University of Groningen

Human functioning in health care

Stallinga, Hillegonda Alida

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2015

Link to publication in University of Groningen/UMCG research database

Citation for published version (APA):
Stallinga, H. A. (2015). *Human functioning in health care: Application of the International Classification of Functioning, Disability and Health (ICF)*. [Thesis fully internal (DIV), University of Groningen]. University of Groningen.

Copyright
Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the “Taverne” license. More information can be found on the University of Groningen website: https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment.

Take-down policy
If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): http://www.rug.nl/research/portal. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.

Download date: 04-12-2023

Human Functioning in Health Care

Application of the International Classification of Functioning, Disability and Health (ICF)

Hillegonda A. Stallinga

Human functioning in health care

Hillegonda Alida Stallinga

Colofon

The research for this thesis was conducted within the School of Nursing and Health at the University Medical Center Groningen, the Department of Rehabilitation Medicine at the University Medical Center Groningen, and the Research Institute SHARE at the Graduate School of Medical Sciences, University Medical Center Groningen, University of Groningen, the Netherlands.

The author gratefully acknowledges the financial support of the University Medical Center Groningen, Research Institute SHARE, and the University of Groningen for printing this thesis.

Cover: Henk Stallinga, Studio Stallinga, Amsterdam: www.stallinga.nl
Lay-out: LS Advies, Ten Post: www.ls.nl
Photograph: Jacob Wilkens, Groningen
Printed by: Gildeprint, Enschede

ISBN/EAN 978-90-367-8061-2 (book)
ISBN/EAN 978-90-367-8060-5 (electronic)

rijksuniversiteit
groningen

Human functioning in health care

Application of the International Classification of Functioning, Disability and Health (ICF)

Proefschrift

ter verkrijging van de graad van doctor aan de
Rijksuniversiteit Groningen
op gezag van de
rector magnificus prof. dr. E. Sterken
en volgens besluit van het College voor Promoties.

De openbare verdediging zal plaatsvinden op

woensdag 14 oktober 2015 om 16.15 uur

door

Hillegonda Alida Stallinga

geboren op 15 oktober 1961
te Amsterdam

Promotores
Prof. dr. P. F. Roodbol
Prof. dr. P. U. Dijkstra

Copromotor
Dr. G. J. Jansen

Beoordelingscommissie
Prof. dr. T. van Achterberg
Prof. dr. M. J. Schuurmans
Prof. dr. A. V. Ranchor

Paranimfen:
Dr. Gert Schout
Dr. Wiebe de Vries

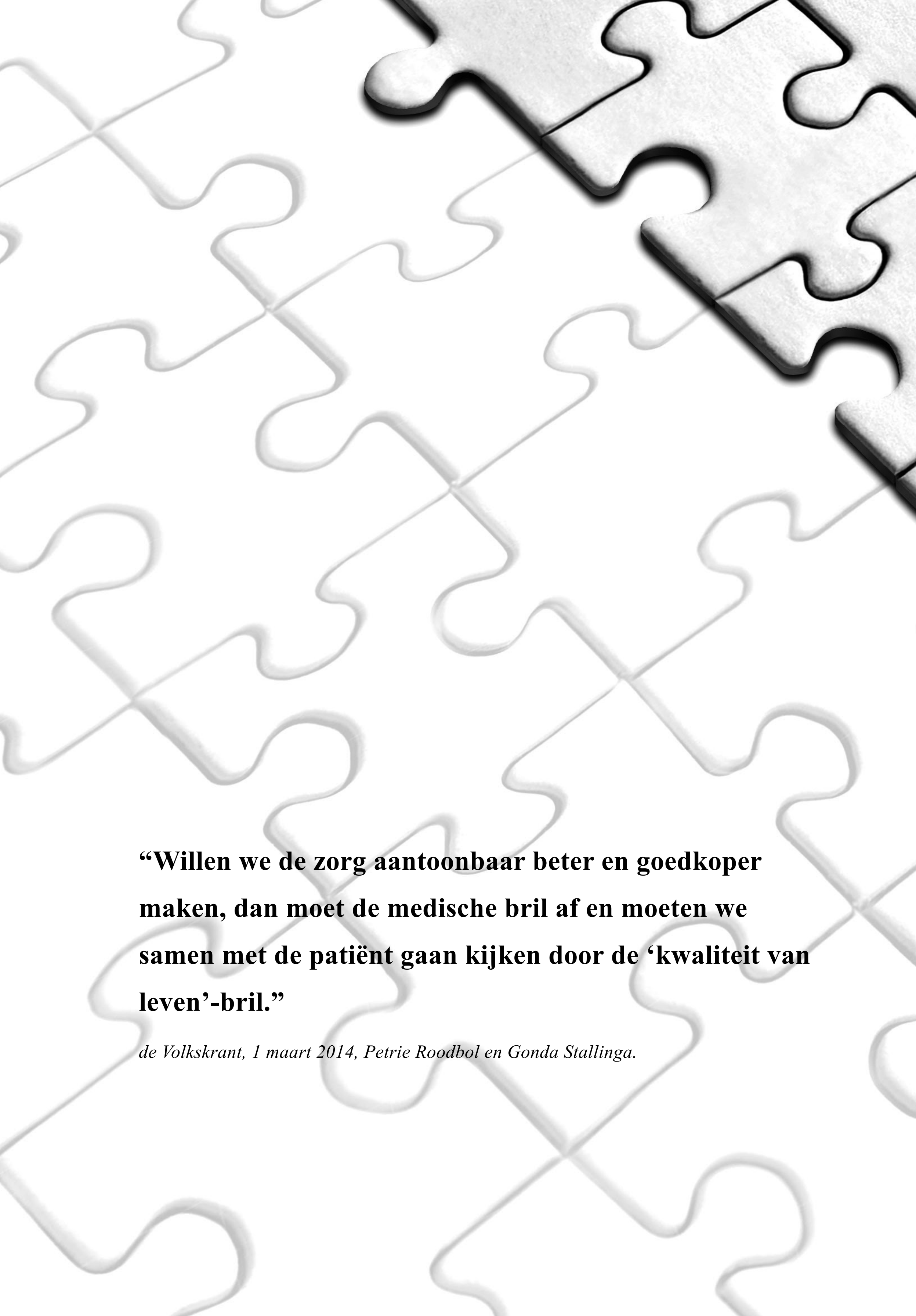
Contents

Chapter 7 Effects of a short training in using the International Classification of Functioning, Disability and Health (ICF) on perceived usefulness of the ICF: a randomized controlled trial in Master of Advanced Nursing Practice students

Submitted

Chapter 8 General discussion

Chapter 9 Summary



“Willen we de zorg aantoonbaar beter en goedkoper maken, dan moet de medische bril af en moeten we samen met de patiënt gaan kijken door de ‘kwaliteit van leven’-bril.”

de Volkskrant, 1 maart 2014, Petrie Roodbol en Gonda Stallinga.

1

General Introduction

1.1 General introduction

1.1.1 Human functioning in health care

The concept of human functioning pertains to how people function in everyday life, in the performance of activities, and in the areas of life in which they participate.[1] Functioning, as described in the International Classification of Functioning, Disability and Health (ICF), is influenced by health conditions (i.e. diseases or disorders) and by contextual factors (i.e. environmental and personal factors).[2] Functioning is currently increasingly recognized as being crucial to the concept of health as its scope has extended in the last decade beyond the prevention of disease to the promotion of well-being.

In the current definition of health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”,[3] functioning is not addressed yet. This definition can be labeled as biomedical because of its emphasis on disease and the state of complete well-being.[4] The biomedical approach to health in the current definition is limiting and even counterproductive for improving health.[5] The emphasis on disease stigmatizes the chronically ill as unhealthy, and the requirement for a state of complete well-being labels most of the people in the world unhealthy for most of the time.[5]

With the knowledge that a disease or disability impacts one’s health but does not define one’s health,[6,7] a new definition has been proposed recently: “health is the ability to adapt and self-manage in the face of social, physical and emotional challenges”.[5] This definition strongly emphasizes ‘the ability to adapt’, i.e. focusing on how to stay healthy, rather than only focusing on causes of disease. This broader view of health originates from the salutogenetic model of health described by Antonovsky.[8] Following the salutogenetic model, the main question for health care provision, especially for the chronically ill, can be reformulated as follows: how can an individual become healthier, while at the same time he/she remains chronically ill?[9,10] The salutogenetic approach fits in with the biopsychosocial model, for the latter model incorporates the biological dimension as well as the sociological and psychological dimensions. The concept of functioning, as described in the ICF, is an essential part of the biopsychosocial model and is expressed in terms of ability. Hence, following the new definition of health, the concept of functioning can be seen as a useful concept in current health care.

Although the principles and importance of the use of functioning and a *biopsychosocial* model in health care are acknowledged,[11,12] they are not incorporated in current health care practice. Moreover, they do not fit easily in the current predominant *biomedical* model in health care.[13,14] Health care professionals, including nurses, therapists and physicians, deliver their care to patients by using tools and skills embedded in the biomedical model.[15] When information related to functioning is registered in patient records in clinical practice, this information is hardly ever incorporated in the guidelines for clinical decision-making.[16,17] For example, the 2013 updated American guidelines for cardiovascular prevention include blood cholesterol levels in all risk prediction algorithms.[18] The strongest recommendation of these guidelines is the prescription of cholesterol-lowering drugs, particularly statins. However, instead of prescribing statins, a stronger focus on nutrition, which is an aspect of functioning, would have been a more sensible approach.[19] No less than 80 percent of deaths from cardiovascular diseases can be prevented by means of the following changes in functioning: keeping up a healthy diet, engaging in regular physical activity, and reducing tobacco use.[20]

Considering the increase of non-communicable chronic diseases, such as cardiovascular disease, diabetes, obesity, and cancer,[21] the focus of health care provision should be broadened to include functioning.[22] Functioning encompasses the main critical factors that play a role in the development of these diseases, including dietary intake, physical activity patterns, and tobacco use. Non-communicable chronic diseases accounted for approximately 68 percent of the 56 million total reported deaths in the world in 2012.[20] The worldwide incidence of non-communicable chronic diseases is increasing to such an extent that it has been described as epidemic.[23] Non-communicable chronic diseases travel across countries from one population to another like an infectious disease, affecting disease patterns globally.[24] In the Netherlands, almost 30 percent of the population has one or more chronic diseases, and this percentage is similar to the mean of other countries of the European Union.[25] Taking into account the higher average life expectancy in Western countries,[26] this prevalence will be slightly higher compared with the global mean prevalence. However, the proportion of the disease burden of chronic diseases for the global population is expected to increase with 17 percent by the year 2025.[27] Next to the appropriate medical treatment for those already affected, the health approach of primary prevention that induces changes in functioning is assumed to be the most cost-effective, affordable, and sustainable course of action to cope with the worldwide epidemic of chronic diseases.[19,28]

To realize to focus on functioning in health care, all of the parties involved, including health care professionals, policy makers, health insurers, and educational institutes, need to be committed. Additionally, the inclusion of functioning as a focus in health care affects clinical decision-making, patient roles, guidelines, tools, training of professionals, financial issues, and research.[14] With regard to finances, the discrepancy between the current health care policy and the needs of the increasing aging and chronically ill population is visible in the costs of health care. In the Netherlands, the total health care costs are nearly 90 billion euros a year, of which only 3 billion is spent on prevention.[29] From that amount, 2.5 billion euros goes to disease prevention, such as vaccinations, screening, and preventive medication. Only half a billion (= 0.6 percent of the total funding) goes to health promotion measures, such as lifestyle support. In recent years the total health care expenditure has grown much faster at the expense of the prevention part, on which expenditure decreased slightly.[30]

As George Engel stated almost 40 years ago "… nothing will change unless or until those who control resources have the wisdom to venture off the beaten path of exclusive reliance on biomedicine as the only approach to health care".[11] In an attempt to venture off the beaten path, this thesis aims to explore the inclusion of the concept of functioning as a focus in health care by means of applying the ICF in clinical practice.

