are groups of activities and tasks of everyday life.

Functional performance can be defined as the ability to conduct a specific task which could be related to daily living activities, for example picking-up small objects or writing a sentence. It is important to note that measures of occupational performance and measures of functional performance typically differ in an important aspect. While measures of occupational performance refer to what an individual does in his or her current environment, measures of functional performance refer to an individual's ability to execute a task or an action in a 'standardized environment' (4) (page 15). This difference is addressed in the ICF in the distinction of performance and capacity.

Linking to the ICF

In the ICF classification, the letters b, s, d and e, which refer to the components of the ICF, are followed by a numeric code starting with the chapter number (one digit), followed by the second level (two digits) and the third and firth levels (one digit each). The component letter with the suffix of one, three, four or five digits corresponds to

the code of the so-called categories. Categories are the units of the ICF classification. Within each chapter, there are individual two-, three- or four level categories. An example selected from the component *body functions (b)* would result in the following code: '*b2 sensory functions and pain'* is the first level, '*b280 sensation of pain'* represents the second level, '*b2801 pain in body part'* corresponds to the third level and '*b28013 pain in back'* to the fourth level.

Within each component, the categories are arranged in a stem/ branch/ leaf scheme. Consequently, a lower level category shares the higher level categories to which it belongs, i.e., the use of a lower level (more detailed) category automatically implies that the higher level category is applicable, but not the other way round. At the end of each embedded set of third- or fourth-level categories and at the end of each chapter, there are 'other specified' categories (uniquely identified by the final code 8) and 'unspecified' categories (uniquely identified by the final code 9). These unspecified categories were used if the item in the measurement was not explicitly specified.

In order to compare the content of the identified instruments on the basis of the ICF and to examine the differences, every item of the instruments was linked to the appropriate ICF category. Linking rules have been developed to link health-status measures to the ICF in a specific and precise manner (10). On the basis of these linking rules each item of an instrument should be linked to the most detailed ICF category. If the content of an item was not explicitly named in the corresponding ICF category, the 'other specified' option at the third and fourth coding level of the ICF classification was linked. If the content of an item was more general than the corresponding ICF category, the code of the higher level was linked. If an item was not contained in the ICF classification, this item was assigned *nc* (not covered) (10).

In addition, for each item linked to *category d* (activity and participation category), it was examined whether the item refers to a task (capacity) or to life-involvement (performance) according to the ICF model. Capacity refers to an individual's ability to execute a task or an action in a 'standardized environment' and performance describes what an individual does in his or her current environment (4) (page 15). The judgement was made by two health professionals according to the description or definition of the item of the instrument in the literature.

Consensus between health professionals was used to decide which ICF category should be linked to each item of the instruments. To resolve disagreement between the two health professionals concerning the selected categories, a third person trained in the linking rules was consulted. In a discussion led by the third person, the two health professionals that linked the item stated their pros and cons for the linking of the concept under consideration to a specific ICF category. Based on these statements, the third person made an informed decision.

Results

Literature search

Literature was included for further analysis if it either described an instrument used in rheumatology and musculoskeletal rehabilitation based on occupation, occupational and/ or functional performance in detail or if it described its validity or reliability. Books were only included if they referred to a publication in a peer reviewed journal. From the literature review, 24 relevant articles and 3 books were selected for further analysis.

The following instruments were identified in the analysed articles and selected for inclusion for our study: Canadian Occupational Performance Measure (COPM), Assessment of Motor and Process Skills (AMPS), Sequential Occupational Dexterity Assessment (SODA), the Jebsen-Taylor Hand Function Test (JT-HF), the Moberg Picking Up Test (MPUT), the Button Test (Button), and the Functional Dexterity Test (FDT). The FDT was included as an example for other pegboard tests that measure exactly identical functions, e.g. the Purdue Pegboard Test (11). The FDT was chosen as an example for other pegboard tests because a peer-reviewed publication on validity in musculoskeletal rehabilitation was only found for the FDT.

Instruments

Canadian Occupational Performance Measure (COPM)

The COPM evaluates the performance, satisfaction and importance in up to five 'problems' that the individual has to identify in the areas of self-care, productivity and leisure. Each area is divided into three more specific items. Individuals rate their performance and satisfaction on the self-selected activities on a 10-point Likert scale. The COPM is a semi-individualized, client-centred instrument that is based on the underlying Canadian Model of Occupational Performance. The test-retest reliability was .63 for performance and .84 for satisfaction. Validation studies have been done in a variety of clinical fields. Average time to administer is 40 min (12-15).

The Assessment of Process and Motor Skills (AMPS)

The AMPS evaluates motor and process skills (in two different scales) and assesses their impact on clients' ability to perform personal and instrumental activities of daily living. The AMPS is a semi-individualized, client-centred, task-oriented functional assessment. The client must select an activity from a specific list of calibrated

activities. Reliability has been demonstrated (intra-rater r=.93, test-retest motor r=.88 and process r=.86). Studies show validity in adult rehabilitation and cross-cultural validity. Average time to administer is 30 - 60 min (16-22).

Sequential Occupational Dexterity Assessment (SODA)

The SODA is an instrument designed specifically for persons with rheumatoid arthritis to measure bimanual hand dexterity. The intention is to measure the consequences of the disease on functional performance and activity. The SODA includes 12 task items, e.g. writing a sentence (item 1) and pouring water into a glass (item 10). Test-Retest reliability was found to be .93. Validity was demonstrated in rheumatology in relation to demographic variables and the disease activity score (DAS). Average time to administer is 20 min. A short version with six items exists (23; 24).

The Jebsen-Taylor Hand Function Test (JT-HF)

The JT-HF is a hand function test with seven items. It is a unilateral test because it tests one hand after the other. It includes items such as simulated feeding (item 4) and picking up large light objects (item 6). Reliability was found to be .60 to .99. The JT-HF has been validated in adult rheumatology and rehabilitation. Average time to administer is 60 min (25).

The Button Test

The Button Test is an instrument that measures sensory and motor hand function. It is a bilateral, but single-handed test. It assesses the ability to manipulate and un-button and re-button 5 buttons (with one hand at a time) while the time is taken with a stop watch. The standard protocol requires a standardized button board that has to be placed on the table in front of the individual. Reliability was found to be .80.

Validity has been established in rheumatology. Average time to administer is 10 min (26-28).

Moberg Picking Up Test (MPUT)

MPUT is a unilateral measurement of hand function. It assesses the picking up function of both hands. MPUT consists of 12 small objects which have to be picked up with one hand while time is taken with a stop watch. A standard protocol has been established and intra-rater reliability has been found to be .87. When administered blindfolded, MPUT has been described to assess sensory function grip of the hand (29), when administered with open eyes validity was demonstrated in persons with inflammatory joint diseases in comparison with consensus core set measures in rheumatology. Average time to administer is 5 min (30).

The Functional Dexterity Test (FDT)

The FDT measures hand dexterity on one specific item: to take 16 pegs out of a board, turn them once and place then again back in their place in the board. The time is taken with a stop watch. Interrater reliability was found to be .62 for uninjured and .82 for injured hands. Validity was established in adult rehabilitation (31).

Linking to the ICF

The 86 items of the seven instruments were linked to 53 different ICF categories. Items were linked to eight categories of the component *body functions* and to 45 categories of the component *activities and participation*. No items were linked to the components *body structures*, *environmental factors* and *personal factors*. Five items from the AMPS could not be linked to the ICF and were coded *nc* (Table 1). These

five items included the following: ‘Calibrates’ and ‘flows’ from the motor skill items, ‘restores’, ‘heeds’ and ‘benefits’ from the process skill items.

Table 1 shows the comparison of the items in the instruments using the ICF categories as a reference and ordered by component. The numbers in the table represent the frequencies with which the ICF categories were addressed in the different instruments. A higher number indicates that several items from a specific instrument were linked to the same ICF category. For example, the category *b1643 cognitive flexibility* was linked to the following three items in the AMPS: ‘navigates’, ‘accommodates’ and ‘adjusts’ in the process skill items.

The areas covered by the occupation-based instruments differ importantly. *Body functions* are covered only in the AMPS and the SODA, whereby the SODA specifically covers *b2801 pain in body part* and the AMPS addresses a broader number of functions including mental and mobility related functions. All the other instruments focus on the component *activities and participation*. Items from four of these instruments, JT-HF, MPUT, Button and FDT, were linked to categories from *chapter 5 mobility*. Button and MPUT were linked to one single ICF category. The JT-HF and the SODA cover a broader spectrum in chap*ter 5 mobility.* Especially, the categories *d440 fine hand use* or *d445 hand and arm use* are addressed.

The COPM covers a large spectrum in the *chapters 5 (self-care), 6 (domestic life), 8 (major life areas* that includes *education, work and employment, economic life*) and *9 (community, social and civic life)*. For 21 items of the COPM a performance perspective was differentiated, for 4 items a capacity and performance perspective was attributed, all other items were found to have a capacity perspective (Table 1).

The linking table of the COPM was included as an example for the linkage procedure (Table 2). The SODA covers a smaller spectrum than the COPM, but seems to be a usable complement for the COPM as it covers exclusively other categories than the COPM. The SODA was linked to a larger spectrum of ICF categories than the JT-HF. Nevertheless, both instruments address concepts within the *chapter 5 mobility*.

Discussion

The ICF covers the concepts that are represented by these 7 occupation-based instruments in musculoskeletal rehabilitation. It was possible to link all items to the ICF, except 5 items that were not covered. The perspective of capacity or performance could be attributed to every item from the *category d* (activity and participation) of the ICF.

All 7 instruments were found to be etiologically neutral as they do not bridge to the health condition that causes the disability. For example, the first item in the COPM is *personal care*. The COPM does not question about the reason for the disability, nor about an underlying health condition. The item was linked to the *chapter d self-care* on the activity and participation level of the ICF. The first item of the SODA is writing a sentence which was linked to d170 writing. The patient has to rate the ability and the level of pain when performing the task, but there is no question about the causal relationship to the underlying health condition. This is different to condition specific instruments as they often bridge between an impairment and a health condition, such as for example the self-administered WOMAC-Questionnaire for hip and knee osteoarthritis: the item B.1 in the WOMAC asks about morning stiffness associated *to the left knee*. This item bridges to the health condition '*osteoarthritis (in the left knee)'* and is thus specific for this health condition. Based on these results, the ICF proved

to be useful for examining these instruments because it provides future methodological suggestions. It may be interesting to repeat this kind of analysis for instruments which are used in other fields of occupational therapy and which are based on occupational or functional performance in order to find out whether all these instruments are disease neutral. Our hypothesis is that if occupational therapists focus on the occupational problems of their patients independent of their health condition, they might need disease neutral assessments. Further research is suggested.

The content of the occupation-based instruments differs importantly (table 1) and some areas are not covered at all. No item was found to be related to the ICF chapter *personal factors*. *Environmental factors* are included in part 2 *contextual factors* in the ICF. In all seven measurements, environmental factors are not explicitly covered. For example, the COPM does not explicitly ask about the environmental factors. It may be argued that environmental factors are implicitly represented in the COPM items because the underlying theoretical model of occupation, the Canadian Occupational Performance Model, includes environmental factors as an important component of meaningful occupation. The manual of the COPM suggests that it is essential for the therapist to use their interview skills when performing the COPM. The COPM is understood as initial assessment for the therapeutic process that focuses on the underlying factors for the problem areas (14). From this perspective, it could be argued that some of the items might target environmental factors additionally: for example the item 'community management: transportation' in addition to *d4709 using transportation, unspecified,* the item could as well be linked to the environmental factor *e5409 transportation services, systems and policies, unspecified* as a basis and a relevant for using transportation (in the *activity and participation* component).

But because the environmental factors are not explicitly addressed in the instrument, the item was only linked to the *activity and participation* component of the ICF in our study. Environment is a major contribution to occupation. It can be discussed whether the measurement of occupation or occupational performance should include the *environmental factors* explicitly to cover a broader perspective of occupation and to guarantee a certain aspect of reliability of its use. However, the COPM is ambiguous in a certain aspect: a clients who identifies a present problem in the COPM might relate the problem to an environmental component or a personal component due to the individualised nature of the problem. Because of this ambiguity, we decided according to the linking rules to link only what was explicitly mentioned in the COPM.

To make a distinction between capacity and performance for each category is important for health professionals if they want to differentiate between occupational and functional performance. Only the COPM was found to address the performance component of the ICF as all other instruments involve the execution of tasks in test environments. Instruments that focus only on specific areas of functional performance (such as MPUT, Button, FDT) cover only a very narrow and specific field of ICF components.

Pegboard tests do not reflect occupation. However, at least according to the definition of the ICF, pegboard tests refer to activities. Accordingly, we linked the FDT to the ICF categories *d4400 Picking up* and *d4402 Manipulating*. The intuitive objection against the attribution of the pegboard test comes from the fact that the patient performs the task in a test environment which refers to a standard situation and not to the performance in real life. In the ICF, the pegboard test therefore describes a capacity rather than a performance. Such instruments could be used to

assess the specific category that is covered. These instruments might be adequate measures for the underlying components of occupational performance as a possible outcome of treatment. In order to cover a broader spectrum of ICF categories, one could use the COPM in addition to instruments that assess underlying functions for occupational performance such as the AMPS. The AMPS covers a variety of body functions and could be used as an instrument if this is considered a relevant outcome for the treatment.

The AMPS uses a task that the individual has to perform in order to evaluate the motor and process skill items. Different from the COPM, where the items were attributed a participation perspective, the items in the AMPS were linked to the activity perspective only because in administering the AMPS the therapists sets up the environment either in the clinic or at home, the individual has to perform the chosen task.

In our linking process, it turned out to be highly useful to discuss the linking between different professional groups. In adult rehabilitation and rheumatology, occupational therapists apply and add a specific perspective to the rehabilitation team when they use the components and categories of the ICF: the engagement in meaningful occupations. Assessment should then be on this level as well. By linking the items of the analysed instruments to the ICF, it became obvious that the occupation-based instruments are intended to be used in this specific perspective. The specific perspective of occupational therapists might be represented by the underlying conceptual models such as the Canadian Model of Occupational Performance which is the underlying model of the COPM (12). Occupational therapists might use these models in addition to the ICF when they work in multidisciplinary teams.

For the use of more complex instruments (such as the AMPS) a training course is a requirement in order to address all the relevant issues. Some of the instruments (such as SODA, JT-HF, MPUT, Button or FDT) were found to be mostly related to functional performance. It can be questioned whether these instruments address a too narrow spectrum of ICF categories to give a comprehensive picture of occupation and the treatment outcome. But if these instruments are only used to assess the specific category that is addressed or if they are used to assess underlying factors for occupational performance (for example in the MPUT, Button or FDT the categories *d4400 picking up* and *d4402 manipulating)*, these measures could be highly useful.

In conclusion, the ICF proved to be very useful for examining clinical occupation-based instruments. Clinicians and researchers who need to select an occupation-based instrument must be aware of the areas that are covered by this instrument and the potential areas that are not covered at all. This content comparison based on the ICF could enable occupational therapists, other health professionals and researchers in rheumatology to choose the adequate instrument that covers the area of problem and treatment to evaluate a specific outcome. It could also serve as a basis for further development of occupation-based instruments in occupational therapy in musculoskeletal rehabilitation.