1.1.2 Functioning and the International Classification of Functioning, Disability, and Health (ICF)

The World Health Organization (WHO) uses the term 'functioning' as a basic concept in the ICF.[1] The ICF was published in 2001 by the WHO as the international standard terminology for functioning and environmental factors.[2] The WHO published the ICF together with the conceptual model of health (Figure 1), which is based on the biopsychosocial model.[2]

The conceptual model of health

The conceptual model of health represents the components of the individuals' health status in which functioning has been conceptualized as a result of a dynamic interaction between a health condition (disease or disorder) and contextual factors (environmental and personal factors).

In the conceptual model of health, functioning is presented as a tripartite construct (Figure 1.1) including the components of body functions and structures (what people have: e.g. sensory functions; eyes), activities (what people do: e.g. reading), and participation (the type of relationships in which people are involved: e.g. family, work).[1] The environmental factors include all aspects of the physical, social, and attitudinal world (e.g. devices, family, political opinions). Personal factors include age, gender, race, education, profession and so forth. Personal factors are not classified yet in the ICF; they are currently under construction.[31] Diseases or disorders (i.e. health conditions) are included in the conceptual model of health, but they are classified in the International Classification of Diseases and Related Health Problems (ICD).[32] The ICF and the ICD are complementary; both classifications have to be used to describe an individual's health status.[2]

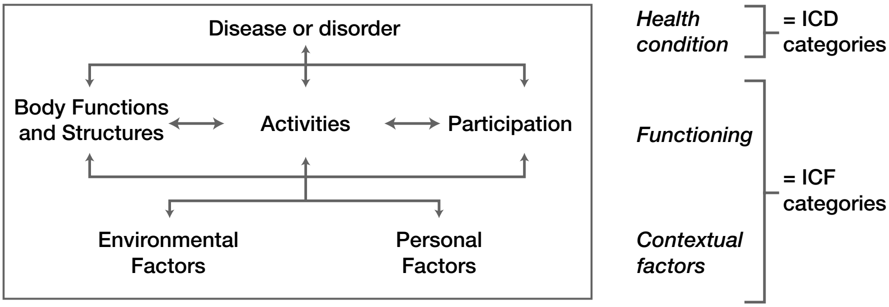


Figure 1.1 WHO's conceptual model of health representing the interactions between the components (disease, body functions and structures, activities, participation, environmental and personal factors) of the health status.[2] ICD: International Classification of Diseases; ICF: International Classification of Functioning, Disability and Health.

The first step in health care provision is to identify the patient's problems and needs.[33] The conceptual model gives an overview of the relationship between health condition, functioning, and contextual factors.[34] The model can be applied to describe the patient's problems, capacities, resources, and targets to get a complete picture of the patient's health status, which is relevant to determining multidisciplinary health care provision.[35-37] The model represents what affects the patient and addresses those (i.e. the target mediators and abilities) with the most potential for improving the patient's health.[2,35-37] This model facilitates the process of clinical decision-making by the members of the multidisciplinary team and acknowledges that characteristics and status of functioning of patients with the same health condition may differ more than those between patients with different health conditions.[36]

Standard terminology of the ICF

The components of functioning and environmental factors are listed in the standard terminology of the ICF. Similar to the conceptual model, in the standard terminology functioning includes body functions and structures, activities and participation. In the standard terminology, however, activities and participation are combined in one list (Figure 1.2).

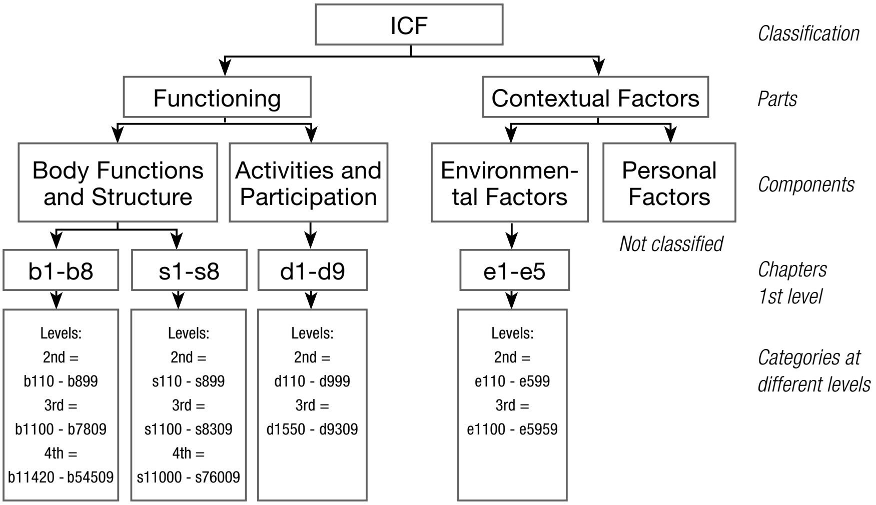


Figure 1.2 The hierarchical structure of the ICF. ICF: International Classification of Functioning, Disability and Health.[2]

The standard terminology of the ICF divides the components of functioning and environmental factors into chapters (=1st level) and categories (at different levels). The component body functions and structures contains 16 chapters, activities and participation contains 9 chapters, and environmental factors contains 5 chapters. Over 1400 categories are included in the classification (Figure 1.2).

Functioning has to be understood as a continuum ranging from completely able (non-problematic) to completely disabled (problematic), which can be expressed by qualifiers ranging from 0 (no problem) to 4 (complete problem). For example, the ICF code d450.1 describes a person's (dis)ability to walk as a mild problem. The environmental factors can act as complete barrier (decreasing ability or producing disability) or as complete facilitator (improving ability or eliminating disability). For example, the ICF code e310.2 means that the 'immediate family' act as a moderate barrier, and e310+2 means that the 'immediate family' act as a moderate facilitator (facilitators are denoted in the code with a plus sign instead of a period).[2,38]

Except for the categories in body structures, definitions, inclusions, and exclusions are provided for all categories. These definitions and inclusions provide a detailed description of the meaning of the category and help health care professionals choose the right categories. Because each category has a discrete meaning and unique code, the ICF can be used as a language-independent terminology. The purpose of the standard terminology is to establish a common, unambiguous language and to improve communication related to functioning and environmental factors. The codes are useful in multilingual applications and in health information systems.[2]

1.2 Aim and research questions

The aim of this thesis is to explore the inclusion of the concept of functioning as an important focus in health care by means of applying the standard terminology of the ICF and the conceptual model of health in clinical practice. The standard terminology aims to improve communication, and the conceptual model aims to facilitate clinical decision-making.[2] By studying these two topics as two inseparable but distinct aspects of functioning, specific information can be obtained that is relevant to developing effective strategies for the implementation of the concept of functioning in health care.

This aim resulted in the following research questions:

1. To what extent does language ambiguity regarding functioning exist in clinical practice and research and what are the consequences for communication?
2. To what extent does the use of standard terminology for functioning and the conceptual model of health facilitate clinical decision-making and what are the effects on clinical practice?
3. To what extent are health care professionals focused on functioning in

health care and what is their opinion on the usefulness of this concept in clinical practice?

1.3 Outline of this thesis

Figure 1.3 presents a schematic overview of the structure of this thesis. Chapters 2, 3, and 4 present studies on the standard terminology.

Chapter 2 explores the use and consequences of ambiguous language related to functioning in clinical practice. Standard terminology aims to improve communication. However, many projects that have attempted to introduce standard terminology in clinical practice, including the ICF, have been unsuccessful.[39]

Chapter 3 investigates the consequences of ambiguous language use in the assessment of patients' participation. The impact of different operationalizations of participation on regression models was explored in a sample of 677 patients with a neuromuscular disease.

Chapter 4 describes the development of a set of relevant ICF categories related to the functioning of patients with a neuromuscular disease. This set provides the basis for an assessment instrument and for clinical decision-making. There are over 1400 categories in the ICF, which makes it difficult for health care professionals to identify relevant categories for use in clinical practice.

Chapters 5, 6, and 7 present studies on the conceptual model.

Chapter 5 describes the results of a randomized controlled trial that analyzed how clinical decisions in 81 patients with severe multiple sclerosis differ depending on the type of assessment used. In this trial, outcomes of an ICF functioning assessment were compared with outcomes of a conventional medical assessment. Additionally, the fit of the two assessments with patients' own perspective of health was analyzed.

Chapter 6 presents a study in which 413 Master of Advanced Nursing Practice graduate theses were analyzed in order to determine to what extent health care professionals are focused on the intersection of cure (disease) and care (functioning) in their health care practice.

Chapter 7 focuses on a randomized controlled trial in 74 Master of Advanced Nursing Practice students that examined the effects of a short training in using the ICF on perceived usefulness of the ICF.

In Chapter 8, the main findings are summarized, reflections and a synthesis of findings are provided, and the practical implications and directions for future research regarding the focus on functioning in health care are presented.

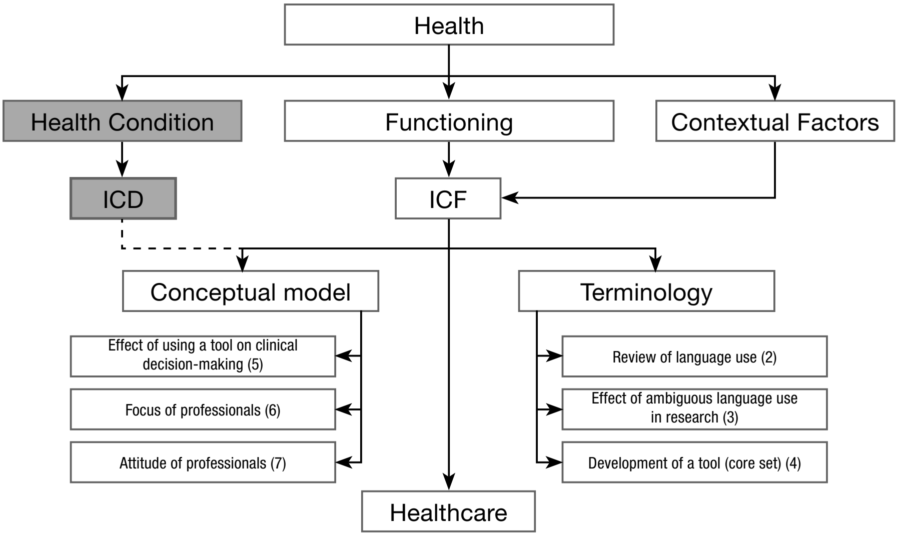


Figure 1.3 Overview of the structure of this thesis (derived from the WHO's conceptual model[2]). Components in grey are not investigated in the present thesis. The numbers in brackets refer to the separate chapters of the present thesis. ICF: International Classification of Functioning, Disability and Health; ICD: International Classification of Diseases.

References

1. Bickenbach J, Cieza A, Rauch A and Stucki G, editors. *ICF Core Sets; manual for clinical practice.* 10th ed. Göttingen, Germany: Hogrefe Publishing, 2012.
2. World Health Organization. *International Classification of Functioning, Disability and Health: ICF.* 1st ed. Geneva: World Health Organization, 2001.
3. *World Health Organization.* Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference. Official Records of the World Health Organization, no. 2: p. 100. 1948.
4. Madden R, Ferreira M, Einfeld S, Emerson E, Manga R, Refshauge K, et al. New directions in health care and disability: the need for a shared understanding of human functioning. *Aust N Z J Public Health* 2012; 36(5): 458-461.
5. Huber M, Knottnerus JA, Green L, van der Horst H, Jadad AR, Kromhout D, et al. How should we define health? *Br Med J* 2011; 343: d4163.
6. Stein MA, Stein PJS, Weiss D and Lang R. Health care and the UN Disability Rights Convention. *Lancet* 2009; 374(9704): 1796-1798.
7. Wade D and Halligan P. New wine in old bottles: the WHO ICF as an explanatory model of human behaviour. *Clin Rehabil* 2003; 17(4): 349-354.
8. Antonovsky A. *Unraveling the mystery of health. How people manage stress and stay well.* 1st ed. San Francisco, CA: Jossey-Bass, 1987.
9. Zeyer A. Salutogenesis and pathogenesis - a change of paradigm viewed from the standpoint of modern physics. *Sozial-Und Praventivmedizin* 1997; 42(6): 380-384.
10. Bengel J, Strittmatter R and Willmann H. *What keeps people healthy? The current state of discussion and the relevance of Antonvsky's salutogenetic model of health.* 10th ed. Germany: Federal Centre for Health Education - (FCHE), 1998.
11. Engel GL. The clinical application of the biopsychosocial model. *Am J Psychiatry* 1980; 137(5): 535-544.
12. Engel GL. The need for a new medical model: a challenge for biomedicine. *Science* 1977; 196(4286): 129-136.
13. de Camargo OK. Systems of care: transition from the bio-psycho-social perspective of the International Classification of Functioning, Disability and Health. *Child Care Health and Development* 2011; 37(6): 792-799.
14. van Dijk-de Vries A, Moser A, Mertens VC, van der Linden J, van der Weijden T and van Eijk JT. The ideal of biopsychosocial chronic care: how to make it real? A qualitative study among Dutch stakeholders. *BMC Fam Pract* 2012; 13: 14-2296-13-14.

15. Pruitt S and Epping-Jordan J. Preparing the 21st century global healthcare workforce. *Br Med J* 2005; 330(7492): 637-639.
16. Iezzoni LI and Greenberg MS. Capturing and classifying functional status information in administrative databases. *Health Care Financ Rev* 2003; 24(3): 61-76.
17. National Committe on Vital and Health Statistics. Classifying and reporting Functional Status. 2001; Available at: http://www.ncvhs.hhs.gov. Accessed March 10, 2015.
18. Stone NJ, Robinson JG, Lichtenstein AH, Bairey Merz CN, Blum CB, Eckel RH, et al. 2013 ACC/AHA guideline on the treatment of blood cholesterol to reduce atherosclerotic cardiovascular risk in adults: a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines. *Circulation* 2014; 129(25 Suppl 2): S1-45.
19. Carlos S, de Irala J, Hanley M and Angel Martinez-Gonzalez M. The use of expensive technologies instead of simple, sound and effective lifestyle interventions: a perpetual delusion. *J Epidemiol Community Health* 2014; 68(9): 897-904.
20. World Health Organization. Global Burden of disease. 2014; Available at: http://www.who.int/topics/global_burden_of_disease/en/. Accessed March 9, 2015.
21. World Health Organization. Nutrician health topics. 2015; Available at: http://www.who.int/nutrition/topics/2_background/en/. Accessed March 9, 2015.
22. Stucki G and Sigl T. Assessment of the impact of disease on the individual. *Best Practice & Research in Clinical Rheumatology* 2003; 17(3): 451-473.
23. Horton R. The neglected epidemic of chronic disease. *Lancet* 2005; 366(9496): 1514-1514.
24. World Health Organization. The world health report 2002 - reducing risks, promoting healthy life. 2002; Available at: http://www.who.int/whr/2002/en/. Accessed March 10, 2015.
25. National Institute for Public Health and the Environment (RIVM). Nationaal Komp Volksgezondheid. Hoeveel mensen hebben één of meer chronische ziekten? 2014; Available at: http://www.nationaalkompas.nl/gezondheid-en-ziekte/ziekten-en-aandoeningen/chronische-ziekten-en-multimorbiditeit/hoeveel-mensen-hebben-een-of-meer-chronische-ziekten/. Accessed April 4, 2015.
26. World Health Organization. World Health Statistics 2014. 2014; Available at: http://www.who.int/mediacentre/news/releases/2014/world-health-statistics-2014/en/. Accessed April 4, 2015.
27. Nugent R. Benefits and Costs of the Non-Communicable Disease Targets for the Post-2015 Development Agenda. 2015; Available at: http://www.dcp-3.org/resources/benefits-and-costs-non-communicable-disease-targets-post-2015-development-

agenda. Accessed April 5, 2015.

28. World Health Organization. *The Global Burden of Disease:* 2004 Update. 10th ed. Geneva: World Health Organization, 2008.

29. Van den Berg M, Post N, Hamberg-van Reenen H, Baan C, Schoemaker C and National Institute for Public Health and the Environment (RIVM). Prevention in health care. Theme Report Health Future Study 2014.
(Preventie in zorg Themarapport Volksgezondheid Toekomstverkenning 2014). 2014; Available at: http://www.volksgezondheidtoekomst verkenningnl/dsresource?type=pdf&disposition=inline&objectid=rivmp:236389&versionid=&subobjectname=. Accessed March 10, 2015.

30. Post N, de Bekker-Grob E, Mackenbach J, Slobbe L and National Institute for Public Health and the Environment (RIVM). Cost of prevention in The Netherlands 2007. (Kosten van preventie in Nederland 2007). 2010; Available at: http://www.rivm.nl/dsresource?objectid=rivmp:12495&type=org&disposition=inline&ns_nc=1. Accessed March 10, 2015.

31. Muller R and Geyh S. Lessons learned from different approaches towards classifying personal factors. *Disabil Rehabil* 2015; 37(5): 430-8.

32. World Health Organization. *International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10).* 10th ed. Geneva: World Health Organization, 1992.

33. Steiner WA, Ryser L, Huber E, Uebelhart D, Aeschlimann A and Stucki G. Use of the ICF model as a clinical problem-solving tool in physical therapy and rehabilitation medicine. *Physical Therapy* 2002; 82(11): 1098-1107.

34. Escorpizo R, Kostanjsek N, Kennedy C, Nicol MMR, Stucki G, Uestuen TB, et al. Harmonizing WHO's International Classification of Diseases (ICD) and International Classification of Functioning, Disability and Health (ICF): importance and methods to link disease and functioning. *BMC Public Health* 2013; 13: 742.

35. Chen H, Katz PP, Eisner MD, Yelin EH and Blanc PD. Health-related quality of life in adult rhinitis: The role of perceived control of disease. *J Allergy Clin Immunol* 2004; 114(4): 845-850.

36. Lollar DJ and Simeonsson RJ. Diagnosis to function: classification for children and youths. *Journal Of Developmental And Behavioral Pediatrics: JDBP* 2005; 26(4): 323-330.

37. Sharma L, Cahue S, Song J, Hayes K, Pai YC and Dunlop D. Physical functioning over three years in knee osteoarthritis - Role of psychosocial, local mechanical, and neuro muscular factors. *Arthritis Rheum* 2003; 48(12): 3359-3370.

38. Kostanjsek N. Use of The International Classification of Functioning, Disability and Health (ICF) as a conceptual framework and common language for disability statistics and health information systems. *BMC Public Health* 201; 11 Suppl 4: S3-S3.
39. Sales AE, Bostrom A, Bucknall T, Draper K, Fraser K, Schalm C, et al. The Use of Data for Process and Quality Improvement in Long Term Care and Home Care: A Systematic Review of the Literature. *Journal of the American Medical Directors Association* 2012; (2): 103-113.

“Maar 40 procent van de medische behandelingen levert aantoonbaar gezondheidswinst op.”

de Volkskrant, 22 februari 2014, Ellen de Visser.

2

Does language ambiguity in clinical practice justify the introduction of standard terminology? An integrative review

Hillegonda A. Stallinga
Huib ten Napel
Gerard J. Jansen
Jan H.B. Geertzen
Pieter F. de Vries Robbé
Petrie F. Roodbol

Journal of Clinical Nursing 2015; 24(3-4): 344-52

Abstract

Aims and objectives: To research the use of ambiguous language in written information concerning patients' functioning and to identify problems resulting from the use of ambiguous language in clinical practice.

Background: Many projects that aimed to introduce standard terminology concerning patients' functioning in clinical practice are unsuccessful because standard terminology is rarely used in clinical practice. These projects mainly aim to improve communication by reducing ambiguous language. Considering their lack of success, the validity of the argument that language ambiguity is used in clinical practice is questioned.

Design: An integrative literature review.

Methods: A systematic search of the MEDLINE (1950-2012) and CINAHL (1982-2012) databases was undertaken, including empirical and theoretical literature. The selected studies were critically appraised using a data assessment and extraction form.