Figure 1. The model of the ICF. The model shows the relationship between the parts of the ICF classification: *health conditions*, *body functions (b)* and *body structures (s)* and *activities and participation (d)* and the contextual factors that include the components: *environmental factors* (e) and *personal factors; modified from WHO* (4).

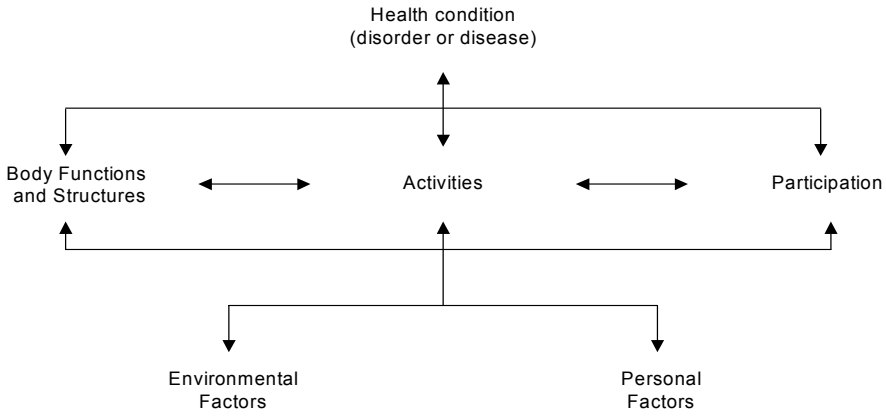

Table 1. Links between the ICF categories to the instruments

ICF Category	COPM	AMPS	SODA	JT-HF	MPUT	Button	FDT
Body functions							
b130 Energy and drive functions, unspecified		1					
b1643 Cognitive flexibility		3					
b1649 Higher level cognitive functions, unspecified		4					
b2801 Pain in body part			12				
b7359 Muscle tone functions, unspecified		1					
b7409 Muscle endurance functions, unspecified		2					
b7658 Involuntary movement functions, unspecified		1					
b7609 Control over voluntary movement functions, unspec.		1					
Activity and participation							
d160 Focusing attention		1					
d170 Writing			1	1			
d177 Making decisions		1					
d179 Applying knowledge, other specified and unspecified		1					
d2108 Undertaking a single task, unspecified		5					
d3609 Communication, unspecified	1∗						
d4109 Changing basic body position, unspecified		1					
d415 Maintaining a body position, unspecified		1					
d4209 Transferring oneself, unspecified	1∗						
d4300 Lifting		1					
d4309 Lifting and carrying, unspecified		1					
d4400 Picking up			2	1	12		16
d4401 Grasping			3	1			
d4402 Manipulating		1	1	1		5	16
d4408 Fine hand use, other specified			1	2			
d4409 Fine hand use, unspecified		1					
d4453 Turning or twisting the hands or arms			1				
d4458 Hand and arm use, other specified			3	1			
d4459 Hand and arm use, unspecified		3					
d4509 Walking, unspecified		1					
d4709 Using transportation, unspecified	2∗						
d499 Mobility, unspecified	1∗	1					
d5100 Washing of body parts			1				
d5109 Washing oneself, unspecified	1•						
d5102 Drying oneself			1				
d5209 Caring for body parts, unspecified	1•						
d5409 Dressing, unspecified	1•						
d599 Self-care, unspecified	1•						
d629 Acquisition of goods and services, unspecified	1∗						
d6309 Preparing meals, unspecified	1∗						
d6409 Doing housework, unspecified	1∗						
d649 Household tasks, other specified and unspecified	1∗						
d6509 Caring for household objects, unspecified	1∗						
d839 Education, other specified and unspecified	1∗						
d8459 Acquiring, keeping and terminating a job, unspecified	1∗						
d859 Work and employment, other specified & unspecified	1∗						
d879 Economic life, other specified and unspecified	1∗						
d9109 Community life, unspecified	1∗						
d9200 Play	1∗						
d9201 Sports	1∗						
d9202 Arts and culture	1∗						
d9203 Crafts	1∗						
d9204 Hobbies	1∗						
d9205 Socializing	1∗						
d9209 Recreation and leisure, unspecified	2∗						
nc		5					

Table 1 shows the categories of the ICF and the linking to the items of the instruments in comparison between the seven instruments. (∗) For all these marked items a performance perspective was attributed. All other items were attributed with an capacity perspective, except theses (•) marked activity and participation domains are coded at both performance and capacity levels.

Table 2. COPM – Canadian Occupational Performance Measure

COPM Item	ICF Category	C&P
Step 1A: Self-Care		
- Personal care (e.g. dressing, bathing, feeding, hygiene)	d599 Self-care, unspecified d5409 Dressing, unspecified d5109 Washing oneself, unspecified d5209 Caring for body parts, unspecified	C, P C, P C, P C, P
- Functional mobility (e.g. transfers, indoor, outdoor)	d499 Mobility, unspecified d4209 Transferring oneself, unspecified	P P
- Community management (e.g. transportation, shopping, finances)	d629 Acquisition of goods and services, unspecified d4709 Using transportation, unspecified d879 Economic life, other specified and unspecified	P P P
Step 1B: Productivity		
- Paid/ Unpaid work (e.g. finding/ keeping a job, volunteering)	d8459 Acquiring, keeping and terminating a job, unspecified d895 Work and employment, other specified and unspecified	P P P P
- Household management (e.g. cleaning, laundry, cooking)	d6309 Preparing meals, unspecified d6409 Doing housework, unspecified d649 Household tasks, other specified and unspecified d6509 Caring for household objects, unspecified	P P P P
- Play/ School (e.g. play skills, homework)	d9200 Play d839 Education, other specified and unspecified	P P
Step 1C: Leisure		
- Quiet Recreation (e.g. hobbies, crafts, reading)	d9209 Recreation and leisure, unspecified d9204 Hobbies d9203 Crafts	P P P
- Active Recreation (e.g. sports, outings, travel)	d9209 Recreation and leisure, unspecified d9201 Sports d9202 Arts and culture d4709 Using transportation, unspecified	P P P P
- Socialisation (e.g. visiting, phone calls, parties, correspondence)	d9205 Socializing d9109 Community life, unspecified d3609 Communication, unspecified	P P P
Step 2 (involved in Step 1A, 1B & 1C)		
The client has to decide for a 'daily activity in self-care, productivity and leisure'. The client has to rate the activity for **importance** from 1 to 10 [with 1 being "not important at all"] and for the level of **current performance** and **satisfaction** also from 1 to 10 [with 1 being "not able to do it" and "not satisfied at all"]		

Table 2 shows the linking of the items of the COPM to the categories of the ICF as an example. Every item of the instrument was linked to the appropriate ICF category. Additionally, an either capacity and/ or performance perspective was attributed to each item (see the row C&P in the table).

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An exploration of the link of conceptual occupational therapy models to the International Classification of Functioning, Disability and Health (ICF)

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Abstract

Since occupational therapy focuses on occupations and activities of daily life in the context of the environment, conceptual occupational therapy models might be closely related to the International Classification of Functioning, Disability and Health (ICF). Therefore, the purpose of this paper was to explore the link of conceptual occupational therapy models to the ICF. A structured literature search for conceptual occupational therapy models was performed. The concepts on which these models are built were linked to the ICF categories and components according to 10 established linking rules. 3 conceptual occupational therapy models were identified in the literature: the Model of Human Occupation (MoHO), the Canadian Model of Occupational Performance (CMOP), and the Occupational Performance Model (Australia) [OPM(A)]. The majority of the concepts from the 3 models could be linked to the ICF. 2 concepts from the conceptual occupational therapy models were found to be not covered by the ICF: The concept 'felt space' of the OPM(A) is not included in the ICF. The concept of the 'habituation subsystem' of the MoHO was also found to be not covered by the ICF. Additionally, 'rest' was found to be a *body function* in the ICF, whereas 'rest' has an *activity* perspective in the OPM(A). We conclude that by applying the conceptual models that underpin their practice, occupational therapists might add an additional perspective to multidisciplinary teams which use the ICF.

Introduction

Occupation includes everything that a human being does, such as physical, mental, social and rest occupations or occupations for productivity, leisure and self-care. Nelson (1994) describes occupation as the relationship between the environment having a physical and a socio-cultural dimension (occupational form) and the active doing of the individual (occupational performance). Occupational form is related to meaning and occupational performance is linked to purpose. Occupational therapists consider meaningful activities of individuals as a contribution to health and apply these meaningful occupations in their treatment (Meyer, 1977) (Yerxa et al., 1989) (Wilcock, 1998) (Townsend, 1999).

In order to improve the theoretical foundation of their discipline, occupational therapists need to explain the theoretical concepts that underpin their practice. Conceptual models explain and link theoretical concepts to each other. A model is defined as a theoretical simplification of a complex reality (Fröhlich, 1993) and consist of several explicitly defined concepts. A concept is an idea or notion. Concepts are formed by combining particulars of characteristics of a thing. In conceptual models, concepts form the basic building material. Conceptual models are schematic or graphic representations of concepts and assumptions that act as a guide for theory development. Thus, concepts form the basic structure of a theory. A theory explains phenomena by specifying which concepts or variables are related. The theory level is rarely reached in applied disciplines because of the number of potential variables and their interactions (Reed & Sanderson, 1999, p 65).

Conceptual models which explain occupational performance have become a major focus of occupational therapy literature in the last two decades (Hagedorn, 2000) (Chapparo & Ranka, 1997). An important aspect of a conceptual model in

occupational therapy is the underlying frame of reference. The frame of reference is based on philosophy or a paradigm and attempts to describe or explain what we believe or value. Models are developed within a frame of reference. Thus, the frame of reference reflects viewpoints, beliefs or values. Two major frames of reference have influenced the development of occupational therapy, the organismic and mechanistic philosophies. The organismic philosophy refers to holistic, qualitative, constructivist viewpoint with an individual who is active, dynamic and self-responsible. The mechanistic philosophy reflects an elementaristic, quantitative, reductionistic viewpoint with an individual who is not passive, reactive and not self-responsible. Occupational therapists began working within the organismic philosophy from the beginning on occupational therapy practice, but through the pressure of medical specialization in rehabilitation medicine in the late 1940s and 1950s, the mechanistic philosophy was increasingly emphasised. For example, the concentration was on behaviour, joint range of motion or muscle strength. Beginning in the 1960s, occupational therapy gradually shifted back to the organismic frame of reference by emphasising concepts such as humanism, holism, and competence (Reed & Sanderson, 1999, p 201ff).

The growing focus on theory and the development of models in occupational therapy has not followed a single school of thought or a single theorist, so a mosaic of frames of reference and inconsistent professional language have been developed. Attempts have been made to analyse and compare the contents of the conceptual models in occupational therapy. Kortman (Kortman, 1995) divided occupational therapy models into three groups: (1) Professional models that provide a wide description of the role and practice of occupational therapists, (2) delineation models that set boundaries and guidelines in terms of expected intervention for particular client groups, such as

biomechanical, neurodevelopmental and behavioural models, and (3) application models that describe specific assessment and intervention techniques. Kortman (1995) argues that the three types of models identified can be organised in a hierarchy with the professional model on the top. He concludes that the further development of occupational therapy models will involve a series of challenges for the profession to develop regarding the definition of a generally accepted conceptual model.

Conceptual occupational therapy models are applied in practice by occupational therapists (Hagedorn, 2000). However, in their daily practice, occupational therapists are often confronted with multi-disciplinary settings in rehabilitation. In multidisciplinary settings different types of models are applied: The traditional 'medical model' which refers to a mechanistic and reductionistic point of view, defines the individual as a passive receiver of medical care without being self-responsible and focuses on the disease, as well as models of functioning, disability and health. Recently, the WHO has established the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) as a model and classification of functioning and disability that can be used for multidisciplinary teams in rehabilitation.

Before the ICF, there have been two major models in the field of functioning and disability: the international classification of impairment, disability and handicap (ICIDH) (WHO, 1980) and the 'functional limitation' or Nagi framework (Nagi, 1964). Contrary to the ICIDH, the Nagi framework was not accompanied by a classification. Contrary to both the ICIDH and the Nagi framework, the current framework of disability – the WHO International Classification of Functioning, Disability and Health (ICF) now focuses on function instead of impairment. The holistic, bio-psycho-social

approach in rehabilitation medicine is addressed by the ICF (WHO, 2001). The ICF is being increasingly applied in clinical research and clinical practice in rehabilitation all over the world (Stucki, Ewert, & Cieza, 2002). The overall aim of the ICF classification is to provide a unified and standard language for the description of health and health-related conditions in rehabilitation and a common framework for all health professions (WHO, 2001).The purpose of the ICF is to serve as a common framework and language for all health professions who work in rehabilitation.

The ICF has two parts, each relating to separate components. Part 1 covers **functioning** and **disability** and includes the components: *body functions* (b) and *body structures* (s) and *activities and participation* (d). Part 2 covers **contextual factors** and includes the components: *environmental factors* (e) and *personal factors* (WHO, 2001) (Figure 1). Activity and participation are core aspects of occupational therapy because they relate to occupational performance.

Reed & Sanderson (1999) state that no perfect or ideal model of health, functioning and disability exists for occupational therapists. Rather, they suggest that occupational therapists should select the aspects from those health models that most closely fit the beliefs and values of occupational therapy (Reed & Sanderson, 1999) (p 224). However, instead of selecting those relevant aspects, it might be useful that occupational therapists explore how their conceptual models which they apply in practice are related to existing models, such as the model of functioning and disability of the ICF. This would facilitate the dialog and communication in multidisciplinary teams on the basis of the ICF. It could enhance further development of the conceptual models. If occupational therapists want to assess specific ICF categories, they need to know which concepts of their conceptual models are represented in the

ICF. If the ICF covers the majority of concepts of the occupational therapy models, the ICF could be a possible framework for comparing the content of these models.

The objective of this paper was to explore the link of conceptual occupational therapy models to the International Classification of Functioning, Disability and Health (ICF). The specific aims were to link all concepts of the conceptual occupational therapy models to the ICF, to examine the similarities and differences and to compare the content of these models with the ICF and based on the ICF.

Methods

Literature search

A structured literature search was undertaken. The following databases were used for the literature search: CINAHL R (database) (1982-1998 and 1999-2003), AMED (1985-2003), Medline (1967-2003), OTD-Base (www.otdbase.org), the literature register of the Vienna University ALEPH. The following keywords or combinations of them were used: occupational therapy, model, theory, concept, conceptual model, frame of reference.

Models

In order to be selected, models had to satisfy all the following criteria: [1] generalisability to all areas of practice of occupational therapy and occupational science, [2] the main focus of the model being on occupational performance, [3] professional models (Kortman, 1995) that take into account that human occupation is the professional focus of occupational therapists, [4] publication of the model, its components or its application in an English peer-reviewed journal, [5] existence of an English version of the model.

The following definition of occupational performance was used: According to Townsend (1999), occupational performance is defined as the result of the dynamic relationship between the person, the environment and the occupation. It refers to the ability to choose and satisfactorily perform meaningful occupations that are culturally defined, and appropriate for looking after one's self, enjoying life, and contributing to the social and economic fabric in the community. Occupations are groups of activities and tasks of everyday life.

Functional performance can be defined as the ability to conduct a specific task which could be related to daily living activities, for example picking-up small objects or writing a sentence. It is important to note that occupational performance and functional performance typically differ in an important aspect. While occupational performance refers to what an individual does in his or her current environment, functional performance refer to an individual's ability to execute a task or an action in a 'standardized environment' (WHO, 2001) (page 15). This difference is addressed in the ICF in the distinction of 'performance' and 'capacity'.