Results: Seventeen of 767 papers were included in the review and synthesis. The use of ambiguous language in written information concerning patients' functioning was demonstrated. Problems resulting from the use of ambiguous language in clinical practice were not identified. However, several potential problems were suggested, including hindered clinical decision-making and limited research opportunities.

Conclusion: The results of this review demonstrated the use of ambiguous language concerning patients' functioning, but health professionals in clinical practice did not experience this issue as a problem. This finding might explain why many projects aimed at introducing standard terminology concerning functioning in clinical practice to solve problems caused by ambiguous language are often unsuccessful. Language ambiguity alone is not a valid argument to justify the introduction of standard terminology.

Relevance to clinical practice: The introduction of standard terminology concerning patients' functioning will only be successful when clinical practice requires the aggregation and reuse of data from electronic patient records for different purposes, including multidisciplinary decision-making and research.

2.1 Introduction

During the past few decades, numerous projects have aimed to introduce standard terminology in clinical practice, particularly in nursing and paramedical practices.[1,2] Many of these projects are motivated by the assumption that standard terminology facilitates precise communication[3] and that it will improve documentation by eliminating and reducing language ambiguity.[2,4-9]

The use of ambiguous language means that one term allows for multiple interpretations. For example, research has shown that physical therapists define the term ‘trainability’ (a commonly used Dutch term) as the extent to which functions related to respiratory and cardiovascular capacity can be trained, whereas nurses define ‘trainability’ as the extent to which an activity to develop skills can be trained.[10]

In contrast to ambiguous language, unambiguous language entails a common understanding of terms or concepts.[5] Unambiguous language is facilitated by standard terminology because in a selected set of terms, each term has a discrete meaning. Standard terminology can enhance the quality of documentation, enable the design of quality assurance and decision support systems, and facilitate the aggregation of research data from electronic patient records (EPRs).[11] The most commonly known standard terminology in health care is the International Classification of Diseases (ICD).[12] The ICD is used as an international standard to compare and share information about causes of death, diseases, injuries, and symptoms using a common language.[13] Examples of other standard terminologies that are unrelated to diseases include the North American Nursing Diagnosis Association,[14] the Uniform Terminology for Occupational Therapy,[15] the American Dietetic Standardized Language,[16] and the International Classification of Functioning, Disability, and Health (ICF),[17] which is a non-discipline-specific standard terminology. The shared goal of all these examples of standard terminologies is related to patients’ functioning.

Functioning is defined by the World Health Organization (WHO) in the ICF as an umbrella term encompassing all body functions (e.g. hearing), activities (e.g. washing oneself), and participation (e.g. community life).[17] The WHO[17] indicates that these components can be expressed in two manners: 1) “they can be used to indicate problems (i.e. impairment, activity limitation, or participation restriction summarized under the umbrella term disability)", and 2) "they can indicate non-problematic (i.e. neutral) aspects of health and health-related states (summarized under the umbrella term functioning)".[17]

Functioning is based on the biopsychosocial model. Engel[18] introduced the clinical application of the biopsychosocial model in response to the disease-centered and reductionist orientation of medical thinking in the mid-twentieth century. Currently, however, health care provision has a broader, more holistic view than the medical model. Knowledge of functioning provides health care providers with a better understanding of the full burden of a health condition and the impact of a disease on an individual's life.[19] The ICF classifies aspects of functioning to obtain a description of health and is intended for use in clinical practice. The ICD classifies disease entities and other health conditions to gather disease diagnostic information but is neither intended nor suitable for the indexing of distinct clinical entities.[13] The WHO's acceptance of the ICF in 2001 has made it possible to communicate about functioning in standard terms between and within all health care disciplines worldwide. The use of both classifications together results in a fuller picture of health or health-related states of an individual. This will provide health professionals with an integrated model, which in turn will support multidisciplinary communication towards a coordinated planning of care to improve health.[20]

However, many projects that have attempted to introduce in clinical practice standard terminology such as ICF or one of the other classifications relating to functioning have been unsuccessful.[21] Until now, none of the standard terminologies concerning functioning have been used throughout all health care organizations and disciplines.[2,22,23] Many settings and systems still use their own language for documentation.[22,23]

A model for effective implementation of standard terminology in health care practice was developed by Grol and Wensing.[24] This model shows that the first step in an effective introduction of a new procedure or innovation involves the analysis of current practice versus proposed practice. This analysis should ideally confirm that the proposed innovations would meet practice needs.[24] Additionally, "without this match, the implementation might not be justified".[25] With regard to the successful introduction of standard terminology in clinical practice, this statement means that the current practice must have problems with language ambiguity. We reviewed the literature to analyze the lack of success of projects aimed at introducing standard terminology related to functioning. We have researched the actual use and problems resulting from the use of ambiguous language to determine whether the practice needs justify the introduction of standard terminology.

2.2 Aims and methods

2.2.1 Aim

The aim of this integrative review was to answer two specific research questions. 1) Is ambiguous language concerning functioning used in written patient information produced by health care professionals in clinical practice? 2) What problems occur in clinical practice because of the use of ambiguous language about functioning in written patient information?

2.2.2 Design

Because of the paucity of published research on the use of language ambiguity in written patient information concerning functioning, we performed an integrative review of the literature. An integrative review is described by Whittemore and Knafl[26] as a specific review method in which data from empirical and theoretical literature are merged to obtain extensive insight into a specific topic. An integrative review allows for the combination of data from primary sources utilizing different methodologies to review evidence.[26]

2.2.3 Search strategy

A comprehensive search was conducted by a librarian and the first author using the term ‘ambiguous language’ as well as synonyms and connotations (i.e. ‘universal language,’ ‘common language,’ and ‘standard language’) of this term. The search string was limited to functioning, disciplines, and setting. Next, the MEDLINE (1950-2011) and CINAHL (1982-2011) electronic databases were systematically searched. We started from the first year of coverage of each database to reduce the risk of missing potentially relevant papers. We limited our search to English language papers with available abstracts.

The information from titles and abstracts of the papers found in the search was used to select papers. To be considered for inclusion, papers had to explicitly report on the use of language in written patient information by health care professionals concerning functioning. Papers were excluded if they reported on spoken patient information or patient information regarding medical status, as well as the use of ambiguous language between patients and health care professionals.

The first author (HAS) screened the titles and abstracts retrieved in the survey. When in doubt, the second author (HtN) was consulted. Differences between these authors were resolved through discussion or by consulting with the research committee, which consisted of experts on functioning (PFR) and terminologies (PdVR). A hand search and author search were conducted but did not yield any new papers.

2.2.4 Search outcome

The database search resulted in 767 potentially relevant papers. After removing duplicates and screening the titles and abstracts, 100 papers were included for full-text evaluation. Finally, 83 papers did not meet the inclusion criteria. Seventeen papers were included for further analysis to answer the research questions. The flow diagram of the study selection process is shown in Figure 2.1.

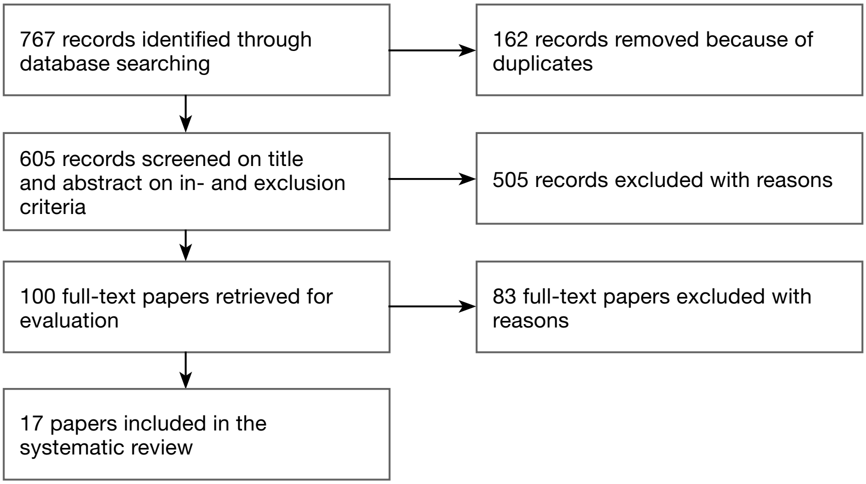


Figure 2.1 Flow diagram of study selection process.

2.2.5 Data abstraction and synthesis

The full text of the potentially relevant papers was independently analyzed by two researchers (HAS and HtN) using a data assessment and extraction form. The reviewers developed this form under the supervision of the research committee. The form contained the following items: general information (i.e. title, authors, country of origin, journal, and publication year), contextual information (disciplines and settings), and content information about the study (objective, design, and results). All papers were thoroughly reviewed and subsequently rejected or assigned with arguments.

After evaluating the included papers, findings that were related to language use were classified into the following groups: 1) ambiguous language, defined as ‘one term reflecting different meanings’; 2) potentially ambiguous language, defined as ‘different terms reflecting the same (one) meaning’; and 3) unambiguous language, defined as ‘one term reflecting one meaning’. The results were synthesized by consensus between the researchers and the research committee. Any disagreements were resolved through discussion.

2.2.6 Quality appraisal

Paper quality was assessed using criteria developed by the reviewers. In an integrative review, a ‘gold standard’ to evaluate the quality of the studies does not exist.[26] The following criteria, which are based on validity domains used to evaluate studies,[27] were developed by the reviewers and confirmed by the research committee: proper description of the study objective (yes/no), adequate research method (yes/no), proper selection of the study sample (yes/no), soundness and completeness of measurement (yes/no), and outcome assessment (yes/no). Given the wide variety of study designs, the number of relevant items varied between papers. Papers were included in the final analysis if they scored ‘yes’ on any relevant item. Papers describing views and opinions were not considered to be suitable for assessment with these criteria. These papers were mainly used in this review to explore the use of ambiguous language and the problems caused by this use in general clinical practice.

2.3 Results

General characteristics of the 17 included papers are presented in Table 2.1 and cited (*) in the reference list. Most papers ($n = 10$) were published in 2002 or later. Seven papers were published in medical informatics journals, such as Journal of the American Medical Informatics Association, Studies in Health Technology and Informatics, and International Journal of Medical Informatics. One dissertation was included.

The study design of half of the included papers was considered to be expert opinion ($n = 8$).[4-9,28,29] Five papers were record analyses.[30-34] One paper was a survey,[35] and the Blewitt and Jones study[36] was both a record analysis and a survey. There was one observational study[2] and one literature review.[37]

Half of the papers were from the USA ($n = 9$). Six papers were from Europe, one was from Canada, and one was from New Zealand. More than 75% ($n = 13$) of the papers were applicable to one discipline, with most papers belonging to the discipline of nursing ($n = 10$). The other papers were applicable to multidisciplinary teams.

Table 2.1 Characteristics of the included papers ordered by reference.

Reference	Design	Country; Discipline	Findings related to language use
Algase et al.[37]	Literature review	USA; Non-specific	Many different terms used for wandering in clinical practice could be reduced to one term with one meaning.
Blewitt & Jones[36]	Survey & Record analysis	USA; Nursing	Nursing documentation was inconsistent with clinical decision-making in practice.
Borst & Nelson[35]	Survey	USA; Occupational therapy	Low levels of agreement between meanings of terms used by occupational therapists and meanings of standard terms
Carlsson et al.[34]	Record analysis	Sweden; Nursing	Care planning was not visible in patient records. The language used was vague and not professional.
Charney[7]	Expert opinion	USA; Dietetic	If standard terminology is lacking, it is impossible to aggregate, manage and share patient data.

Reference	Design	Country; Discipline	Findings related to language use
Coward[32]	Record analysis	Canada; Nursing	Nursing classifications differed significantly in their ability to capture terms used by nurses in clinical practice.
Engelbrecht et al.[5]	Expert opinion	Germany; Non-specific	Communication between heterogeneous environments will only be possible when standard terminologies are available.
Fink & Rosendal[9]	Expert opinion	Denmark; General practitioners	Due to a lack of standard terms for functional somatic disorders, there is no common understanding of this concept.
Florin et al.[6]	Expert opinion	Sweden; Non-specific	Different disciplines reached consensus about the use of one standard terminology to document patient care.
Kane & Mahony[31]	Record analysis	USA; Nursing	Problem descriptions in clinical practice did not sufficiently describe patient problems and were inconsistent with standard terms.
Marin[33]	Record analysis	USA; Nursing	Two thirds of words used in patient documentation, were not linkable to standard terminology.
Ozbolt[28]	Expert opinion	USA; Nursing	Documentation of nursing care has been idiosyncratic and unstandardized.
Ozbolt et al.[30]	Record analysis	USA; Nursing	Terms used to describe patient problems and outcomes in clinical practice, could be reduced based on their meaning by half.
Payne & Martin[4]	Expert opinion	USA; Nursing	Standard terminology facilitate clinical decision making and multidisciplinary communication in research and practice.
Tempest & McIntyre[8]	Review and expert opinion	United Kingdom Non-specific	Standard terminology will clarify team roles and support clinical reasoning.
Thoroddsen & Ehnfors[2]	Observational study	Iceland; Nursing	Statistically significant improvement of the use of standard terminology in the documentation of daily nursing after training.
Wilson & Duke[29]	Expert opinion	New Zealand; Nursing	Standard terminology gave the opportunity to describe, compare, examine and analyse clinical practices and processes.

2.3.1 The use of ambiguous language

Table 2.2 shows the results related to the use of ambiguous language, potentially ambiguous language, and unambiguous language. One paper[35] demonstrated the use of ambiguous language, signifying that one term reflects different meanings. Borst and Nelson[35] examined the level of agreement regarding the meaning of terms between occupational therapists and the uniform terminology for occupational therapists.[15] Occupational therapists were asked to match 15 different meanings with one of the 65 listed standard terms in the uniform terminology. Their paper demonstrated a disagreement between the meanings of 30% of the terms used in the standard terminology and the meanings given to these terms. For example, the term ‘attention span’ was equally well matched with the meaning ‘sustaining a purposeful activity over time’, and with ‘focusing on a task over time.’ According to the uniform terminology, however, the latter meaning does not correlate to ‘attention span’ but to ‘activity tolerance’.[15]

Table 2.2 Results for the use of (un)ambiguous language.

Language use	Paper
Ambiguous language Different meanings for 30% of standard terms	Borst and Nelson[35]
Potential ambiguous language Reduction of documented nursing statements to standard terms: reduction to 47% of the original number of statements	Ozbolt et al.[30]
75% of documented terms were not standard terms but reflected the same meaning as standard terms	Coward[32]
35% of documented terms reflected the same meaning while different terms were used in the two health care settings	Coward[32]
Unambiguous language 7% of documented terms reflected the same term and same meaning as standard terms	Coward[32]
33% of frequently recorded terms had the same term and the same meaning as standard terms	Marin[33]

The use of potentially ambiguous language, signifying that different terms reflect the same meaning, was demonstrated by two record analyses.[30,32] Coward[32] showed that 75% of the documented terms were not standard terms; however, the documented terms did reflect the same meaning as standard terms. Coward[32] also found that 35% of the documented terms used by hospital nurses to describe patients’ problems at the time of discharge (i.e.

‘impaired seeing functions’) differed from the terms used by home care nurses (i.e. ‘almost blind’), but they actually described the same problems. Ozbolt et al.[30] created a standard terminology that reduced the number of terms used in clinical practice to 47% of the documented terms.

The use of unambiguous language, signifying that one term reflects one meaning was demonstrated by two papers. Coward,[32] in the same study mentioned above, indicated that approximately 7% of the documented terms were included in the standard terminology. Marin[33] showed that 33% of frequently used terms in patient records have consistent terms and meanings.

In multiple papers, the use of ambiguous language was not demonstrated but suggested. Three record analyses and one expert opinion paper explained in their overall conclusion that written patient information was often vague, inconsistent, unspecified, and used free text and non-professional terms.[2,29,34,36] One opinion paper[8] noted that clinicians feel that there is a lack of understanding between professionals concerning the terms used to describe patients’ problems and outcomes. A literature review[37] found that no less than 120 different terms are used for ‘wandering’ and that this term included aimless walking, absconding, and elopement. The meanings of these terms were more or less similar.

2.3.2 Problems in clinical practice because of the use of ambiguous language

Clinical practice problems caused by the use of ambiguous language were not found in the literature. None of the included papers examined clinical practice problems because of the use of ambiguous language. However, five papers, including three record analyses[31-33] and two expert opinion papers,[8,9] suggested hindered clinical decision-making regarding patient problems, goals, interventions, and outcomes because of the use of ambiguous language or, more specifically, because of the absence of standard term use. Coward[32] found preliminary evidence that inadequate information transfer related to the use of ambiguous language may lead to adverse patient outcomes caused by wrong decision-making by professionals. Kane and Mahony[31] and Marin[33] reported hindered clinical decision-making in general. Fink and Rosendal[9] suggested that patients with identical clinical pictures may receive different diagnostic labels, depending on the individual professional. Tempest and McIntyre[8] found that clinicians acknowledge that there is no unequivocal understanding about goals and interventions. Consequently, interventions by different members of the multidisciplinary team are not geared to one another. Three opinion papers[4,5,7] described the potential benefits of using standard terminologies for clinical decision-making.

Another frequently mentioned problem, which is not directly related to clinical practice, was the effect of limited use of ambiguous language or the non-use of standard terminologies on research. Thirteen papers[2,4-6,28-31,33-37] stated that it is currently impossible to aggregate, share, and reuse data from patient records.

2.4 Discussion

Our literature review demonstrated the use of ambiguous language and potential ambiguous language in written information concerning patients' functioning. Problems resulting from the use of ambiguous language in clinical practice were not identified. This result might explain the lack of success in many projects that aimed to introduce standard terminology in clinical practice. According to the implementation theory of Grol and Wensing,[24] the success of an effective implementation depends on whether the proposed innovation meets practice needs. If problems related to the use of ambiguous language were not identified, the practice needs may not match the proposed introduction of standard terminology. Such a mismatch is considered to be a crucial barrier to the introduction of a new procedure or innovation.[25] Nevertheless, problems resulting from the use of ambiguous language or lack of standard terminology were suggested in the included papers. These suggested problems included hindered clinical decision-making, particularly in multi-disciplinary collaborations, and limited opportunities for research.

Our results are relevant in the context of the Institute of Medicine's (IOM) recently described vision of the future of health care. IOM presented a transformation of the United States health care system with nurses playing a central role that includes offering multidisciplinary and integrated care (recommendation 2) and improving the collection of data (recommendation 8).[38] In such a health care system, the use of unambiguous language concerning functioning provided by standard terminology is essential and could be employed in accordance with the possibilities of EPR.[39]

More than 50% of the included papers were in the field of nursing. This result could be explained by the fact that nursing is the discipline that is pre-eminently associated with patients' functioning. A second explanation for the large proportion of nursing papers could be because of the development of nursing towards an independent profession in the past decade. During this process, several standard terminologies were developed to encapsulate discipline-specific knowledge with the aim of clarifying nursing contributions to patient outcomes.

The included papers were based on studies in Europe, North America, and New Zealand. This finding might be explained by the increasing number of non-communicable, chronic diseases (e.g. diabetes and cancer) in those geographical regions compared to most countries in the Southern Hemisphere, where the prevalence of communicable, infectious diseases is greater. With respect to non-communicable, chronic diseases, the focus of health care will shift from curing diseases to improving functioning[40] to promote health.

Seven of the 17 papers reviewed were published in medical informatics journals. This finding could indicate that the use of language and standard terms belongs to the field of Information and Communication Technology (ICT). ICT workers, researchers, and policy-makers in particular, found the failure of clinicians to use standard terminology problematic because it hinders the aggregation of data related to functioning from written patient information. This type of analysis is in contrast to the aggregation of data related to diseases. The use of the ICD facilitates the inclusion of diseases in national and international statistics for various policy purposes. Thus, diseases are fully embedded in our society and form the basis for reimbursement.

Our study has certain limitations. First, the term 'ambiguous language' did not prove to be a standard search term in literature databases, which hampered our search for papers suitable for inclusion in our study. Consequently, we had to search the databases using synonyms and connotations of ambiguous language. By using these terms, or likely by not using some alternative terms, we might have missed potentially relevant papers. Furthermore, some selection bias (the probability that a publication is or is not included) and information bias (over/under-representation of reporting on the use of (un)ambiguous language in the included articles) may have occurred. We have tried to minimize this bias by having two reviewers independently assess the studies.

2.5 Conclusion

Our findings demonstrated the use of ambiguous language concerning patients' functioning in clinical practice. However, health professionals in clinical practice did not experience this issue as a problem. Many projects are concerned with introducing standard terminology in clinical practice, but little attention has been paid to the actual problems (in current practice) that are caused by the use of ambiguous language. This issue warrants further research. Following implementation of the Grol and Wensing[24] theory, the lack of success of projects introducing standard terminology might be because clinical practice needs do not require the introduction of such standard language. Standard terminology is mainly aimed at the aggregation and reuse of data from EPRs for several purposes, such as multidisciplinary decision-making and research. If these issues become important to clinical practice, as demonstrated in the IOM report,[38] then standard terminology concerning patients' functioning will likely be successfully introduced. The use of ambiguous language is not a valid argument to justify the introduction of standard terminology in clinical practice. This review provides useful information that can inspire further, much needed research on the use of language and its consequences for clinical practice with regard to the introduction of standard terminology concerning functioning.