Models that describe occupational therapy practice and that involve the occupational therapist as a practitioner in the model were excluded because the present study focused only on conceptual occupational therapy models which explain occupational performance. Models of function or functional performance were excluded from the present study and should be subject of a further analysis. Examples are as follows: The occupational adaptation model of Schkade & Schulz was for example excluded from the present study because its main focus is on occupational adaptation with successful adaptation being defined as carrying out life roles adaptively and masterfully (Schkade & Schultz, 1992) (Schultz & Schkade, 1992). This process of

adaptation is connected to a transition of life roles (Schkade & McClung, 2001) (p 2 & 3), thus being a sub-area of occupational performance. The model of sensory integration was excluded for the present study because its main focus is on functional performance of the nervous system (Ayres, 1972). Frames of reference were not linked to the ICF in the present study, because they represent a philosophy or a paradigm, rather than consisting of explicitly defined concepts which could be linked to the ICF. A different methodology would be needed to link frames of reference to the ICF and should be subject to a further study.

Structure of the ICF classification

In the ICF classification, the letters b, s, d and e, which refer to the components of the ICF, are followed by a numeric code starting with the chapter number (one digit), followed by the second level (two digits) and the third and fourth levels (one digit each). The component letter with the suffix of one, three, four or five digits corresponds to the code of the so-called categories. Categories are the units of the ICF classification. Within each chapter, there are individual two-, three- or four-level categories. An example selected from the component *body functions (b)* would result in the following code: '*b2 sensory functions and pain'* is the first level, '*b280 sensation of pain'* represents the second level, '*b2801 pain in body part'* corresponds to the third level and '*b28013 pain in back'* to the fourth level.

Within each component, the categories are arranged in a stem/ branch/ leaf scheme. Consequently, a lower level category shares the higher level categories to which it belongs, i.e., the use of a lower level (more detailed) category automatically implies that the higher level category is applicable, but not the other way round. At the end of each embedded set of third- or fourth-level categories and at the end of each chapter, there are 'other specified' categories (uniquely identified by the final code 8)

and ‘unspecified’ categories (uniquely identified by the final code 9). These unspecified categories were used if the item in the model was not explicitly specified. The component *personal factors* is not classified yet.

Linking to the ICF

In order to compare the content of the identified models on the basis of the ICF and to examine the differences, every concept of the model was linked to the appropriate ICF category. Concepts were defined as theoretical constructs on which the conceptual models were built and which were defined and described in the models. Linking rules have been developed to link health-status measures to the ICF in a specific and precise manner (Cieza et al., 2002). According to these linking rules, health professionals trained in the ICF are advised to link each concept of a model to the ICF category representing this concept most precisely. If a concept contains sub-concepts such as ‘rest’ in the Occupational Performance Model (Australia) which is defined as ‘purposeful pursuit of non-activity’ and includes ‘sleep’ as well as activities ‘undertaken in order to relax’, it was linked to more than one ICF category. Thus, ‘rest’ was linked to the ICF categories *b1349 Sleep functions, unspecified* and *d9202 Recreation and leisure, unspecified.*

For the sake of comprehensibility of the results of this study, the rules 8 and 10 require special annotation. Rule 8 points out that if the content of a concept was not explicitly named in the corresponding ICF category, the ‘unspecified’ option at the third and fourth coding level of the ICF classification was linked. The unspecified options are uniquely identified by the final code 9. An example is the concept ‘self-maintenance occupations’ in the Occupational Performance Model (Australia) which is defined as ‘routines, tasks and sub-tasks done to preserve a person’s health and well-being in the environment’ (Chapparo & Ranka, 1997). The ICF category *d599*

Self-care, unspecified was linked to this concept. The ICF chapter *Self-care* includes caring for oneself, washing and drying oneself, caring for one's body parts, dressing, eating and drinking, and looking after one's health (WHO, 2001, p 149).

Additionally, if the content of a concept was more general than the corresponding ICF category, the code of the higher level was linked. According to rule 10, if a concept was not contained in the ICF classification, this concept was assigned '*nc'* (not covered) (Cieza et al., 2002). An example is the concept 'habituation subsystem' in the Model of Human Occupation (Kielhofner, 1995) which was linked 'nc'.

Consensus between two health professionals was used to decide which ICF category should be linked to each item of the instruments. To resolve disagreement between the two health professionals concerning the selected categories, a third person trained in the linking rules was consulted. In a discussion led by the third person, the two health professionals that linked the item stated their pros and cons for the linking of the concept under consideration to a specific ICF category. Based on these statements, the third person made an informed decision.

Results

Literature search

The literature search revealed 53 relevant articles, 21 books and 3 internet sources. According to the inclusion criteria, the following 3 models were identified in the literature and selected for inclusion: the Model of Human Occupation (MoHO), the Canadian Model of Occupational Performance (CMOP), and the Occupational Performance Model (Australia) [OPM(A)]. While in the CMOP and the OPM(A), the concepts are explicitly named and defined, the systems and subsystems in the

MoHO (on which the model is built) were used to define the concepts to be linked to the ICF.

Models

The Model of Human Occupation (MoHO)

The centre of the MoHO is the human system. A system refers to any complex of elements which interact and together constitute a logical whole with a purpose of function. Occupational behaviour is a result of the human system, the task and the environment. The human system has three sub-systems: the volition subsystem (for making occupational choices; consists of values, interests and personal causation), the habituation subsystem (consists of habits of occupational behaviour) and the mind-brain-body performance subsystem (describes the performance capacity). In addition, the environment influences human occupational behaviour: Physical, social and cultural environment constitute occupational behaviour settings such as home, school or workplace and recreation sites (Kielhofner, 1995) (Kielhofner & Forsyth, 1997).

The Canadian Model of Occupational Performance (CMOP)

In the centre of the CMOP is occupational performance. Occupational performance is defined as the overlap of three key terms: occupation, environment and a person. The result of the dynamic relationship between occupation, environment and a person is occupational performance. The key elements of the environment are cultural, institutional, physical and social. Purposes of occupations can be either leisure, productivity or self-care. The CMOP presents the person as integrated whole who incorporates spirituality and affective, cognitive and physical needs (Law et al., 1997) (Townsend, 1999).

The Occupational Performance Model (Australia) [OPM(A)]

In the centre of the OPM(A) is occupational performance. Five main components constitute occupational performance: the biomechanical performance component, the sensory-motor performance component, cognitive performance component, intra-personal performance component and an inter-personal performance component. The external environment is divided into the physical, sensory, cultural and social environment. Core elements of occupational performance are the body element, the mind element and the spirit element. Occupational performance is embedded in space and time. Space refers to physical matter (physical space) and the person's experience of space (felt space). Time refers to the temporal ordering of physical events (physical time) as well the meaning that is attributed to time by the person (felt time) (Chapparo et al., 1997).

Linking to the ICF

The 41 concepts of the 3 models were linked to 16 different ICF categories and 4 higher-ranking ICF components (Table 1). 8 concepts were linked to 6 categories of the higher-ranking component *body functions.* 2 concepts were linked to the higher-ranking ICF component *body functions*. 3 concepts were linked to the higher-ranking ICF component *body structures*. 10 concepts were linked to 5 categories of the component *activities and participation.* 12 concepts were linked to 5 categories of the component *environmental factors*. 1 concept was linked to the higher-ranking ICF component *environmental factors*. 3 concepts were found to relate to the presently not-developed ICF component *personal factors*. The following 2 concepts were found to be not covered by the ICF and were coded *nc*: The concept 'felt space' in the OPM(A) and the concept of the 'habituation subsystem' in the MoHO.

The concept ‘space’ in the OPM(A) is separated into ‘physical space’ and ‘felt space’. ‘Felt space’ refers to *a person's view of the experience of space* (Chapparo et al., 1997). Similarly, the concept ‘time’ is separated in ‘physical time’ and ‘felt time’. Different from ‘felt time’ which is included in the ICF, the concept ‘felt space’ is not included in the ICF. ‘Felt time’ was linked to the ICF category ‘*b1802 experience of time’* which is defined as *specific mental functions of the subjective experiences related to the length and passage of time.* A similar ICF category such as *‘experience of space’* which would have been appropriate for ‘felt space’ does not exist. The ICF category *b1565 visual perception* is defined as *mental function involved in distinguishing by sight the relative position of objects in the environment or in relation to oneself*. However, this ICF category does not include the subjective experience of the individual and was therefore not linked to ‘felt space’.

The concept of the ‘habituation subsystem’ of the MoHO is not covered in the ICF. The MoHO is a behavioural model. The habituation subsystem consists of occupational patterns and routines as habits which are necessary in order to conduct occupations on a daily basis (Kielhofner, 1995). The ICF does not include routines and habits which the MoHO claims to be essential when people conduct occupations and activities.

The concept ‘rest’ is used differently in the conceptual occupational therapy models and the ICF. In contrast to the ICF where ‘rest’ is a *body function*, ‘rest’ has an activity perspective in the OPM(A). The category *d9209 recreation and leisure, unspecified* was therefore linked to the following two concepts in the OPM(A): ‘leisure’ and ‘rest’. The concept of ‘rest’ in the OPM(A) was linked to an *activities and participation* ICF category because the authors of the OPM(A) refer to *the purposeful*

pursuit of non-activity. This can include time devoted to sleep (Meyer, 1977), as well as routines, tasks, sub-tasks and rituals undertaken in order to relax (Chapparo et al., 1997).

3 concepts of the occupational therapy conceptual models were linked to the higher-ranking ICF component *personal factors* which is not developed at present. The following 3 concepts were linked to the ICF component *personal factors*: 'The intra-personal performance component' of the OPM(A), the 'mind' concept of the OPM(A) and the 'volition subsystem' of the MoHO.

Table 1 shows the comparison of the items in the models using the ICF categories as a reference and ordered by component. The numbers in the table represent the frequencies with which the ICF categories were addressed in the different models. A higher number indicates that several items from a specific model were linked to the same ICF category.

Table 2 shows how the concepts of the OPM(A) have been linked to the ICF in order to given an example for the linking procedure. In order to perform the linking of the concepts, the definitions of the concepts as well as the description of the model (Chapparo et al., 1997) were used.

Discussion

The majority of the concepts from the 3 conceptual occupational therapy models could be linked to the ICF according to the established linking rules. The ICF proved to be useful as a frame of reference for comparing the similarities and differences of conceptual occupational therapy models. However, 2 concepts from the conceptual

occupational therapy models were found to be not covered by the ICF: ‘Felt space’ form the OPM(A) and the ‘habituation subsystem’ from the MoHO. The concept of ‘rest’ was found to be used differently in the models and the ICF.

This shows that occupational therapists should be aware of the theoretical concepts in the conceptual models that underpin their practice when they use the ICF. It might suggest that occupational therapists should use their conceptual models in addition to the ICF: The activity perspective of the concept ‘rest’ adds an important quality to the concept ‘rest’ in daily functioning which is seen from a body function perspective in the ICF. The ‘habituation subsystem’ is another important aspect for a successful functioning and mastery of daily life. ‘Felt space’ emphasises that occupational performance is closely related to the perception and the experience of the environment. Occupational therapy conceptual models might add an additional valuable perspective, if a multidisciplinary team uses the ICF.

3 concepts of the occupational therapy conceptual models were linked to the higher-ranking ICF component *personal factors* which is not developed at present. The higher-ranking ICF component *personal factors* needs further development in order to be useful for the linking process and the comparison.

‘Sensory environment’ in the OPM(A) was linked to the higher-ranking ICF component *environmental factors* rather then to a more detailed ICF category because of its definition in the OPM(A). ‘Sensory environment’ in the OPM(A) refers to the *sensory surroundings of a person. Sensory aspects of the environment give a person information about the physical-socio-cultural aspects of the environment and its survivability* (Chapparo et al., 1997). No detailed ICF categories which matches this definition could be found, although it seemed that all aspects of the definition of

sensory environment in the OPM(A) were covered by the higher-ranking ICF component *environmental factors*.

'Cultural environment' and 'social environment' were both linked to the ICF category *e465 social norms, practices and ideologies* among the *environmental factors.* In the OPM(A), 'cultural environment' is defined as *an organised structure composed of systems of values, beliefs, ideals and customs which contribute to the behavioural boundaries of a person or group of people* (Chapparo et al., 1997). In the CMOP, 'cultural environment' is defined as *ethnic, racial, ceremonial and routine practices, based on ethos and value system of a particular group* (Townsend, 1999). The ICF includes the category *e465 social norms, practices and ideologies* among the *environmental factors* which is defined from both cultural and social perspectives. Therefore this category was linked to both concepts 'cultural' and 'social environment'. However, the 'cultural environment' is not a separate category in the ICF.

The OPM(A) and the CMOP were linked to almost similar ICF categories and components, compared to the MoHO. This could be due to the fact that the MoHO is strongly built on behavioural theory. According to Kielhofner & Forsyth (1997), the MoHO as a theory provides a way of thinking about peoples occupational behaviour and about occupational dysfunction that may result from disease, trauma, stress and other factors (p 103). The MoHO defines occupational performance from a behavioural perspective: occupational performance is the result of the mind-brain-body performance subsystem which involves a complex interplay of musculoskeletal, neurological, perceptual and cognitive phenomena (Kielhofner et al., 1997) (p 107). The 'volition subsystem' of the MoHO is defined as *a system of dispositions and self-*

knowledge that predisposes and enables persons to anticipate, choose, experience and interpret occupational behaviour (Kielhofner, 1995). This definition underpins that the MoHO strongly builds on behavioural theory and therefore has a different content and structure than the OPM(A) and the CMOP. The centre of the MoHO might be 'occupational behaviour' instead of 'occupational performance'.

The centre of both the OPM(A) and the CMOP is occupational performance and both use a similar definition of occupational performance. The OPM(A) defines occupational performance as *the ability to perceive, desire, recall, plan and carry out roles, routines, tasks and sub-tasks for the purpose of self-maintenance, productivity, leisure and rest in response to demands of the internal and/ or external environment* (Chapparo et al., 1997). The CMOP defines occupational performance as *the result of the dynamic relationship between the person, the environment and the occupation. It refers to the ability to choose and satisfactorily perform meaningful occupations that are culturally defined, and appropriate for looking after one's self, enjoying life, and contributing to the social and economic fabric in the community. Occupations are groups of activities and tasks of everyday life* (Townsend, 1999). The similarities between the OPM(A) and the CMOP could clearly be observed because of the linking to the ICF (Table 1). The ICF was used as a frame of reference. This emphasises the value of the ICF as a common language for the health professions and its value for such comparisons of models or instruments.

Hagelund & Kjellberg (1999) argue that the MoHO lacks the influence of the environment on human behaviour. The MoHO includes environmental factors, but has more emphasis on the person. It only acknowledges the influence of environment, but does not explain the interaction and relationship between the

person and the environment. Accordingly, the ICF does also not explain the relationship between its components. Nevertheless, in the ICF it is suggested that data should be collected in order to explore the relationships between the ICF components.

Both the CMOP and the OPM(A) explain the relationship between the concepts which are included in the model. In the COPM, some concepts are first level concepts, others are second level concepts (Townsend, 1999). The OPM(A) includes a hierarchical order of the concepts it is constructed of. A scheme defines which concepts relate to each other. For example, 'occupational performance components' are *the physical, sensory-motor, cognitive, and psychosocial dimensions of any task performed. These components of occupational performance are classified as biomechanical components, sensory-motor components, cognitive components, intrapersonal components and interpersonal components*. The occupational performance components relate to the 'core elements of occupational performance' and the 'occupational performance areas' (Chapparo et al., 1997).

Conclusion

The majority of the concepts from the following 3 conceptual occupational therapy models, the MoHO, the CMOP and the OPM(A), could be linked to the ICF. The ICF proved to be useful as a frame of reference for comparing the similarities and differences of conceptual occupational therapy models. However, 2 concepts from the conceptual occupational therapy models were found to be not covered by the ICF. By applying the conceptual models that underpin their practice, occupational therapists might add an additional perspective to multidisciplinary teams that use the ICF.

Table 1. Links between the ICF categories to the models

Table 1 shows the categories and components of the ICF and the linking to the concept of the models. The concept of the models were linked to ICF categories and the three components *body functions*, *body structures* and *personal factors*.

ICF Category	MoHO	CMOP	OPM(A)
Year of development	1985	1997	1997
Country	USA	Canada	Australia
Body functions	1	1	
b1349 Sleep functions, unspecified			1
b1529 Emotional functions, unspecified		1	
b1802 Experience of time			1
b199 Mental functions, unspecified		1	1
b299 Sensory functions and pain, unspecified			1
b799 Neuro-musculoskeletal and movement-related functions, unspecified			2
Body structures	1	1	1
Activity and participation			
d599 Self-care, unspecified		1	1
d799 Interpersonal interactions and relationships, unspecified			1
d859 Work and employment, other specified and unspecified		1	1
d9209 Recreation and leisure, unspecified		1	2
d9309 Religion and spirituality, unspecified		1	1
Environmental factors			1
e199 Products and technology, unspecified	1	1	1
e2459 Time-related changes, unspecified			1
e299 Natural environment and human made changes to environment, other specified and unspecified	1		1
e465 Social norms, practices and ideologies	1	2	2
e599 Services, systems and policies, unspecified		1	
Personal factors	1		2
NC	1		1

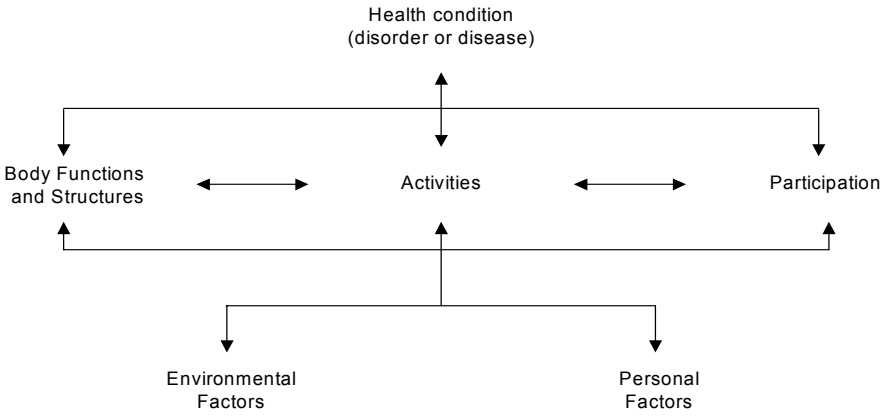
Table 2. Occupational Performance Model (Australia)

Table 2 shows the linking of the concepts of the OPM(A) to the ICF as an example. Every concept was linked to the appropriate ICF category or component according to established linking rules (Cieza te al, 2002).

OPM(A) Concept	ICF Category
Sensory Environment	Environmental factors
Physical Environment	e199 Products and technology, unspecified
Social Environment	e465 Social norms, practices and ideologies
Cultural Environment	e465 Social norms, practices and ideologies
Space (Physical space)	e299 Natural environment and human made changes to environment, other specified and unspecified
Space (Felt space)	NC
Time (Physical time)	e2459 Time-related changes, unspecified
Time (Felt time)	b1802 Experience of time
Self-Maintenance	d599 Self-care, unspecified
Rest	b1349 Sleep functions, unspecified d9209 Recreation and leisure, unspecified
Leisure	d9209 Recreation and leisure, unspecified
Productivity	d859 Work and employment, other specified and unspecified
Bio-mechanical	b799 Neuromusculoskeletal and movement-related functions, unspecified
Sensory-motor (sensory)	b299 Sensory functions and pain, unspecified
Sensory-motor (motor)	b799 Neuromusculoskeletal and movement-related functions, unspecified
Cognitive	b199 Mental functions, unspecified
Intra-personal	Personal factors
Inter-personal	d799 Interpersonal interactions and relationships, unspecified
Body	Body structures
Mind	Personal factors
Spirit	d9309 Religion and spirituality, unspecified

Figure 1. The model of the ICF.

The model shows the relationship between the parts of the ICF classification: *health conditions*, *body functions (b)* and *body structures (s)* and *activities and participation (d)* and the contextual factors that include the components: *environmental factors* (e) and *personal factors,* modified from WHO (WHO, 2001).



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Validating the Comprehensive ICF Core Set for Rheumatoid Arthritis from the Patient Perspective: A Qualitative Study

Revised version

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Abstract

Objective: The 'Comprehensive ICF Core Set for RA' (ICF RA Core Set) is a short list of categories from the International Classification of Functioning, Disability and Health (ICF) which should represent the typical spectrum of functioning of patients with rheumatoid arthritis (RA). It was developed by health professionals. The objective of this qualitative study was to validate the ICF RA Core Set from the patient perspective.

Methods: Patients with RA were interviewed about their problems in daily functioning. Interviews were tape-recorded and transcribed verbatim. Interview texts were divided into meaning units. The concepts contained in these meaning units were linked to the ICF according to 10 established linking rules. 15% of the transcribed data were analysed and linked by a second health professional and the degree of agreement was calculated using kappa statistic.

Results: 21 patients were interviewed. 220 different concepts contained in 367 meaning units were identified in the qualitative analysis of the interviews and linked to 109 second-level ICF categories. 63 (83%) of the 76 second-level categories from the ICF RA Core Set were also found in the interviews. 25 second-level categories which are not part of the current ICF RA Core Set were identified in the interviews. The result of the kappa statistic for agreement was .62 (95% bootstrapped CI .59 - .66).

Conclusion: The validity of the ICF RA Core Set was supported by the perspective of individual patients. However, some additional issues raised in this study but not covered in the current ICF RA Core Set need to be investigated further.

Introduction

Rheumatoid arthritis (RA) is a chronic disabling disease (1) which is often associated with inability to conduct occupations, such as paid work and other daily activities, ultimatively leading to the experience of limitation in the patients' daily activities and restriction in societal participation (2-9). People with RA experience a decrease in overall functional ability and quality of life (2) and a greater loss of their life activities than people without RA (7).

To assess, explore and understand the patients' daily functioning is essential when treating people with RA. Especially health professionals specialised on rehabilitation focus on the daily functioning of the patient (10). Current recommendations regarding assessment of disease and disease consequences include recommendations to measure function mainly referring to physical function (11). In order to map and assess daily functioning and disability from a holistic bio-psycho-social perspective in rehabilitation, the framework of the WHO International Classification of Functioning, Disability and Health (ICF) can be used. The overall aim of the ICF classification is to provide a unified and standard language for the description of health and health-related conditions in rehabilitation and a common framework for all health professions (12-14).

The ICF has two parts, each containing separate components. Part 1 covers **functioning** and **disability** and includes the components: *body functions* (b) and *body structures* (s) and *activities and participation* (d). Part 2 covers **contextual factors** and includes the components: *environmental factors* (e) and *personal factors* (Figure 1). Each component consists of several chapters, and within each chapter, categories which are the units of the classification (14). Chapters represent health

domains which are used to organize the classification. An example is *Chapter 5 Self-care* within the component *activity and participation*.

In order to facilitate the application of the ICF in clinical practice, specific Comprehensive ICF Core Sets (abbreviated in this article to 'ICF Core Sets') for certain health conditions have been developed. ICF Core Sets are short lists of ICF categories which are important for patients with a specific disease. The Comprehensive ICF Core Set for RA (abbreviated in this article to 'ICF RA Core Set') is a short list of ICF categories which are important for patients with RA and is meant to include all relevant ICF categories by representing the typical spectrum in functioning of patients with RA (15).

The ICF RA Core Set was developed by experts consisting of rheumatology health professionals in a formal decision-making and consensus process. In this process, evidence was integrated from preliminary studies. These preliminary studies included a Delphi exercise involving health professionals as experts, a systematic literature review, and an empiric data collection which was done quantitatively with a checklist (15). The consensus process revealed a current, preliminary version of the ICF RA Core Set. The current, preliminary version of the ICF RA Core Set now needs to be validated and further developed.

One aspect in this validation process is to explore the patient perspective. In order to explore the perspective of patients, a qualitative research approach was considered most appropriate. When measuring and assessing daily functioning in people with RA from a holistic bio-psycho-social perspective in rehabilitation, it is important to include the patient perspective because personal values for outcomes vary between and within patients and professionals (16,17). Qualitative methodology

provides the possibility to explore the perspective of those who experience the disease (the patient perspective) (16, 18, 19).

ICF Core Sets have been developed for other chronic diseases apart from RA and preliminary versions have been established. The next step is the validation. The ICF RA Core Set is the first to undergo validation. Therefore, the present study is also considered to be a methodological pilot study for the validation and development of other ICF Core Sets for other diseases and health conditions.

The objective of this study therefore was to validate the current, preliminary version of the ICF RA Core Set from the patient perspective using a qualitative approach. The specific aims were (i) to explore the aspects of functioning and health which are important to patients with RA, (ii) to examine how these aspects are represented by the current version of the ICF RA Core Set, (iii) to possibly identify aspects of functioning important for people with RA which are not included in the ICF RA Core Set and (iv) to explore the qualitative methodology in this pilot study for further validation and development of ICF Core Sets for other diseases.

Methods

We conducted a qualitative study based on interviews with patients with RA.

Participants

All patients with RA diagnosed according to the revised ACR criteria (20) who had appointments on five consecutive, randomly selected days in the outpatient department of the Rheumatology Outpatient Clinic of the Vienna Medical University were asked whether they would like to participate in the study and were fully informed about the study procedures. Patients who were willing to participate gave written

informed consent according to the Declaration of Helsinki 1996. The study was approved by the institutional review board of the Vienna Medical University.

Sample size

A small sample size with a diverse range of participants was used to obtain the required level of rich and meaningful data (21). Patients were included in the study until saturation was reached. Saturation refers to the point at which an investigator has obtained sufficient information from the field (22). Saturation was defined in our study as the point during data gathering when the linking of the qualitative data of two consecutive interview revealed no additional information which was not obtained before.

Interviews

All participants were interviewed by the same interviewer (TS). The interviews were tape-recorded and transcribed verbatim. A short introduction to the concepts of the ICF was given in lay terms to all patients at the beginning of each interview. Then, two different types of interviews were performed: Interview type 1 included open-end questions which were formulated around functioning in daily life: Patients were asked (A) which RA-related problems of their body functions they were experiencing, (B) which body structures were involved, (C) which limitations of activities and restrictions in participation were significant to them and (D) which environmental factors and (E) which personal factors were barriers or facilitators for them.

In interview type 2 patients were presented all titles and definitions of the ICF chapters of which categories are included in the ICF RA Core Set. After having presented the title and definition to them, the patients were asked open-ended

questions to describe in their own words any problems they personally experienced related to each specific ICF chapter.

Each patient was randomised to being interviewed either according to type 1 or type 2 schedule. As it is not possible today to define a single appropriate, accepted interview method for the purpose of this study, both interview types were applied in order to gather the richest possible data for the qualitative analysis and to cover a broad spectrum of possible questions for the patients. The analysis and the results of the two types of interviews were performed and reported together.

Qualitative data analysis

Qualitative data analysis followed the method of ‘meaning condensation’ (19): In the first step, the transcribed interviews were read through to get an overview over the collected data. In the second step, the data were divided into meaning units and the theme that dominates a meaning unit was determined. A meaning unit was defined as a specific unit of text, either a few words or a few sentences with a common theme (23). Therefore, a meaning unit division does not follow linguistic grammatical rules. Rather, the text was divided where the researcher discerned a shift in meaning (19). In the third step, the concepts contained in the meaning units were identified. A meaning unit could contain more than one concept. In the final fourth step, every concept was linked to ICF categories according to published linking rules (24).

An example for a meaning unit is ‘using a shopping device which I can pull behind me because I have problems with shopping’. In this meaning unit, the concepts ‘problems with shopping’ and ‘shopping device’ were identified.

Linking to the ICF

In the ICF classification, the letters b, s, d and e, which refer to the components of the ICF, are followed by a numeric code starting with the chapter number (one digit), followed by the second level (two digits) and the third and fourth levels (one digit each). The component letter with the suffix of one, three, four or five digits corresponds to the code of the category. Categories are the units of the ICF classification. Within each chapter, there are two-, three- as well as four level categories. An example selected from the component *body functions (b)* would result in the following code: '*b2 sensory functions and pain'* as first level, '*b280 sensation of pain'* representing the second level, '*b2801 pain in body part'* corresponding to the third level and '*b28013 pain in back'* to the fourth level.

Within each component, the categories are arranged in a stem/ branch/ leaf scheme. Consequently, a lower level category shares the higher level categories of which it is a member, i.e., the use of a lower level (more detailed) category automatically implies that the higher level category is applicable, but not the other way round.

Every concept of each meaning unit from the interviews was linked to the most precise ICF category using the same linking rules which have been developed to link health-status measures to the ICF in a specific and precise manner (24). According to these linking rules, health professionals trained in the ICF are advised to link each concept of a model to the ICF category representing this concept most precisely. If a meaning unit contains more than one concept, it was linked to more than one ICF category. An example is the meaning unit 'using a shopping device which I can pull behind me because I have problems with shopping' which contains the concepts 'problems with shopping' and 'shopping device'. The concept 'problems with

shopping' was linked to the ICF category *d6200 Shopping*. The concept 'shopping device' was linked to the ICF category *e120 Products and technology for personal indoor and outdoor mobility and transportation, specification: shopping device.*

According to rule 10, if a concept was not contained in the ICF classification, this concept was assigned 'nc' (not covered) (24). An example is the concept 'employer's policies' which was found to be not covered by the ICF and was therefore linked 'nc'. One interviewee who was a nurse reported that although she was able to do her job as a nurse, she was not able to do other physically stressful tasks which she had to do. She had to handle and carry heavy objects, such as carrying lunch trays from the kitchen being a long distance away to the patients. She did not consider this related to her job as a nurse, but rather thought that her employer's policy was a barrier for her doing her job.

However, two modifications beyond the linking rules were made for this study, namely, if the content of a concept was not explicitly named in the corresponding ICF category, the second level of the ICF classification was linked, rather than the 'other specified' option at the third and fourth coding level of the ICF classification. The second modification was that, if a patient was more specific than the ICF, the specification of the patient was documented.

Procedure to confirm the ICF RA Core Set categories

A category for the ICF RA Core Set was regarded as confirmed, if the identical or a similar category emerged from the interviews. An example is the ICF category *s299 Eye, ear and related structures, unspecified* was regarded as confirmed by *s230 Structures around eyes* (Table 2).