2.6 Relevance to clinical practice

The introduction of standard terminology concerning functioning will only be successful when clinical practice requires the aggregation and reuse of EPR data related to functioning for several purposes, including multidisciplinary decision-making and research.

References

1. Bjorvell C, Wredling R and Thorell-Ekstrand I. Improving documentation using a nursing model. *J Adv Nurs* 2003; 43(4): 402-410.
2. *Thoroddsen A and Ehnfors M. Putting policy into practice: pre- and posttests of implementing standardized languages for nursing documentation. *Journal of Clinical Nursing* 2007;16(10): 1826-1838.
3. Kannry JL, Wright L, Shifman M, Silverstein S and Miller PL. Portability issues for a structured clinical vocabulary: mapping from Yale to the Columbia medical entities dictionary. *Journal of the American Medical Informatics Association* 1996; 3(1): 66-78.
4. *Payne RL and Martin MC. Defining and classifying skin tears: need for a common language. A critique and revision of the Payne-Martin Classification System for Skin Tears. *Ostomy Wound Management* 1993; 39(5): 16.
5. *Engelbrecht R, Ingenerf J and Reiner J. Educational standards - terminologies used. *Stud Health Technol Inform* 2004; 109: 95-113.
6. *Florin J, Ehnfors M and Ostlinder G. Developing a national integrated classification of healthcare interventions in Sweden. *Int J Med Inform* 2005; 74(11-12): 973-979.
7. *Charney P. The nutrition care process and standardized language of dietetics: implications for the nutrition support dietitian. *Support Line* 2006; 28(2): 16-19.
8. *Tempest S and McIntyre A. Using the ICF to clarify team roles and demonstrate clinical reasoning in stroke rehabilitation. *Disabil Rehabil* 2006; 28(10): 663-667.
9. *Fink P and Rosendal M. Recent developments in the understanding and management of functional somatic symptoms in primary care. *Current Opinion in Psychiatry* 2008; 21(2): 182-188.
10. Stallinga HA, Napel ten H and Jansen G. Inhoudsvalidering van functionerings-problemen van CVA patienten in relatie tot de ICF. [Stroke patients and ICF, content validation of stroke related disabilities]. *Verpleegkunde [Nursing]* 2007; 22(1): 31-45.
11. Hardiker N, Bakken S, Casey A and Hoy D. Formal nursing terminology systems: a means to an end. *J Biomed Inform* 2002; 35(5-6): 298-305.
12. World Health Organization. *International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10*). 10th ed. Geneva: World Health Organization, 1992.
13. World Health Organization. International Statistical Classification of Disease and Related Health Problems, 10th Revision (ICD-10) Volume 2 Instruction Manual. 2010; Available at: http://www.who.int/classifications/icd/ICD10Volume2_en_2010.pdf.

Accessed January 23, 2014.

14. North American Nursing Diagnosis Association. *NANDA Nursing Diagnoses: Definitions and Classification.* 10th ed. Philadelphia: NANDA/North American Nursing Diagnosis Association, 1992.
15. Dunn W, Foto M, Hinojosa J, Schell B, Thomson LK and Hertfelder SD. Uniform terminology for occupational-therapy - 3rd ed. *American Journal of Occupational Therapy* 1994; 48(11): 1047-1054.
16. Hakel-Smith N and Lewis NM. A standardized nutrition care process and language are essential components of a conceptual model to guide and document nutrition care and patient outcomes. *J Am Diet Assoc* 2004; 104(12): 1878-1884.
17. World Health Organization. *International Classification of Functioning, Disability and Health: ICF.* 1st ed. Geneva: World Health Organization, 2001.
18. Engel GL. The clinical application of the biopsychosocial model. *Am J Psychiatry* 1980; 137(5): 535-544.
19. Ustun TB, Chatterji S, Bickenbach J, Kostanjsek N and Schneider M. The International Classification of Functioning, Disability and Health: a new tool for understanding disability and health. *Disabil Rehabil* 2003; 25(11-2): 565-571.
20. Escorpizo R, Kostanjsek N, Kennedy C, Nicol MMR, Stucki G, Uestuen TB, et al. Harmonizing WHO's International Classification of Diseases (ICD) and International Classification of Functioning, Disability and Health (ICF): importance and methods to link disease and functioning. *BMC Public Health* 2013; 13: 742.
21. Sales AE, Bostrom A, Bucknall T, Draper K, Fraser K, Schalm C, et al. The use of data for process and quality improvement in long term care and home care: a systematic review of the literature. *Journal of the American Medical Directors Association* 2012; 13(2): 103-113.
22. Bowles KH. The barriers and benefits of nursing information systems. *Computers In Nursing* 1997; 15(4): 191-198.
23. Maas ML and Delaney C. Nursing process outcome linkage research - issues, current status, and health policy implications. *Med Care* 2004; 42(2): 40-48.
24. Grol R and Wensing M. Effective implementation: a model. In: Grol R, Wensing M and Eccles M, editors. *Improving Patient Care: The Implementation of Change in Clinical Practice.* 10th ed. London: Elsevier; 2005. p. 41-57.
25. Van Achterberg T, Schoonhoven L and Grol R. Nursing implementation science: how evidence-based nursing requires evidence-based implementation. *J Nurs Scholarsh* 2008; 40(4): 302-310.
26. Whittemore R and Knafl K. The integrative review: updated methodology. *J Adv Nurs*

2005; 52(5): 546-553.

27. Sanderson S, Tatt I and Higgins J. Tools for assessing quality and susceptibility to bias in observational studies in epidemiology: a systematic review and annotated bibliography. *International Journal Of Epidemiology* 2007; 36(3): 666-676.
28. *Ozbolt J. Terminology standards for nursing: collaboration at the summit. *Journal of the American Medical Informatics Association* 2000; 7(6): 517-522.
29. *Wilson SK and Duke J. Toward standardising nursing language in New Zealand. *Stud Health Technol Inform* 2006; 122: 753-757.
30. *Ozbolt JG, Fruchtnicht JN and Hayden JR. Toward data standards for clinical nursing information. *J Am Med Inform Assoc* 1994; 1(2): 175-185.
31. *Kane AT and Mahony DL. Issues in the integration of standardized nursing language for populations: a study of drug-exposed infants' records. *Public Health Nurs* 1997; 14(6): 346-352.
32. *Coward PM. *Use of Standardized Nursing Language in Home Care Referral.* Unpublished doctoral dissertation. Case Western Reserve University (Health Sciences), Cleveland, MI, 1998.
33. *Marin HF. Comparing nursing terms from patient records to the ICNP, beta version. *Stud Health Technol Inform* 2002; 90: 232-235.
34. *Carlsson E, Ehrenberg A and Ehnfors M. Recording of nursing assessment and interventions for stroke patients with eating difficulties. *Stud Health Technol Inform* 2006; 122: 909-909.
35. *Borst MJ and Nelson DL. Use of uniform terminology by occupational therapists. *Am J Occup Ther* 1993; 47(7): 611-618.
36. *Blewitt DK and Jones KR. Using elements of the nursing minimum data set for determining outcomes. *J Nurs Adm* 1996; 26(6): 48-56.
37. *Algase DL, Moore DH, Vandeweerd C and Gavln-Dreschnack DJ. Mapping the maze of terms and definitions in dementia-related wandering. *Aging & Mental Health* 2007; 11(6): 686-698.
38. Institute of Medicine. *The future of nursing: Leading Change, Advancing health.* The National Academic Press, Washington, 2011.
39. Chalmers R. Health care terminology for the electronic era. *Mayo Clin Proc* 2006; 81(6): 729-731.
40. Stucki G and Sigl T. Assessment of the impact of disease on the individual. *Best Practice & Research in Clinical Rheumatology* 2003; 17(3): 451-473.

“Wat zijn de doelen in uw leven? Die vraag moet gesteld worden voordat een besluit genomen wordt over de medische behandeling.”

TvZ | Tijdschrift voor Verpleegkundigen, 2012 nr 6, Gonda Stallinga.

3

The ambiguity of the concept of participation in measurement instruments: operationalization of participation influences research outcomes

Hillegonda A. Stallinga
Pieter U. Dijkstra
Isaac Bos
Yvonne F. Heerkens
Petrie F. Roodbol

Clinical Rehabilitation 2014; 28(12): 1225-1236

Abstract

Objective: This study explores, based on the International Classification of Functioning, Disability and Health, the consequences of different operationalizations of participation in regression models predicting participation in one sample of patients.

Design: Cross-sectional, comparative study.

Setting: Department of Neurology of a University Hospital.

Subjects: A total of 677 patients with a Neuromuscular Disease.

Measures: Participation was measured using the Neuromuscular Disease Impact Profile questionnaire, the RAND-36 Item Health Survey (social functioning, role limitations-physical, role limitations-emotional) and the Impact on Participation and Autonomy questionnaire (autonomy outdoors, social relations). Potential predictors of participation included type of neuromuscular disease, body functions (measured with Neuromuscular Disease Impact Profile), activities (measured with Neuromuscular Disease Impact Profile), environmental factors (measured with Neuromuscular Disease Impact Profile), and personal factors (measured with the 13-item Sense of Coherence questionnaire). The results were controlled for patient characteristics.

Results: Participation was statistically predicted by different determinants depending on the operationalization used for participation. Additionally, the regression coefficients differed significantly. Body functions and activities were predictors in five out of six operationalizations of participation. Sense of coherence predicted participation in all of the operationalizations. The explained variance of the different models ranged from 25% (RAND-36 role limitations- emotional) to 65% (Neuromuscular Disease Impact Profile).

Conclusions: Different operationalizations of participation result in different prediction models. Lack of conceptual consensus makes participation an ambiguous concept in research, and this ambiguity makes evidence-based decisions directed at enhancing participation difficult. Participation needs to be operationalized in an unambiguous and standard way in order to improve the comparability of outcomes.

3.1 Introduction

Disease affects patients' functioning.[1,2] The International Classification of Functioning, Disability and Health (ICF) can be used to describe functioning and the factors that influence functioning. The ICF describes functioning as an umbrella term encompassing the components body functions and structures, activities, and participation.[3] Participation is defined in the ICF as an individual's involvement in life situations. Participation is related to health conditions (i.e. disease), to the components body functions and structures and activities, and to the environmental factors and personal factors (Figure 3.1).[3]

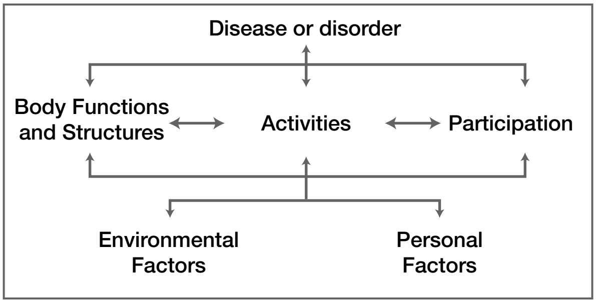


Figure 3.1 ICF framework representing the interactions between the components.[3]
Note: ICF categories and chapters are not shown in this figure.