For the analysis, all third and fourth level categories were moved to the second level. In general, concepts were only counted once.

Accuracy and rigor of the analysis

In addition to the linking by the first author, 15% of the transcribed interview-text covering two whole interviews and several parts of other interviews were analyzed and linked by a second health professional (MC). The degree of agreement between the two investigators regarding the linked concepts was calculated by means of the kappa statistic (25). Values of kappa generally range from 0 to 1, whereas 1 indicates perfect agreement and 0 indicates no additional agreement beyond what is expected by chance alone.

Kappa by definition is bounded by 1, i.e. its sampling distribution becomes progressively skewed to the left as kappa approaches 1. Since the asymptotic confidence interval does not take this skewness into account, especially with small sample sizes, and can produce upper confidence limits that exceed 1, bootstrapped intervals, which are produce by percentiles of samples based on the observed data, were calculated (26).

The data analysis was performed with SAS for windows V8.

Results

Participants and interviews

21 patients participated in this qualitative study. Demographic data of the participants are shown in table 1. Saturation was reached after 13 interviews from type 1 (participant A-M) and after 8 interviews from type 2 (participant N-U). Mean time for type 1 interviews was 54.9 minutes (SD +/-6.9) compared to 63.9 minutes (SD +/- 8.2) for type 2 interviews. The transcribed data resulted into 4,128 lines of text.

Linking of the qualitative interview data to the ICF

220 different concepts contained in 367 meaning units were identified in the qualitative analysis of the interview data of the patients and linked to 109 second-level ICF categories. 7 concepts from the interviews could not be linked to detailed ICF categories because of their broader meaning, but instead were linked to the following 7 higher-ranking ICF chapters: *mental functions, structures related to movement, mobility, self-care, domestic life, support and relationships* and *attitudes*.

15 ICF categories were only identified in type 1 interviews, 26 categories were only identified in type 2 interviews, 68 ICF categories were found in both interview types. For all further analyses, the categories of both interview types were documented and reported together because the purpose of using the two interview types was to gather the richest possible data.

The following 9 concepts were assigned to the not yet developed ICF component *personal factors*: ‘development and maintenance of habits’, ‘lying as a strategy to deal with RA’, ‘self-perception’, ‘to keep up’, ‘attitudes of oneself’, ‘to want to reach something in life’, ‘to make the best out of it’, ‘knowledge’ and ‘the biographical experience of time’. One concept was found to be not covered by the ICF among the environmental factors: ‘employer’s policies’.

The result of the kappa statistic for agreement between the two investigators was .62. The 95% bootstrapped confidence interval, which indicates the precision of the estimated kappa coefficient, was .59 - .66. Thus, the lower limit of the confidence interval exceeded the value 0.5.

If all categories from the third and fourth level were moved to the second level and all specifications were excluded, 63 second-level categories from the ICF RA Core Set (83% of the categories) were found identically in the interviews (Table 2-4).

'Carrying out daily routine' is included in the ICF RA Core Set and was not confirmed in the interviews. However, patients were more specific by presenting examples in the interviews instead of staying on a more general level such as carrying out daily routine: For example in the area of caring for the body which can be considered daily routine, the categories *d510 Washing oneself*, *d5100 Washing body parts*, *d5102 Drying oneself*, *d5201 Caring for teeth* and *d5204 Caring for toenails* emerged from the interviews.

Instead of *d770 Intimate relationships,* the category *b640 Sexual functions* was linked in the interviews because the patients reported problems with their body functions in this area rather than their intimate relationships. *b640 Sexual functions* is included in the ICF RA Core Set. *D859 Work and employment, other specified and unspecified* was considered to represent a more general aspect of *d850 Remunerative employment*. Instead of *d449 Carrying, moving and handling objects, other specified and unspecified, d430 Lifting and carrying objects* emerged in the interviews (table 3).

25 additional second-level categories emerged from the interviews which are not represented in the current version of the ICF RA Core Set (table 5). *D8451 Maintaining a job* and *d3452 Terminating a job* which emerged in the interviews were regarded as covered by the *d850 Remunerative employment* which is included in the ICF RA Core Set. *B4350 Immune response* was regarded as covered because *b430 Functions of the haematological and immune systems* is included in the ICF RA Core Set.

Discussion

In this qualitative study, the validity of the ICF RA Core Set was supported by the perspective of the individual patients. We could demonstrate that a large number of the categories included in the ICF RA Core Set are addressing issues considered important to patients. However, some additional issues were raised in this study which are not covered in the current version of the ICF RA Core Set. An example is 'fatigue': 'Fatigue' came up in our interviews and was linked to the *b130 Energy and drive functions* as well as to the third-level category *b4552 Fatiguability* because the patients' description of 'fatigue' was related to the definitions of both ICF categories. *B130 Energy and drive functions* is included in the ICF RA Core Set, but *B4552 Fatiguability* is not included. 'Fatigue' was identified at OMERACT VI as an area of particular importance to patients with RA (18). In a qualitative study on rheumatology outcomes important to patients with RA, the patients identified fatigue, pain, disability and a general feeling of wellness as their major concerns (27). Thus, from the results obtained, we would suggest that the third-level category *b4552 Fatiguability* should be included in the ICF RA Core Set in order to fully cover the concept of 'fatigue' as experienced by the patients.

The categories *d8700 Personal economic resources* and *e1650 Financial assets* emerged from the interviews and are not included in the current version of the ICF RA Core Set. Economic consequences in relation to the loss of paid work due to physical disability were also found to be important issue to patients with RA in the literature (3-6).

Some additional categories were interpreted to be related to side effects: The patients explicitly assigned some categories from the ICF component *Body functions* to side effects of medication, such as *b1400 Sustaining attention, b5106*

Regurgitation and vomiting and *b5252 Frequency of defecation*. This information provided by the patients was documented without further valuation. Some of these causal relationships can also be found in the literature. Among the additional categories which emerged from the interviews, *b1263 Psychic stability, b1400 Sustaining attention, b820 Repair functions of the skin* and *b840 Sensations related to the skin* could be related to side effects of steroids (28); *B5252 Frequency of defecation* could be related to gastrointestinal side effects due to NSAIDs (29) and DMARDs (30). This information was attributed by the researchers according to the existing literature. Side effects were only found in the ICF component *Body Functions.*

The degree of agreement between health professionals was found to be moderate according to the Kappa coefficient. However, the lower limits of confidence intervals exceed 0.5. Additionally, the calculation of agreement did not only involve the linking of concepts to the ICF, but the whole process of the qualitative analysis which was done by two researchers for 15% of the transcribed data. This includes the division of the transcribed interview data into meaning units, the identification of the concepts and the linking to the ICF which was all done independently by the two researchers. From the qualitative research perspective, the limitation of calculating the Kappa coefficient might still be that it is a quantitative measure.

We performed interviews in order to validate the ICF RA Core Set from the patient perspective. In our study, interviews were chosen in order to explore the life context of the patients. Frequently, the patients reported specific problems from their own life context by giving specific examples. These specific examples may represent their individual perspective, compared to a more general perspective of the experts. For example, for the second-level category *d445 hand and arm use*, the following 4 specifications were documented: ‘opening a milk package’, ‘using a coffee machine’,

‘using one’s hand while sailing’ and ‘using hand and arm to lean on something’. The specifications were not presented in this study, but an additional analysis would be highly valuable. Patients thus may find their individual problems not always acknowledged, but nevertheless a more general category or component might be covered. On the other hand, experts might have in mind the typical or general patient, while patients focus on their own individual problems in every day life.

Most difficult to understand for the patients were the technical terms in the ICF component environmental factors, for example chapter 1, *products and technology*. This could be a limitation of interview type 2 in which patients were presented the titles and terms of the ICF chapters instead of the open questions in interview type 1. Problems with the ICF terms thus only turned up in type 2 interviews. However, 26 ICF categories emerged only in the type 2 interviews, compared to 15 in the type 1 interviews. It might have been important to present the ICF chapters to the patients - as it was done in the type 2 interviews - in order to facilitate that the patients would talk about their problems in daily life, although saturation was reached earlier after 8 interviews in the type 2 interviews, compared to 13 in the type 1 interviews. However, a limitation of the type 2 interviews might have been that the questions related closely to the ICF terms. In contrast, the open-ended questions in type 1 interviews facilitated that the patients focused on their life experiences and revealed concepts not covered by the ICF.

However, some patients were able to clearly follow the ICF terminology of all chapters during the type 2 interviews. These patients related problems in their daily life to either problems in body functions and structures, activities and participation or environmental factors. They were able to identify causes and effects according to the ICF model which they were presented prior to the interview. Patient N identified

problems with her teeth and related that to a change in the body structure teeth (*s3200 Teeth*) with a temporal relation to RA, as well as to her decreased ability to care for the teeth because brushing her teeth was painful in her hands (*d5201 Caring for teeth*). Further in the interview, she reported another cause for her teeth problems: Frequent vomiting and nausea which were a side effect from the drugs she had to take (*b1506 Regurgitation and vomiting*) increased during brushing of her teeth, therefore she had to terminate teeth brushing.

Among the personal factors, 'lying as a strategy to deal with RA' emerged from one interview: The patient had to lie that she did not have a chronic disease in order to reach her personal goals. She wanted to become and work as a nurse. She had to lie to the nursing school she applied to and later had to lie to her employer in order to get a job as a nurse. This person also indicated that the employer's policy was an important issue to be considered: In her employer's organisation it was not possible for her to ask other employees or her boss for help, when she, for example, had to handle and carry heavy objects or when she had to walk long distances. Thus, the organisational policy of her employer is a barrier for her in her work environment.

Our study followed a qualitative methodology. Problems of all participants were treated as equally important without implying a quantitative perspective such as frequencies or increasing importance if an issue was mentioned more often. In qualitative research, sample sizes typically remain small because intensive data analysis is required. However, this aspect allowed us to include and explore individual perspectives of patients in the validation of the ICF RA Core Set. Further research from an epidemiological perspective is suggested with the aim to test out the frequency and importance of the issues that were identified as problematic and

relevant areas to patients with RA in our qualitative study. A limitation of our study is that the sample included only patients from Austria, although patients were from different gender, age groups and professional backgrounds. Further studies with patients from other cultures are suggested which could use the same methodology as the present study.

From a methodological perspective, this study may serve as a model for further validation studies and ongoing development of other ICF Core Sets in other countries and in other diseases.

Conclusion

In this qualitative study, the validity of the ICF RA Core Set was supported by the perspective of individual patients. However, some additional issues raised in this study but not covered in the current ICF RA Core Set need to be investigated further.

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Figure 1. The model of the ICF

The model shows the relationship between the ICF components *body functions (b)* and *body structures (s)*, *activities and participation (d)* and the contextual factors: *environmental factors* (e) and *personal factors.*

Each component consists of chapters which then consist of categories. Within the component *activities and participation*, *Chapter 5 Self-care* includes the categories *d510 Washing oneself* (second-level) and *d5100 Washing body parts* (third level) among many others.

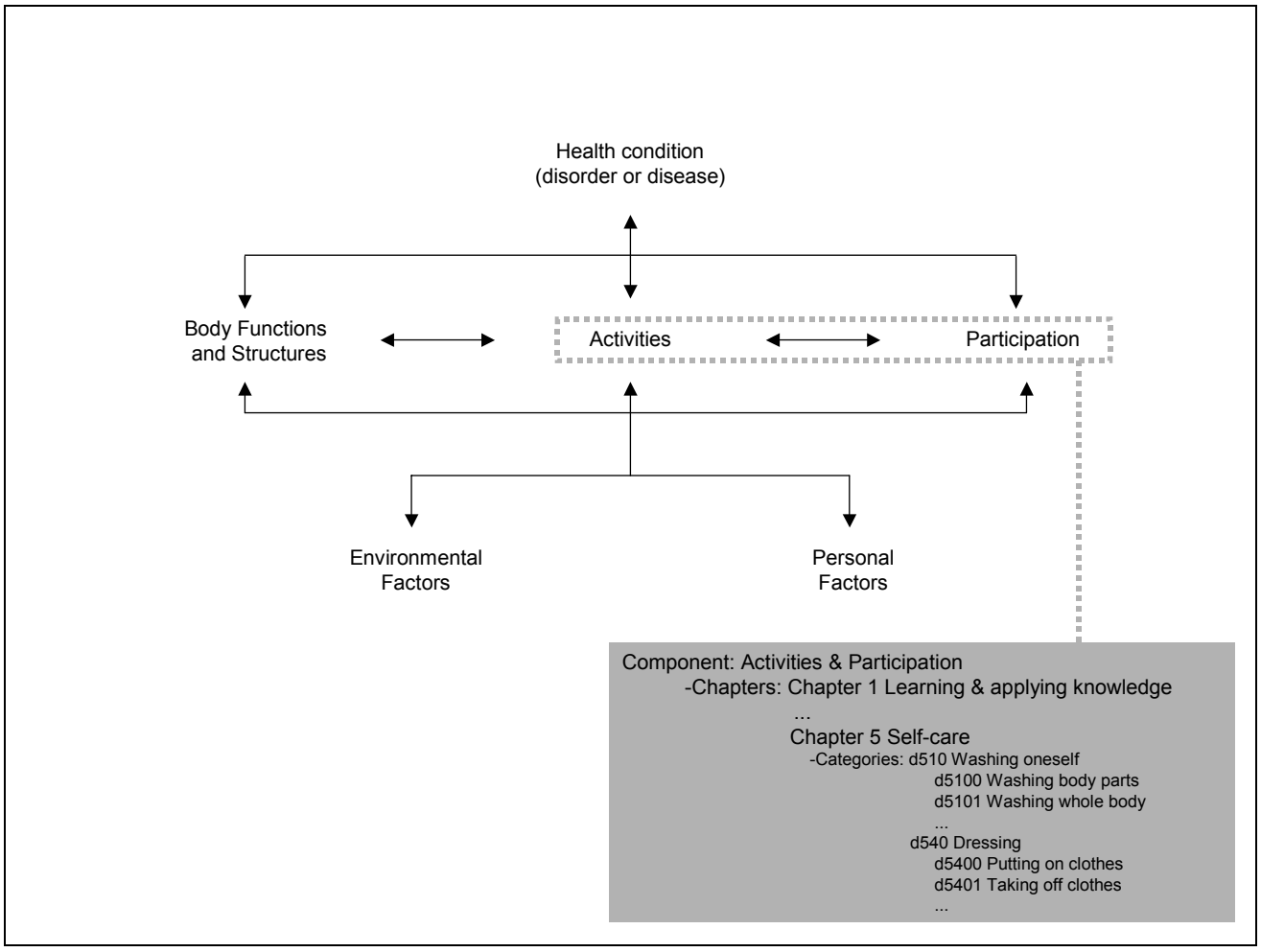

Table 1. Demographic data of the patients

Patients in our sample seem to be rather old, but represent the typical average age group of patients with RA in our outpatient clinic (mean age was 52 in our 'early RA cohort' and 57 in the 'late RA cohort', respectively (31)).