Participation is often the main target of interventions aimed at improving the health of chronically ill patients.[4] Because the number of people with a chronic disease is rapidly increasing, participation has become essential to clinical practice as an outcome of health care.[5] As a result, the need for valid and reliable instruments that measure participation has also increased.[6] Several such instruments have been developed in the last decades,[6-8] including generic measurement instruments such as the Keele Assessment of Participation,[9] the Social Role Participation Questionnaire,[10] the Assessment of Life Habits[11] as well as disease-specific measurement instruments such as the Juvenile Arthritis Foot Disability Index.[12]

However, measurement instruments differ in their operationalization of participation.[13] For instance, the Keele Assessment of Participation operationalizes participation in restrictions in mobility, self-care, domestic life, interpersonal interaction, major life areas, community, and social life. In contrast, the Social Role Participation Questionnaire operationalizes participation in role relevance and satisfaction in community, social events, physical leisure, hobbies, casual contact, travel, employment, education, and relationships.[14] The instruments differ in the content of the items included and in the aspects measured, (e.g. restrictions, satisfaction).[15] In the current study we focused on the content of items.

Participation has proven to be difficult to operationalize, which is partly caused by the multidimensionality of the concept itself and by the fact that there is no consensus on its conceptualization.[6,8,15-20] To date, a clear definition of participation is lacking.[21] In the current study we used the definition of participation listed in the ICF.

The ICF is a universal conceptual framework and classification system based on the biopsychosocial model.[3] The ICF describes all components, with the exception of personal factors, and subdivides these components into chapters and categories. As such, the ICF can be used as a reference terminology. Participation is differentiated as a separate component in the framework, but in the classification system it is combined with the activity component in a single list divided into nine chapters (d1-d9). The ICF offers four options for distinguishing between activities and participation, one of which involves using a distinct set of activities and participation.[3] We chose this option and have operationalized participation using the ICF category d660 'assisting others' and the ICF chapters d7, 'interpersonal interactions and relationships', d8, 'major life areas', and d9, 'community and social life'.[3] This distinct set is in accordance with literature measuring participation, which emphasizes the performance of roles in a social context.[8,19,21,22]

Previous studies have found associations between participation and the effect of interventions[23] and between participation and the impact of the disease, activities, environmental factors, and personal factors.[24] However, outcomes are difficult to compare because the measurement instruments employed used different operationalization of participation. Additionally, differences in sample characteristics also hinder a comparison between the results of different studies.

The main objective of this study was to explore, based on the ICF, the consequences of differences in operationalizations of participation in regression models to predict participation in one sample of patients.

3.2 Method

Patients diagnosed with a neuromuscular disease and treated at the Neurological Center of a University Hospital in the North of the Netherlands were selected for this cross-sectional study. The neuromuscular disorder was diagnosed by a neurologist and registered in the patient's medical record.

Inclusion criteria for this study were: having been diagnosed with one of the following four neuromuscular disorders[25] (described along with their corresponding code of the International Classification of Diseases, 10th Revision):[26] motor neuron disorder G70-G73 (e.g. amyotrophic lateral sclerosis), muscle disorder G10-G13 (e.g. Duchenne muscular dystrophy), junction disorder G70-G73 (e.g. myasthenia gravis), and peripheral nerve disorder G60-G64 (e.g. polyneuropathy); living independently in the community; ≥ 18 years; Dutch speaking; and being able to give informed consent. Eligible patients (*n* = 978) were selected from the hospital's records. They received information about the purpose of the study and were invited to take part in the study by means of a letter. The study was approved by the Institutional Review Board (METc2009.310).

After giving informed consent, patients received the following questionnaires: the Neuromuscular Disease Impact Profile questionnaire,[27] the RAND-36 item Health Survey[28] (quite similar to the Short-Form-36-item Health Survey), the Impact on Participation and Autonomy questionnaire,[29] and the 13-item Sense of Coherence questionnaire.[30]

3.2.1 Measurement instruments

The measurement instruments used in the present study were grouped according to the components of the ICF framework (Figure 3.1). Health condition (disorder or disease), body functions and structures, activities, environmental factors, and personal factors were used as predictor variables, and participation was used as an outcome variable.

Body functions, activities, and environmental factors were measured with the corresponding components of the Neuromuscular Disease Impact Profile questionnaire. Personal factors are not included in the Neuromuscular Disease Impact Profile questionnaire; these were measured with the 13-item Sense of Coherence questionnaire.[31]

Participation was measured with six subscales covered by three measurement instruments: the Neuromuscular Disease Impact Profile questionnaire; the RAND-36 Item Health Survey, and the Impact on Participation and Autonomy questionnaire. All data used in this study are patient self-reported, except for the type of neuromuscular disorder which was obtained from the medical record.

3.2.2 Disorder or disease

Disease characteristics included the type of neuromuscular disorder diagnosed by the neurologist and obtained from the medical record. Data on duration of symptoms and disease in years were retrieved from the patient self-reported questionnaire.

3.2.3 Body functions and structures, activities and environmental factors

The Neuromuscular Disease Impact Profile questionnaire.[27]

The Neuromuscular Disease Impact Profile is a validated patient self-reported questionnaire that measures the severity of disability related to neuromuscular disease with a set of 45 relevant ICF categories divided into the components body functions (16 items related to the ICF chapters b1 ‘mental functions’; b2 ‘pain’; b3 ‘speech functions’; b4 ‘exercise tolerance functions’; b5 ‘functions related to the digestive system’; b6 urination functions, sexual functions’ and b7 ‘neuromusculoskeletal and movement functions’), activities (16 items related to the ICF chapters d3 ‘communication’; d4 ‘mobility’; d5 ‘self-care’ and d6’domestic life’), participation (nine items, described below under the header participation), and environmental factors (four items related to the ICF chapters e3 ‘support and relationships’ and e5 ‘services, systems and policies’).[32]

In the current study, the items of the Neuromuscular Disease Impact Profile questionnaire related to body functions, activities, and environmental factors were used as predictors. Scoring options of the Neuromuscular Disease Impact Profile questionnaire range from 0 (no disability) to 4 (complete disability) and from 0 ((strong) facilitator) to 2 (not a facilitator). The mean component scores are calculated by dividing the sum score by the number of completed items. Each component must be answered for at least 75% of the items. In cases where less than 75% of the items are answered, the total score was not calculated. Internal consistency of the scales ranges from 0.69 to 0.93.[27]

3.2.4 Participation

We included participation measurement instruments based on items in the ICF category d660 and the ICF chapters d7, d8 and d9 by employing established linking rules.[33] By using the ICF as a reference terminology and by linking the items of the measurement instruments to the corresponding ICF codes, we were able to compare measurement instruments.

Three measurement instruments representing six different scales related to participation were included in the current study. The scales are described below including their linked ICF code.

The Neuromuscular Disease Impact Profile questionnaire.[27]

The items of the Neuromuscular Disease Impact Profile questionnaire, indicated as participation, were used as outcome variables. It included eight questions about restrictions in performing specific actions caused by barriers in the environment using communication devices and techniques (d360); moving around in different locations (d460); using transportation (d470); performing daily self-care (d510-d540); preparing meals (d630); entering into informal social relationships and family relationships (d750-d760); engaging in remunerative employment (d850); and engaging in community life, recreation and leisure (d910/d920).

The RAND-36 item Health Survey.[34 35]

The RAND-36 item Health Survey measures perceived health status. It is a short version of the RAND Health Insurance Study Questionnaire, consisting of 36 items quite similar to the Medical Outcome Studies (MOS) Short-Form -36 item Health Survey.[36] The RAND-36 item Health Survey is divided into eight scales.[37] In the current study, the subscales role limitations-physical, including four questions about the extent and frequency of problems related to work or other regular daily activities (d8, d9) caused by physical health; role limitations-emotional, including three questions about the extent and frequency of problems related to work or other regular daily activities (d8, d9) caused by emotional health; and social functioning, including two questions about the extent and the frequency of restrictions in performing social activities (d7), were used as operationalizations of participation.

Scales ranges from 0 to 100, higher scores reflect higher level of perceived health or well-being. Internal consistency of the RAND-36 scales ranges from 0.71 to 0.93.[35] If a respondent missed one of the items, the total score was not calculated.

The Impact on Participation and Autonomy questionnaire.[38]
The Impact on Participation and Autonomy questionnaire assesses the perceived personal impact of illness on participation.[29,38] It consists of 31 items divided into five scales. In the current study, the scale autonomy outdoors, including four questions about the frequency and the degree to which one can determine where and when actions are undertaken with regard to visiting neighbors and friends (d730-d750), and making trips and spending free time (d910-d920); and the scale social life and relationships, including six questions about the experiences of social relations (d710-d720), were used as operationalizations of participation. Scoring options of the Impact on Participation and Autonomy questionnaire range from 0 (no impact) to 4 (most negative impact). The mean scores are calculated by dividing the sum score by the number of completed items. Each scale must be answered for at least 75% of the items, otherwise the total score was not calculated. Internal consistency of these scales ranges from 0.81 to 0.91.[29]

3.2.5 Personal Factors

Information about gender, age, education level, marital status (yes/no) and having children (yes/no) was obtained by a patient self-reported questionnaire. Education level was categorized as low, middle or high. Marital status included cohabitation.

The 13-item Sense of Coherence questionnaire.[30]
The 13-item Sense of Coherence questionnaire includes 13 questions that measure an individual's sense of coherence, meaning the degree to which an individual views the world as comprehensible, manageable, and meaningful.

Scoring options range from 1 (lowest) to 7 (highest). A total score is calculated by adding up item scores. The total score ranges from 13 to 91. Individuals who score high on the 13-item Sense of Coherence questionnaire are more likely to stay healthy than individuals with a low score.[31,39] Internal consistency of this questionnaire is 0.48.[30] If a respondent had one missing response, the missing response was replaced with the individual mean score. If more than one item was missing, the total score was not calculated.

3.2.6 Data analysis

The original scores of all the measurement instruments used in this study are included in Table 3.1. However, for reasons of comparability in the regression analysis, all scores were standardized by dividing the sum score of each component by the maximum score of that component and by multiplying it by a hundred to obtain a result ranging from 0 (good health) to 100 (poor health).