Name	Gender	Employment	Educational level	Disease duration (years)	Age
A	w	retired	commercial college	2	57
B	w	nurse	nursing school	6	30
C	w	retired - self-employed	commercial school	5	79
D	w	retired	secondary school	26	65
E	m	retired	university	4	66
F	m	unemployed	vocational training	5	57
G	w	retired	commercial school	4	59
H	w	retired	secondary school	23	64
I	w	retired	secondary school	29	69
J	w	clerical work	commercial school	1	39
K	w	retired	commercial school	2	61
L	w	retired	school for housekeeping	1	66
M	w	homemaker, student	university	16	43
N	w	retired	commercial college	13	58
O	w	retired	vocational training	3	61
P	m	retired	teacher	7	73
Q	w	retired	vocational training	23	64
R	w	retired	vocational training	11	70
S	w	clerical work	university	9	46
T	w	unemployed	vocational training	1,5	25
U	w	retired	sales training	26	59
			Mean	10,71	57,86
			SD	9,52	13,79
			Median	6	61

Table 2 - 4: ICF categories of the four ICF components included in the ICF RA Core Set compared to the patient perspective.

If a category was linked to a concept which emerged from the interviews, the category from the ICF RA Core Set was regarded as confirmed (C*).

2

ICF Code	2nd level	ICF Category Title	Patient Perspective
		Body functions	
b130	**b130**	**Energy and drive functions**	**C***
b134	**b134**	**Sleep functions**	**C***
b152	**b152**	**Emotional functions**	**C***
b180	**b180**	**Experience of self and time functions**	**C***
b280	**b280**	**Sensation of Pain**	**C***
b430	**b430**	**Haematological system functions**	**C***
b455	**b455**	**Exercise tolerance functions**	**C***
b510	**b510**	**Ingestion functions**	**C***
b640	**b640**	**Sexual functions**	**C***
b710	**b710**	**Mobility of joint functions**	**C***
b715	b715	Stability of joint functions	Not confirmed
b730	**b730**	**Muscle power functions**	**C***
b740	**b740**	**Muscle endurance functions**	**C***
b770	b770	Gait pattern functions	Not confirmed
b780	b780	Sensations related to muscles and movement functions	Not confirmed
		Body structures	
s299	**s299**	**Eye, ear and related structures, unspecified**	**Confirmed according to similar category: s230**
s710	**s710**	**Structure of head and neck region**	**C***
s720	**s720**	**Structure of shoulder region**	**C***
s730	**s730**	**Structure of upper extremity**	**C***
s750	**s750**	**Structure of lower extremity**	**C***
s760	**s760**	**Structure of trunk**	**C***
s770	**s770**	**Additional musculoskeletal structures related to movement**	**C***
s810	**s810**	**Structure of areas of skin**	**C***

3

ICF Code	ICF Category Title	Patient Perspective
	Activities and participation	
d170	**Writing**	**C***
d230	Carrying out daily routine	Not confirmed
d360	Using communication devices and techniques	Not confirmed
d410	**Changing basic body position**	**C***
d415	**Maintaining a body position**	**C***
d430	**Lifting and carrying objects**	**C***
d440	**Fine hand use**	**C***
d445	**Hand and arm use**	**C***
d449	**Carrying, moving and handling objects, other specified and unspecified**	**Confirmed according to similar category: d430**
d450	**Walking**	**C***
d455	**Moving around**	**C***
d460	**Moving around in different locations**	**C***
d465	**Moving around using equipment**	**C***
d470	**Using transportation**	**C***
d475	**Driving**	**C***
d510	**Washing oneself**	**C***
d520	**Caring for body parts**	**C***
d530	**Toileting**	**C***
d540	**Dressing**	**C***
d550	**Eating**	**C***
d560	**Drinking**	**C***
d570	**Looking after one`s health**	**C***
d620	**Acquisition of goods and services**	**C***
d630	**Preparing meals**	**C***
d640	**Doing housework**	**C***
d660	**Assisting others**	**C***
d760	Family relationships	Not confirmed
d770	Intimate relationships	Not confirmed
d850	**Remunerative employment**	**C***
d859	**Work and employment, other specified and unspecified**	**Confirmed according to similar category: d850**
d910	**Community life**	**C***
d920	**Recreation and leisure**	**C***

4

ICF Code	ICF Category Title	Patient Perspective
	Environmental factors	
e110	**Products or substances for personal consumption**	**C***
e115	**Products and technology for personal use in daily living**	**C***
e120	**Products and technology for personal indoor and outdoor mobility and transportation**	**C***
e125	Products and technology for communication	Not confirmed
e135	**Products and technology for employment**	**C***
e150	Design, construction and building products and technology of buildings for public use	Not confirmed
e155	**Design, construction and building products and technology of buildings for private use**	**C***
e225	**Climate**	**C***
e310	**Immediate family**	**C***
e320	**Friends**	**C***
e340	**Personal care providers and personal assistants**	**C***
e355	**Health professionals**	**C***
e360	Other professionals	Not confirmed
e410	**Individual attitudes of immediate family members**	**C***
e420	**Individual attitudes of friends**	**C***
e425	**Individual attitudes of acquaintances, peers, colleagues, neighbours and community members**	**C***
e450	**Individual attitudes of health professionals**	**C***
e460	**Societal attitudes**	**C***
e540	Transportation services, systems and policies	Not confirmed
e570	**Social security services, systems and policies**	**C***
e580	**Health services, systems and policies**	**C***

Table 5. Additional ICF categories from the interviews

25 additional second-level categories emerged from the interviews with are not included in the current version of the ICF RA Core Set. *SE* indicates that some these categories could be related to side effects of drugs according to the existing literature.

IC	***F co de***	***ICF Category Title***	***2nd level***
b	*126 3*	*Psychic stability - SE*	*b 126*
b	126 5	Optimism	
b	*140 0*	*Sustaining attention - SE*	*b 140*
b	144	Memory functions	b 144
b	144 2	Retrieval of memory	
b	164 1	Organisation & planning	b 164
b	164 2	Time management	
b	455 2	Fatiguability	
b	*525 2*	*Frequency of defecation - SE*	*b 525*
b	760 1	Control of complex voluntary movements	b 760
b	760 2	Coordination of voluntary movements	
b	*820*	*Repair functions of the skin - SE*	*b 820*
b	*840*	*Sensations related to the skin - SE*	*b 840*
s	240	Structures of external ear	s 240
d	420 1	Transferring oneself while lying	d 420
d	650 5	Taking care of plants indoors and outdoors	d 650
d	750 0	Informal relationships with friends	d 750
d	870 0	Personal economic resources	d 870
e	140 0	General products and technology for culture, recreation and sport	e 140
e	165 0	Financial assets	e 165
e	315	Extended family	e 315
e	325	Acquaintances, peers, colleagues, neighbours and community members	e 325
e	330	People in positions of authority	e 330
e	350	Domesticated animals	e 350
e	430	Individual attitudes of people in positions of authority	e 430
e	445	Individual attitudes of strangers	e 445
e	455	Individual attitudes of other professionals	e 455
e	465	Social norms, practices and ideologies	e 465
e	555 0	Associations and organisational services	e 555
e	585 0	Education and training services	e 585
e	585 2	Education and training policies	

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Appendix 1 – Linking results of the qualitative study

Appendix 1 shows the result of linking the concepts which emerged from interview data to the ICF. Each concept was linked to the most detailed ICF category according to established linking rules. The numbers in the far right columns indicate how often the category was linked in each interview.

IC	F	Co	de	ICF Category title	Specification	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U
b	126	3		Psychic stability			2													1			1	1		1
b	126	5		Optimism																		2	1			
b	130			Energy and drive functions				2				1			3	1			3	1			1		1	
b	130			Energy and drive functions	Coordination of energy		1																			
b	130			Energy and drive functions	General fatigue					1														2			
b	130			Energy and drive functions	General fatigue/ SE					1																	
b	134	2		Maintenance of sleep							2																
b	134	3		Quality of sleep			1																				
b	144			Memory functions																1							
b	140	0		Sustaining attention	SE																			3			
b	144	2		Retrieval of memory																2							
b	152			Emotional functions	Feeling depressed/ feeling bad		2													2					1		
b	152			Emotional functions	Fear	1	4										1										
b	164	1		Organisation & planning				3											1					2			
b	164	2		Time management				1																			
b	180	2		Experience of time											1												
b	280			Sensation of pain			2	2		1				2	4	2	1	2	3					1	2	2
b	280			Sensation of pain	During night						1								1								
b	280			Sensation of pain	Massive pain																	2					
b	280			Sensation of pain	Pain from inflammation																	1					
b	280			Sensation of pain	Getting used to pain																		1				
b	280			Sensation of pain	Including numbness																			1			
b	280	1		Pain in body part	In joints							1															
b	280	1		Pain in body part	Increased pain when hitting oneself																			1			
b	280	1	4	Pain in upper limb			2	1				2				2			1					1	1	
b	280	1	5	Pain in lower limb			1					1												2		
b	430	3		Clotting functions																				1		
b	435	0		Immune response															2					2		1
b	445			Exercise tolerance functions	HC															1						
b	455	2		Fatigability						1					2									2			
b	455	2		Fatigability	SE					1																	
b	510	6		Regurgitation and vomiting	SE														1					1			
b	525	2		Frequency of defecation																1				1			
b	640			Sexual functions	Decreased desire																			1	1		
b	710			Mobility of joint functions		3		1											2	1		1					
b	710			Mobility of joint functions	Morning stiffness							1				2									3	1		
b	710	0		Mobility of single joint																1			1				
b	710	2		Mobility of joints, generalised																1		1	1				

ICF Co de	ICF Category title	Specification	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U
b 730	Muscle power functions										1	3		1									
b 730 1	Power of muscles of one limb				1						1								1		1		1
b 740	Muscle endurance functions				2						1	2											
b 760 1	Control of complex voluntary movements			1																			
b 760 2	Coordination of voluntary movements									3													
b 820	Repair functions of the skin																				1		
b 840	Sensations related to the skin																				2		
s 230	Structures around eyes															1					2		1
s 240	Structures of external ear															1							
s 320 0	Teeth															2							
s 710	Structure of head and neck region	Neck																	1				
s 720	Structure of shoulder region																1					1	
s 720 1	Joints of shoulder region							1									1						
s 730	Structure of upper extremity	Arms							1														
s 730 0	Structure of upper arm															1							
s 730 0 1	Elbow joint					1		1															
s 730 2	Structure of hand		2	2	5		1	1	2	2		4	4		1	2		1	1			1	1
s 730 2	Structure of hand	Finger		1				1		1													
s 730 2 1	Joints of hand and fingers								6														
s 750	Structure of lower extremity		3								1	1											
s 750 0 1	Hip joint		1					2													1		
s 750 1 1	Knee joint		1		2			1	2			3	2		1	1		1				3	
s 750 2	Structure of ankle and foot			3				2				1	2						1			1	
s 750 2 1	Ankle joint and joints of foots and toes		1	1	3			1		1													
s 760 0	Structure of vertebral column		1		3	1								1			1						
s 770 0	Bones																1						
s 770 1	Joints		1	1	1	1		1							1		1		1				
s 770 1	Joints	Friction																	1				
s 810	Structure of area of skin																1				1		1
d 170	Writing						3																
d 410	Changing basic body position	Getting out of bath tube								1													
d 410	Changing basic body position	Getting into a car																			2		
d 410 4	Standing			2					2	1	1		1	4	1	1	2				1		1
d 410 5	Bending																1	1					
d 415 0	Maintaining a lying position							1									1					1	
d 415 4	Maintaining a standing position				1																1	2	
d 420 1	Transferring oneself while lying																1						
d 430	Lifting and carrying objects			4	1								1			4	1		2		1	1	4
d 430	Lifting and carrying objects	Shopping goods																			2		1
d 430 0	Lifting								2														
d 430 1	Carrying in the hands			1																			
d 440	Fine hand use									1													
d 440 1	Grasping		1	1	1	1				2		1									2		
d 440 2	Manipulating					1																	
d 445	Hand and arm use		1						2				2			1							1
d 445	Hand and arm use	Opening a milk package							1														
d 445	Hand and arm use	To lean on something								1													
d 445	Hand and arm use	Using a coffee machine																	1				
d 445	Hand and arm use	Sailing																			1		
d 445 0	Pulling								1														
d 445 3	Turning or twisting the hands or arms		4		1											1			2				3
d 450	Walking		3	1		2				1		1				2	1	1		1		1	2
d 455	Moving around	From one place to														1							

ICF Code	ICF Category title	Specification	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U
		another																					
d 455	Moving around	To ascend																		1			
d 455 1	Climbing					1			2			1	3				1		1	1	4	3	1
d 455 2	Running											1			1		2						
d 460	Moving around in different locations	Mountaineering/ Walking up-hill	2							1								3			1	1	
d 460	Moving around in different locations	Going outside with dog										1											
d 460 0	Moving around within home				1									2									
d 465	Moving around using equipment	Skiing equipment	2																		1		
d 470	Using transportation								2			1											
d 470 2	Using public motorized transportation																				2		
d 475	Driving							1															
d 475 0	Driving human powered transportation																	1			1		
d 475 1	Driving motorized vehicles								2												1	1	
d 510	Washing oneself			1																			
d 510	Washing oneself	Taking a shower		1																			
d 510 0	Washing body parts															1			1			2	
d 510 2	Drying oneself																		1			1	
d 520 1	Caring for teeth												1			2							
d 520 4	Caring for toenails																	1					
d 530 1	Regulating defecation															1							
d 540	Dressing								1							1							
d 540 0	Putting on clothes																1		1				
d 540 2	Putting on footwear					1											1						
d 550	Eating															1							
d 560	Drinking					1																	
d 570	Looking after one's health	Diet	1									1	1							1	1		
d 620 0	Shopping					1			2							1				1	1		
d 630	Preparing meals				1					1										1			
d 630	Preparing meals	Breakfast							1					1									
d 630	Preparing meals	Preparing vegetables and other ingredients			2	2										1							
d 630	Preparing meals	Stirring				1																	
d 630	Preparing meals	To pour off a cooking pot														1							
d 640	Doing housework		1	1								1		1									
d 640 1	Cleaning cooking area															1							
d 640 2	Cleaning living area											2								1			
d 640 3	Using household appliances			2					1		1	1	1				1			1			1
d 650 5	Taking care of plants indoors and outdoors							1	1							1							
d 660	Assisting others																1						1
d 660 0	Assisting others with self-care				1																		
d 660 5	Assisting others in health maintenance				1																		
d 750 0	Informal relationships with friends															1					1	1	
d 845 1	Maintaining a job			3			3		2														
d 845 2	Terminating a job								1														
d 850	Remunerative employment			6				1											1			4	
d 870 0	Personal economic resources			1																			
d 910 2	Ceremonies																	1					
d 920	Recreation and leisure	Gardening						1	1							1							
d 920	Recreation and leisure	To make a day trip																	1				
d 920	Recreation and leisure	To go outside with children										1											
d 920 1	Sports		2															1			3		
d 920 2	Arts and culture		1															5					

ICF Co de	ICF Category title	Specification	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U
d 920 5	Socializing																			1			
e 110 0	Food		1																	1			
e 110	Products and substances for consumption	Smoking																		1			
e 110 1	Drugs +			3	1		2	2	2	1	3	3				1	2	1			2	3	2
e 110 1	Drugs +/-	Side effects	1	3								1									4	1	
e 115	Products and technology for personal use in daily living	Dishes																			1		
e 115	Products and technology for personal use in daily living	Bath tube		1						1													
e 115 1	Assistive products and technology for personal use in daily living	Splints		1																			
e 115 1	Assistive products and technology for personal use in daily living	Assistive devices		7		2															5		1
e 115 1	Assistive products and technology for personal use in daily living	Orthopaedic shoes		1																1			
e 115 1	Assistive products and technology for personal use in daily living	Resting splints						1															
e 115 1	Assistive products and technology for personal use in daily living	Ready made food																		1			
e 120	Products and technology for personal indoor and outdoor mobility and transportation	Device for carrying shopping goods		2	1				1		1												
e 120	Products and technology for personal indoor and outdoor mobility and transportation	Products for carrying patients		1																			
e 120 0	General products and technology for indoor and outdoor mobility and transportation	Car															1						
e 120 1	Assistive products and technology for personal indoor and outdoor mobility and transportation												1										
e 135 0	General products and technology for employment	Computer					1																
e 140 0	General products and technology for culture, recreation and sport		1																				
e 140 0	General products and technology for culture, recreation and sport	Music instruments																2					
e 155	Design, construction and building products and technology of buildings for private use	Apartment		1	1											1					2		
e 165 0	Financial assets															1						1	
e 225 5	Seasonal variation											2					1						2
e 310	Immediate family members		2	8	9						3	1		1	4	8			1	1	1	2	2
e 315	Extended family																				1		
e 320	Friends															4					1		
e 325	Acquaintances, peers, colleagues, neighbours and community members			2								1											
e 330	People in positions of authority																		1				
e 340	Personal care providers and personal assistants								2		1			7		1							1
e 350	Domesticated animals											1											
e 355	Health professionals			3			2		3	1		3		2				1			2		
e 410	Individual attitudes of immediate family members			6																	1	1	
e 420	Individual attitudes of friends															1					1	1	
e 425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members			1																			
e 430	Individual attitudes of people in positions of authority			3																			
e 445	Individual attitudes of strangers																				1		
e 450	Individual attitudes of health professionals			1																	1	1	
e 455	Individual attitudes of other																				1	1	

ICF Code	ICF Category title	Specification	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U
	professionals																						
e 460	Societal attitudes			1					1			2									1		
e 465	Social norms, practices and ideologies			1																			
e 555 0	Associations and organisational services	Self-help group										1											
e 570	Social services, systems and policies															1							
e 570 0	Social security services				1									1									
e 570 1	Social security systems															1							
e 570 2	Societal security policies																				1	2	
e 580	Health services, systems and policies	Health insurance		2																			
e 580 0	Health services		1	2			2	2	1	1		1						1			1	1	1
e 580 0	Health services	Occupational therapy							1												1		
e 580 2	Health policies	Insurance companies																			1	1	
e 585 0	Education and training services			2																			
e 585 2	Education and training policies			2																			
	Mental functions		1																				
	Structures related to movement							2								1	1					1	
	Mobility	Moving in general	2		2				1						1	2	1				2		
	Self-care			1															1				
	Domestic life	Removing snow			1				1	1			3										
	Support and relationships																			1			
	Support and relationships	People of environment	1		2																		
	Support and relationships	Being alone																			1		
	Attitudes	Attitudes of patients		1																			
	Attitudes	Asking for help																			1		1
	nd-b	Physical stress		2								1							1				
	nd-b				1									1									
	nd-s								1														
	nd-qol	Quality of life		1				1					1										
	nd-time-d (duration)	Factor time: Breaks reduce time						2															
	nc-hc	Changes in disease activity	1	1					1			3			1		3			2	1	2	1
	nd-d (a+p)			1			1								3								
	nd-gh						1																
	nc	Factor time: To compare between earlier and now									1				1			2	1			1	
	nc	PF-SP		4																	1	1	
	nc	PF: Attitudes of oneself															1					1	
	nc	PF: To keep up		1																			
	nc	PF: To want to reach something		1																			
	nc	PF: Habits								1	1					1							
	nc	PF: To make the best out of it																	1				
	nc	Employer's policies		3															1				
	nc	Prevention		1																			
	nc	PF-kn		1								6				1						1	
	PF	Lying		2																	1		

SE = Side effects of drugs; hc = Health condition; nc = not covered; nd = not definable; nd-b = not definable, body functions; nd-s = not definable, body structures; nd-d = not definable, activities & participation; nd-qol = not definable, quality of life; nd-d (nd-a+p) = not definable, activities and participation; nd-gh = not definable, general health; PF-sp = personal factor, self-perception; PF-kn = personal factor, knowledge;

Appendix 2 – An example of one transcribed interview

Appendix 2 shows an example of a transcribed open interview and the meaning condensation analysis in which the concepts (in bold letters) were identified and linked to the ICF (in the far right column). Each paragraph contains one meaning unit.

Gaby – 1.2.2004 - 1.2	
Introduction to the ICF	
T: Wenn Sie jetzt an Ihren Körper denken: Was funktioniert nicht oder womit gibt es Schwierigkeiten?	
G: Am **Fuß** habe ich **Schwierigkeiten** und mit den **Händen**, **allgemein**.	S7502 Structure of ankle and foot S7302 Structure of hand Nd-a
So **wegen meiner Arbeit und wegen meiner alltags habe ich Probleme**. Z.B. ich bin belastet, dann hab ich **viele Dienste,** dann hab ich bemerkt, ich **kann meine Energie nicht koordinieren**,	d850 Remunerative employment B130 Energy and drive functions: Coordination of energy
also (Pause) mein **Gleichgewicht nicht so gut**.	B7601 Control of complex voluntary movements
Und dann am Abend meine **Füße** ist **irrsinnig**	S7502 Structure of ankle and

schmerzhaft, geschwollen, meine **Hände** auch, wegen meiner Berufstätigkeit sozusagen. Also es sind meine **Hände** und meine **Füße**.	foot S7302 Structure of hand B28014 Pain in upper limb B28015 Pain in lower limb
T: Mit welchen Bereichen oder Teilen Ihres Körpers haben Sie Probleme?	
G: Direkt in **Gelenken** und von **Händen die Finger**, und **wegen Lauferei, der Fuß**, also direkt.	S7701 Joints S7302 Structure of hand: Finger S7502 Structure of ankle and foot
T: Wenn Sie jetzt an Ihren Alltag denken, was sind Ihre größten Probleme? Welche Lebenssituationen oder welche Alltagssituationen sind für Sie problematisch?	
G: Für mich problematisch in Alltagssituation: Mein Zustand ist schlecht sozusagen, mache 3 Tage Dienst, dann habe ich **Probleme beim Aufstehen**, dann habe ich **Probleme Glas zu halten**, dann habe ich **Probleme Duschen** (Pause) letztes Mal, dann **hab ich keine Duschwanne**, sondern eine **Badewanne**, ich konnte mich nicht	Nd: HC D4104 Standing D4401 Grasping D510 Washing oneself: taking a shower E115 Products and technology

herauszukommen, z.B. Oder **zum Einkaufengehen** habe ich extra **Einkaufwagerl** gekauft, weil sonst kann ich nicht mit den **Händen zum Tragen**, oder **Rucksack zum Einkaufengehen**, weil direkt in der **Hand** kann ich nicht tragen. Und **beim Arbeiten**, ich sag' ehrlich, das hab ich nicht gesagt, welche Krankheit hab ich, weil z.B. da hab ich die Pflegenostrifikation gemacht, da kriegen wir ein Formular, da müssen wir draufschreiben: Haben Sie zur Zeit Behandlung, oder haben Sie eine chronische Erkrankung? **Ich sag ehrlich, hab ich gelogen, weil ich weiß, kann ich dann nicht in die Schule teilnehmen.** Für das Diplom z.B. jetzt muss ich auch wieder lügen, **weil für den Fall hab ich eine chronische Erkrankung, dann hab ich keine Chance, zur Schule zu gehen**. Das geht in diese Richtung. **Ich bin diplomierte Krankenschwester** von meinem Land und ich **möchte das nostrifizieren lassen**, und **möchte noch eine Schule machen, mit einem leichteren Job.** Aber für mich dieses	for personal use in daily living: Bath tube e120 Products and technology for personal indoor and outdoor mobility and transportation: devices for carrying shopping goods (2x) d430 Lifting and carrying d4301 Carrying in the hands d850 Remunerative employment nc: lying E5850 Education and training services E5852 Education and training policies D850 Remunerative employment E5850 Education and training services nc: lying

Studium muss ich durchkämpfen. Und leider Gottes, **ich darf nicht die Wahrheit sagen,** weil ich eine chronische Erkrankung hab.	
Z.B. im Dezember war ich zur Kontrolle hier im Krankenhaus, da hab ich die **Spritzentherapie** bekommen, bei der **Krankenkasse muss ich dort das bewilligen lassen** und die **Frau Doktor** hat mich 3 Stunden untersucht. Da hat sie mir nicht geglaubt, wie kann ich mit meiner Krankheit zum Arbeiten gehen diesen Beruf. **Warum sind Sie nicht im Rollstuhl?** Hat sie mir das gesagt, weil die Hände waren auch (Pause)	E1101 Drugs E580 Health services, systems and policies: Health insurance E355 Health professionals E450 Individual attitudes of health professionals
und die **Schmerzen in den Füßen, das war für mich eine Qual, dort hinzugehen.** Aber ich wollte zeigen, wirklich, wie mein Zustand sieht aus. Die Frau Dr. hat zu mir gesagt: Das ist ein Wunder überhaupt, dass Sie sitzen nicht im Rollstuhl. Und wie können Sie im Beruf täglich das machen, was Sie machen. Ich hab gesagt: **Das halte ich durch, ich möchte** eine gewisse - **etwas zum Erreichen, da hab ich keine andere Wahl.** Ich liebe meinen **Job,** das sag ich mit ganzem Herzen, aber ich weiß, ich kann diesen Beruf nicht	B28015 Pain in lower limb D450 Walking PF: To keep up PF: To want to reach something D8451 Maintaining a job

20 Jahre machen wegen meiner Erkrankung, das ist schwer, (Pause) hab ich ihr gesagt (Pause) Sehnenscheidenentzündung, das habe ich gelogen, weil ich trage einen **Schutz oder Schiene** oder so was. Ich weiß, mein tägliches Leben, **das wird nicht akzeptiert** ein chronisch kranker Mensch, mit meinem Beruf, das wird nicht akzeptiert. **Ich kriege keinen Job, wenn ich sage, ich hab chronische Polyarthritis,** Entschuldigung, **ich muss jeden 3. Monat oder 8 Wochen Kontrolle zu gehen**, weil ich krieg keinen Job.	e1151 Assistive products and technology for personal use in daily living: splints e430 Individual attitudes of people in positions of authority E5800 Health services
T: Man ist gezwungen, zu lügen in dem Fall.	
G: Im gewissen schon. Sehen Sie, die Formular für die Schule, es wird ganz genau gefragt: Haben Sie kurze Zeit Therapie gehabt? Haben Sie langzeitige Therapie? Haben Sie chronische Erkrankungen? Welche Medikamente nehmen Sie? Welche nehmen Sie? **Und ich möchte das machen, möchte das schaffen, und darum darf ich das nicht schreiben.** Das darf ich nicht. Was mach ich dann? **Wo kann ich hingehen? Wer will mir helfen? Ich bin eine Ausländerin.** Irgendwie wegen meiner Selbst-Sicherheit und was ich möchte zum Erreichen, nein, es geht	E5852 Education and training policies B152 Emotional functions: Fear B152 Emotional functions: Feeling bad PF-SP E460 Societal attitudes

nicht. Das gefällt mir nicht, **aber das jetzige System ist so,** leider Gottes so.	
Wirklich, können Sie meine **Chefin** anrufen. Außer meiner großen Klappe habe ich keine große Probleme. Aber ich arbeite sehr gern. **Alle meine Patienten zufrieden mit mir.** Ich hab **keine Probleme mit meinen Kollegen, Kolleginnen.**	E465 Social norma practicies and ideologies e430 Individual attitudes of people in positions of authority Attitudes: Attitudes of patients e425 Individual attitudes of acquaintances, peers, colleagues, neighbours and community members
Ich liebe meinen Job. **Ich möchte** in der Altenpflege **bleiben, aber ein bisschen leichterer,** weil ich weiß, wegen meiner Krankheit, leider Gottes, kann ich nicht. Jetzt hab ich eine gute (Pause), sozusagen, die **Spritzentherapie.** Ich hoffe immer, ich geb' das nicht auf, es wird ändern, besser werden. Aber ich weiß, **ich bin krank, ich werde nie gesund.** Es wird dauern, bis eine neue Generation wird geboren, dann ist es möglich, diese Krankheit zu besiegen, sozusagen (Pause) überhaupt.	D8451 Maintaining a job E1101 Drugs B152 Emotional functions: Feeling depressed PF: Lack of knowledge
Und ich muss mein ganzes Leben das tragen,	

jeden Tag, Nacht, mein ganzes Leben, das mach ich bewusst. Das mach ich bewusst. Weil ich weiß, wo ist meine Grenze, was kann ich machen. Manchmal ich übertreibe (Pause) die Menschheit. Ich denke so im Pflegeheim, das kann meine Großmutter sein, das kann mein Großvater sein, wir sind Menschen, und machen auch Fehler, also Menschlichkeit. Leider habe ich geraucht, (Pause) in letzter Zeit habe ich eine Patientin verloren, habe ich psychisch viel gelitten. Am nächsten Tag hab ich bemerkt, ich hab wenig geschlafen, psychisch war nicht gut, (Pause) weiß ich auch selbst, kann ich auch, muss mich beherrschen, und zurückzuhalten, und lernen tief atmen, eins, zwei, drei, vier, fünf, zehn - geht weiter. Werde das ich nicht machen, dass meine Kollegin sagt: Du bist (Pause) In letzter Zeit (Pause) **Ich muss mich ändern, mich selbst ändern, weil für mich wird es nicht besser,** für die andern (Pause) phantastisch und gut, aber für mich selbst wird es nicht gut sein.	Nd: PF-SP
T: Wenn Sie so an Ihre Lebensumstände denken, was ist da bezogen auf die Krankheit hinderlich für Sie und was ist eine Hilfe für Sie?	
G: Also, hinderlich für mich und meine Krankheit	

ist, ich hab **viel körperliche Belastung** mit meinem **Job**. Ich muss **gehen**, ich kann auch **keine extra Maschine** für den Patient vom Bett zum Rollstuhl, oder vom Rollstuhl zum Bett, das machen wir selber. Die Umlagerung, das auch allein geht nicht. Haben wir große Patienten, schwere Patienten mit Gewicht.	Nc: Physical stress D8451 Maintaining a job E1208 Products and technology for indoor and outdoor mobility and transportation
Noch dazu, wir sind - Wenn ich nur mit meinem **Job** zu tun hätte, dann wäre das nicht eine **große Belastung.** Aber, wo ich arbeite, **ich bin Putzfrau, ich bin Kellnerin, ich bin alles, und dann als letzte Schwester. Und das belastet mich, wissen Sie.** Nicht mein Job. Ich hab jemanden gebadet, oder jemanden habe ich geduscht, oder jemanden habe ich angezogen, ausgezogen, oder eingeschmiert, oder Verband hab ich gewechselt. Das macht mich nicht körperlich müde. Sondern, **wo ich arbeite, die Küche ist weit weg,** ich muss wegen kleinen oder großen Tableau zu holen für die Patienten für jeden Stock, zehn, zwölf Essen. Und nicht mit Wagerl, wir können in die Küche für die Gebäude nicht Platz (Pause). **Wir müssen mit Händen zu tragen**. **Und das macht mich kaputt.** Das ist	d850 Remunerative employment NC: Employer's policies e430 Individual attitudes of people in positions of authority d430 Lifting and carrying objects Body structures d430 Lifting and carrying objects

schwer. Viele meiner ehemaligen Kollegen oder Kolleginnen darum ist weggegangen, nicht nur wegen dem Lohn, sondern wegen der **körperlichen Belastung**, viel zum **Tragen**. Und wir wissen, das gehört nicht zu unserem Job. An Wochenenden, Feiertagen müssen wir **putzen**, **müssen wir Betten machen**. Also (Pause) oder Schwester. Und das, wirklich der Job, was ich wirklich möchte, das macht mich nicht müde, das macht mich nicht kaputt. Diese Lauferei, hin und her, und dann zurück, das macht mich müde. Wirklich, ich konzentriere für die Patienten, dann bin ich nicht müde. Aber jetzt versuchen wir mit unserer Chefin **Änderungen,** mehr Abteilungspraktikanten zum Aufnehmen, von diese Tragerei, können die das machen. Und wir konzentrieren uns für die Patienten. Wissen Sie, wie schön ist das? Ab und zu geht, nicht Montag bis Freitag, das leider Gottes nicht, wegen die Stunden, das geht nicht, aber zweimal in die Woche. Ich merke die Unterschied, wenn hab ich die Patienten gehabt wirklich, wenig müde bin ich, wenig belastet, körperlich und seelisch, als nachher noch (Pause).	nc: Physical stress d850 Remunerative employment NC: Employer's policies NC: Employer's policies

Also wirklich, ich liebe meinen Job, aber das macht mich kaputt. Ich geh im gleichen Kleid in die Küche. Wie schaut das aus. Vorher haben wir die ganzen Vorschriften gehabt: Kopftuch, Mundschutz, alles angezogen Es ist schwer. Darum hab ich viele Kollegen und Kolleginnen verloren. Ich bin seit 5 Jahren in diesem Pflegeheim.	
T: Und welche Faktoren sind eine Hilfe für Sie?	
G: Für mich was ist eine Hilfe, ich hab z.B. für **meine Küche habe ich spezielle Sachen hab ich gekauft.** Hab ich **Schere, spezielle Schere,** und zum **Schneiden, Brot schneiden, spezielle Messer.** Dann hab ich **Aufmacher für Glas** hab ich gekauft. Dann es gibt da, ich kann nicht links etwas zum **Tragen**, sondern nur rechts zur Seite, rechts **spezielle Becher** so von beiden Seiten, nicht von einer Seite, sondern von beiden Seiten. (Pause) Manchmal hab ich, ich kann nicht von einer (Pause), ich muss so halten (Pause). Dann für mich, hab ich noch **die Schienen, das brauch ich im Haushalt, wenn ich staubsauge oder bügle, das muss ich unbedingt, weil dann später hab ich Probleme.** Das hab ich. Dann hab ich jetzt spezielle **orthopädische Schuhe** machen	E1151 Assistive products and technology for personal use in daily living (5x): assistive devices d430 Lifting and carrying objects E1151 Assistive products and technology for personal use in daily living (2x): assistive devices/ splints D640 Doing housework D6403 Using household appliances (2x) Prevention E1151 Assistive products and

lassen, **die Krankenkasse hat das nicht bezahlt,** bis hier Leder (Pause) spezielle Schuhe hatte ich 2 Jahre schon kaputt. Das ist für **die Füße** und **meine Arbeit**.	technology for personal use in daily living: orthopedic shoes E580 Health services, systems and policies: Health insurance d850 Remunerative employment S75021 Ankle joint and joints of foots and toes
T: Wenn Sie an Ihre Person denken, was ist entscheidend, wie Sie mit Ihrer Krankheit umgehen? Wenn Sie an sich selber denken.	
G: **Am Anfang** hab ich **Angst gehabt**. Hab ich irrsinnige Angst gehabt, weil hab ich ... **Langzeitmedikamentation, hab ich Zyste gehabt in den Nieren**, nicht groß geworden, Gottseidank. Habe ich operieren lassen. Wegen der Medikamente hab ich Angst gehabt am Anfang. Ich hab **meine Scheidung** gehabt. Ja, was mach ich dann? Im Rollstuhl sitzen**, wer kann sich kümmern,** wie kann ich von meiner **Mutter** das machen. (Pause) Sie ist auch nimmer jung, sie ist auch Krankenschwester. **Aber wie schaut das aus, sie betreut mich,** und nicht ohne **Geld** kann ich zu ihr gehen. Am Anfang hab ich eine	B152: Emotional functions: fear E1101 Drugs e310 Immediate family (2x) Self-care e410 Individual attitudes of immediate family members d8700 Personal economic resources

irrsinnige Angst gehabt. Die jetzige Angst, jetzt hab ich Angst allgemein wegen meiner Krankheit. **Ich möchte Familie gründen, möchte ein Baby haben,** anatomisch gesehen, ich bin gesund, **aber wegen der Therapie**. Deswegen hab ich **Angst**. Ich möchte schwanger werden. Es gibt diese Möglichkeit, aber unter Aufsicht und Kontrolle vom **Arzt.** Aber ich sag ehrlich und bewusst, wenn wird festgestellt, mein Kind ist behindert von meiner Schwangerschaft, kann ich abtreiben lassen. Ich möchte nicht dieses Risiko aufnehmen, wenn ich weiß, mein Kind/ mein Baby kann meine Krankheit bekommen. **Wie kann ich das sehen, wenn mein Kind leidet**, weil ich (Pause) deswegen die Krankheit, hab ich **Schmerzen,** und hab ich dann **Probleme.** Wie kann ich ihn oder es betreuen. Und die tägliche Pflege **mit baden und waschen.** Dann hab ich Probleme, wie kann ich mein Kind das so lassen. Unlängst hab ich **eine ungarische Dame kennen gelernt**, die hat einen Bub und ein Mädchen, aber	B152: Emotional functions: fear (2x) e310 Immediate family E1101 Drugs E355 Health professionals Nd: PF-SP B280 Sensation of pain D510 Washing oneself E325 Acquaintances, peers, colleagues, neighbours and community members (chapter support)

sie hat die Krankheit schon als 6 Jahre altes Kind. Also irgendwie hab ich so gefragt, hab ich gesehen, **es gibt schwangere Frauen mit meiner Krankheit** und es gibt immer natürlich jede Woche Kontrolle wegen der Schwangerschaft. Ich sage so: wenn es festgestellt wird, darf ich, ich versuche. Und wenn festgestellt wird, dass ich nicht darf, dann lass mich sterilisieren.	E325 Acquaintances, peers, colleagues, neighbours and community members (chapter support) e310 Immediate family
Ich hab mit **meinem Freund** auch gesprochen, hab ich Angst gehabt davon, welche Antwort ich von ihm bekommen werde. Aber er hat zu mir gesagt, wenn wir uns besser fühlen, können wir Kinder bekommen. Es ist kein Problem, man darf so nicht, er hat gesagt, wegen meiner Krankheit kannst du in einen schlechten Zustand kommen. Dann kein Problem, können wir (Pause). Also ihn ist es auch bewusst. Er weiß, **er hat mich schon im schlechten Zustand gesehen, musste mich tragen, ich konnte nicht aufstehen.** Am nächsten Tag hat **er mich zum Arzt gebracht**, er hat schon mich gesehen, wie mein Zustand ist, wenn ich schon in schlechter Phase, hab ich sozusagen, ich hoffe, ich geb' nicht auf. Aber ich	E410 Individual attitudes of immediate family members D4104 Standing e310 Immediate family

akzeptiere dann, wird so gesagt, tut mir leid (Pause). Ich möchte nicht, ich selber nicht psychisch, körperlich ich leide davon. Wie kann ich mein Kind sehen, es hat Schmerzen, muss eine Schiene tragen, und ein ganzes Leben vielleicht im Rollstuhl sitzen, das mach ich nicht mit.	
Ich war schon dreimal schwanger, aber habe in der Schwangerschaft Entzündungen gehabt und leider Gottes hab ich es verloren, das war fast 6 Monate und war ich zwanzig, dann bin ich wieder zufällig war ich schwanger geworden. (Pause) Weil, das ist sozusagen unerwartet und nicht gewünschte Schwangerschaft gewesen. Ich hab darüber gefreut, aber mein **Partner** nicht, das hat mich sehr belastet. Ich bin ehrlich zu ihm, aber er hat zu mir gesagt, das ist kein Problem, das werden wir durchmachen. **Also er steht zu mir**, er weiß über meine Krankheit Bescheid, hab ich ihm ein Prospekt und Buch gegeben, er hat es gelesen, also er weiß es. **Macht sich große Sorgen** über mich (Pause), **sagt nicht: du musst jetzt Holz tragen** und mach den Haushalt, dauert zwei Tage und dauert drei Tage, so **akzeptiert er, was ich kann.** Er schätzt das, was ich mache	e310 Immediate family E410 Individual attitudes of immediate family members E410 Individual attitudes of immediate family members E410 Individual attitudes of immediate family members e310 Immediate family

(Pause). Nein, das ist nicht so. Z.B. mein **Exmann** hat zu mir gesagt, wann diese Krankheit hab ich gekriegt, was soll ich machen. Ich musste mich selbst, ich bin jetzt allein, niemand steht zu mir, o.k. versuchen wir.	E410 Individual attitudes of immediate family members
Du musst gesund werden, du musst Arbeit suchen, und und und, eines nach dem anderen, also so langsam. Und jetzt habe ich geschafft, habe eine **kleine schöne Wohnung**, o.k. gemietete Wohnung, aber was drinsteht, das ist alles meins. **Das habe ich allein geschafft.**	E155 Design, construction and building products and technology of buildings for private use: Wohnung Nd: PF-SP Nd: Educational interest
Jetzt ich versuche die Nostrifikation für das Diplom (Pause) **Führerschein machen**, (Pause) egal wie sich mein Freund entscheidet ... im August werde ich fertig, ich werde jetzt 31, am 2. Februar. **Und dieses Hin- und Herzufahren, er fehlt mir sehr.** Wissen Sie, ich möchte mit ihm zusammenleben, weil es ist nichts, jede zweite Woche ein paar Tage wir sehen uns, als jeden Tag. Es ist wieder anders, es ist wunderschön, aber keine Zeit zum Streiten, weil dann freuen wir uns und er kennt meine Seite, beide Seiten, dann hab ich (Pause) Leider Gottes hab ich (Pause) schlecht dann, ich	e310 Immediate family

kann dann sehr korrekt zu sein. Ich kenne von ihm nur seine gute Seite, aber ich hab ihn nie aggressiv gesehen oder explodiert gesehen oder enttäuscht. Er hat immer unterstützt und redet mit mir. Für mich ist es jetzt wichtig, das erzielen.	
Jetzt kann ich in ungarischer Sprache die Fahrschule machen, es gibt in Wien auch in ungarischer Sprache die Fahrschule machen. Noch etwas muss ich warten wegen die Papiere, wegen dem Diplombescheid, das wird anders beurteilt. Also langsam, bis jetzt hab ich es geschafft. Bitte schön, meine Mama war über 50, wie sie in die Schule gegangen ist wieder. Da hab ich noch genug Zeit. **Lernen mein ganzes Leben**, besser sterben (Pause) das ist bei uns ein Sprichwort. Also, ich muss mich beruhigen, wegen meiner Arbeit auch. Für mich ist nicht egal die Menschen, das macht mich nervös.	Nd: Educational interest B1263 Psychic stability (2x)
Darum hab ich **viele psychische Belastungen** auch, d.h. es ist nicht egal. Für mich ist es nicht egal, und warum, weil ich bemerke,	B1343 Quality of sleep B280 Sensation of pain
weil ich schlafe wenig, und hab ich so **viele**	Nd-qol

Sorgen sozusagen, dann **meine Gesundheit ist auch schlecht**, habe ich **Schmerzen, ich fühle mich mies, körperlich und seelisch.**	
T: Das hängt auch zusammen.	
G: Genau, das habe ich bemerkt. Und meine praktische **Ärztin** möchte eine **Kur beantragen**.	E355 Health professionals E5800 Health services

Curriculum Vitae

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Akademischer Grad:	Magistra Philosphiae

Berufliche Tätigkeit

Seit Jänner 2003	Wissenschaftliche Mitarbeiterin und Doktorandin am Institut für Physikalische Medizin und Rehabilitation an der Ludwig Maximilians Universität München, Deutschland
Seit Oktober 2001	Lehr- und Unterrichtstätigkeit für Wissenschaftliches Arbeiten und Evidence Based Practice als freie Mitarbeiterin an verschiedenen Institutionen im Gesundheitsbereich
Seit Juni 1999	Projektmanagerin und wissenschaftliche Biometrikerin am Institut für Rheumatologie, Universität Wien
Seit Oktober 1998	Freiberufliche Tätigkeit als Ergotherapeutin
März 2001 – März 2003	Vorstandsmitglied im Berufsverband der Dipl. Ergotherapeuten Österreichs, Wien
November 1998 - Mai 1999	Mobile Ergotherapie im Bezirk Klosterneuburg, NÖ Hilfswerk, Niederösterreich
Februar 1996 – Oktober 1998	Ergotherapeutin am Orthopädischen Spital Speising, Wien

Studium

Oktober 2001 – Oktober 2003	Studium für Betriebswirtschaft und Management, MBA Degree, an der TU Wien und Donau Universität Krems, Niederösterreich
September 2000 – September 2002	Studium für Medizinische Wissenschaft in Occupational Therapy, MSc Degree, in den Niederlanden, Schweden, Dänemark und Großbritannien

Oktober 1995 – April 1999	Studium der Pädagogik und Sonder- und Heilpädagogik an der Universität Wien
Oktober 1992 – Oktober 1995	Studium der Ergotherapie an der Akademie für Ergotherapie, 1090 Wien

Schulausbildung

1980 – 1984	Volksschule, 1180 Wien
1984 – 1992	Neusprachliches Gymnasium Haizingergasse, 1180 Wien
Juni, 1992	Abschluss mit Matura
Sprachen	Englisch (TOEFL 270), Französisch, Russisch (Basics)

Fortbildungen

1995 - 2002	Wissenschaftliche Methodik, Projektmanagement, Business Englisch, Rechnungswesen, Sensorische Integration, Handtherapie, Cyriax-Therapie, Therapeutisches Klettern

Weitere Tätigkeiten

Seit Juni 2000	Jugendführerin des Österreichischen Alpenvereins – Sektion Österreichischer Gebirgsverein

Zusätzliche Qualifikationen

EDV	Windows 2000, Microsoft Word, Microsoft Excel, Microsoft Power Point, SPSS, NVivo, Graph Pad Prism, Microsoft Access
Rechnungswesen	Buchhaltung, Kostenrechnung
Statistik	Planung, Erstellung und Auswertung von medizinischen Datenbanken
Forschung	Planung, Durchführung und Leitung quantitativer und qualitativer wissenschaftlicher Projekte
Projektmanagement	Planung, Durchführung und Leitung von Projekten im Bereich Qualitätssicherung und Entwicklung im Gesundheitswesen
Betreuung von Studenten	Betreuung von Diplomarbeiten, Praktikumbetreuung

Persönliche Interessen

Reisen, verschiedene Kulturen kennen lernen
Sport: Klettern, Bergsteigen, Schifahren, Kampfsport

.....
Wien, 24.1.2005

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