To make the results of the regression parameters more meaningful for clinical interpretation, age was centered to the mean age of 60 years. This means that the intercept in the regression analysis represents the participation scores of a 60-year-old person. To examine to what extent the various participation instruments measured the same concept, a Pearson product-moment correlation coefficient was computed. Correlations of > 0.80 were interpreted as high.[40]

The associations of the predictor variables with the outcome variables were assessed by multivariate linear regression models (method: enter).[40] Interaction terms between the predictor variables were explored. The regression analyses were controlled for age, gender, education, marital status (including cohabitation) yes or no, having children or not, level of education, duration of disease in years (since medical diagnosis), and duration of the symptoms of the disease in years. Associations with p-values ≤ 0.05 were considered statistically significant. The analyses were performed using SPSS for Windows version 20 (SPSS Inc., Chicago, IL, USA).

Table 3.1 Baseline characteristics of the responders (total *N* = 677) and non-responders (total *N* = 301).

Variable	**Responders** ***n*** **(%)**	**Non-responders** ***n*** **(%)**
Health condition		
NMD diagnosis		
Motor neuron disorder	33 (4.9%)	13 (4.3%)
Muscle disorder	154 (22.7%)	63 (20.9%)
Junction disorder	234 (34.6%)	86 (28.6%)
Peripheral nerve disorder	256 (37.8%)	137 (45.5%)
Years since NMD symptoms (mean (SD))	15.2 (12.6)	
Years since NMD diagnosis (mean (SD))	11.6 (10.8)	
Body functions		
NMDIP body functions(mean (SD)) (range 0-100)	21.4 (12.3)	
Activities		
NMDIP activities (mean (SD)) (range 0-100)	21.6 (22.3)	
Environmental factors		
NMDIP environmental factors (mean (SD)) (range 0-100)	30.8 (28.9)	
Participation		
NMDIP participation (mean (SD)) (range 0-100)	9.9 (14.5)	
RAND-36 (mean (SD)) (range 0-100)		
Social functioning	73.5 (23.3)	
Role limitations-physical	49.2 (42.4)	
Role limitations-emotional	72.7 (39.6)	
IPA (mean (SD))		
Autonomy outdoor (range 0-16)	5.8 (3.8)	
Social relations (range 0-24	5.7 (3.7)	
Personal factors		
Age years (Mean (SD))	59.1 (15.7)	53.4 (18.8)
Gender		
Male	344 (50.8%)	163 (54.0%)
Education level		
Low	229 (33.8%)	
Middle	261 (38.6%)	
High	180 (26.6%)	
Cohabitation/married		
Yes	480 (70.9%)	
Children		
Yes	540 (79.8%)	
SOC-13* (mean (SD)) (range 13-91)	68.6 (12.6)	

NMD: Neuromuscular Disease; NMDIP: Neuromuscular Disease Impact Profile,[27] higher scores indicate a worse health or not a facilitating environment); RAND-36: RAND36-item Health Survey,[34] (higher scores indicate a better health); IPA: Impact on Participation and Autonomy questionnaire[38] (higher scores indicate a worse health); SOC-13: Sense of Coherence questionnaire 13-item version[30] (higher scores indicate a better health). *n = 625

3.3 Results

A total of 677 patients (response rate of 69%) returned the questionnaire. Mean age of responders was significantly higher (59.3; SD 15.8) (Table 3.1) than that of non-responders (53.4; SD 18.8; $n = 301$) ($p < 0.001$). No significant differences in gender ($p = 0.42$) were found. There was a difference between the number of responders and non-responders with respect to the neuromuscular disease diagnoses junction disorder (34.6% versus 28.6%) and peripheral nerve disorder (37.8% versus 45.5%). The difference was not statistically significant ($p = 0.07$).

The results of the Pearson product-moment correlation coefficient between the participation measurement instruments (Table 3.2) ranged from 0.26 to 0.69.

Table 3.2 Pearson correlations between participation measurement instruments.

		2	3	4	5	6
1	NMDIP participation[a]	.54**	.26**	.36**	.65**	.46**
2	RAND-36 social functioning[b]	-	.47**	.58**	.68**	.57**
3	RAND-36 role limitations-emotional[b]		-	.49**	.37**	.37**
4	RAND-36 role limitations-physical[b]			-	.58**	.44**
5	IPA autonomy outdoor[c]				-	.69**
6	IPA social relations[c]					-

[a] Neuromuscular Disease Impact Profile component participation.[27]
[b] RAND36-item Health Survey, subscales: social functioning, role limitations-emotional, role limitations-physical.[34]
[c] Impact on participation and autonomy subscales: autonomy outdoor and social relations.[38]
** $p < .01$

Table 3.3 Comparison of six multiple regression analyses for predicted participation (operationalized in six different ways) as dependent variable and kind of diagnosis (motorneuron disorder- peripheral nerve disorder-muscle versus junction disorder), body functions, activities, interaction term body functions*activities, environmental factors and personal factors as independent variables.

	NMDIP participation[a]	**RAND-36 social functioning**[b]	**RAND-36 role limitations-emotional**[b]	**RAND-36 role limitations-physical**[b]	**IPA autonomy outdoor**[c]	**IPA social relations**[c]
R^2 control	0.04**	0.04**	0.06**	0.04**	0.07**	0.07**
R^2 total	0.65**	0.50**	0.25**	0.36**	0.60**	0.44**
	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)
Reference	8.63** (2.87 to 14.39)	40.53** (29.44 to 51.63)	69.09** (45.9 to 92.29)	29.12** (6.17 to 52.08)	25.55** (15.41 to 35.68)	36.04** (28.20 to 43.88)
Motorneuron disorder	2.43 (-1.28 to 6.14)	-7.37* (-14.51 to -0.22)	0.27 (-14.67 to 15.20)	-4.89 (-19.66 to -9.89)	-2.19 (-8.72 to 4.33)	0.04 (-5.01 to 5.09)
Peripheral nerve disorder	-1.13 (-2.88 to 0.62)	-2.82 (-6.18 to 0.55)	-1.23 (-8.26 to 5.81)	-3.06 (-10.02 to 3.90)	-2.49 (-5.57 to 0.58)	-0.96 (-3.34 to 1.42)
Muscle disorder	0.88 (-1.40 to 3.15)	-5.15* (-9.53 to -0.78)	4.34 (-4.80 to13.49)	-0.15 (-9.21 to -8.90)	-2.95 (-6.95 to 1.05)	2.80 (-0.30 to 5.89)
Body functions[a]	0.02 (-0.08 to 0.11)	0.84** (0.65 to 1.03)	0.89** (0.49 to1.28)	2.29** (1.90 to 2.68)	1.03** (0.85 to 1.20)	0.56** (0.42 to0.69)
Activities[a]	0.29** (0.21 to 0.36)	0.18* (0.03 to 0.34)	0.09 (-0.23 to 0.41)	0.71** (0.40 to 1.02)	0.81** (0.67 to 0.95)	0.27** (0.16 to 0.37)
Body functions* activities[a]	0.005**(0.003 to 0.007)	0.000 (-0.004 to 0.005)	-0.004 (-0.012 to 0.005)	-0.024** (-0.032 to -0.015)	-0.014** (-0.018 to -0.010)	-0.006** (-0.009 to -0.003)
Environment[a]	0.03** (0.00 to 0.05)	-0.00 (-0.05 to 0.05)	-0.001 (-0.012 to 0.100)	-0.06 (-0.16 to -0.04)	0.01 (-0.03 to 0.06)	0.03 (-0.01 to 0.06)
Personal factors SOC-13[d]	-0.13** (-0.19 to -0.06)	-0.47** (-0.59 to -0.34)	-0.90** (-1.16 to -0.64)	-0.36**(-0.62 to -0.10)	-0.28** (-0.39 to -0.16)	-0.03** (-0.01 to -0.06)

NMDIP: Neuromuscular Disease Impact Profile; RAND-36: RAND36-item Health Survey; IPA: Impact on Participation and Autonomy questionnaire; R^2 control: explained variance owing to control variables-age, gender, marital status, education, having children or not, duration disease in years\duration symptoms in years; R^2 total: explained variance due to all predictor variables together; Reference: middle-educated man of 60 years old with junction disorder, married/cohabitation, and having children or not; B: unstandardized regression coefficient; CI: confidence interval; SOC-13: Sense of Coherence questionnaire 13-item version.

[a] Neuromuscular Disease Impact Profile components: participation, body functions, activities and environmental factors.[27]

[b] RAND36-item Health Survey, Dutch version subscales: social functioning, role limitations-emotional, role limitations-physical.[34]

[c] Impact on participation and autonomy subscales: autonomy outdoor and social relations.[38]

[d] Sense of Coherence questionnaire 13 items version.[30]

Note: $N = 677$; $*p < 0.05$; $**p < 0.01$; for comparison of the scales standardized scores were used ranging from 0 (good health) to100 (worse health).

The explained variance of the different regression models ranged from 25% (RAND-36 role limitations-emotional) to 65% (Neuromuscular Disease Impact Profile Participation). The explained variance of the control variables ranged from 4% to 7% (Table 3.3).

The predictor variables that contributed significantly to the regression equation varied between the models.

If participation was operationalized with the RAND-36 social functioning, the diagnosis of a motor neuron disorder or a muscle disorder was significantly associated with a higher participation score compared with the diagnosis of a junction disorder.

Body functions (measured with the Neuromuscular Disease Impact Profile questionnaire) contributed significantly to five out of the six operationalizations of participation. The Neuromuscular Disease Impact Profile Participation was the exception here. Activities also contributed significantly to the regression equation in five out of the six operationalizations of participation. The RAND-36 role limitations-emotional proved to be the exception here. The interaction between body functions and activities was significant in four out of the six operationalizations of participation. This interaction was not significant for the RAND-36 social functioning and the RAND-36 role limitations-emotional.

Environmental factors contributed only significantly to the prediction of participation when operationalized in the Neuromuscular Disease Impact Profile questionnaire.

Personal factors, represented by the 13-item Sense of Coherence questionnaire, contributed significantly to the regression equation in the six different operationalizations of participation.

3.4 Discussion

In this study we have shown that different operationalizations of the concept of participation result in different outcomes of prediction models. Our study is the first to demonstrate the consequences of these different operationalizations on research outcomes in a single population of patients.

The differences between the percentages of explained variance (ranging from 25% for the RAND-36 role limitations-emotional to 65% for the Neuromuscular Disease Impact Profile Participation) and between the regression coefficients of the predictors can be explained by differences in measurement instruments in which participation is operationalized, because a single population was studied, the same measurement procedure was applied for all participants, the same time frame for all participants was applicable and the same set of predictors was used. Method variance, i.e. variance in response due to measurement methods,[41] may also contribute to this explained variance, but it cannot explain the large range of explained variance in the current study. The full extent of method variance is unknown.[41]

The measurement instruments included in this study differ in number, content, and aspects of the items used, as was demonstrated by the linking of the items to the ICF categories and chapters. These differences show that the measurement instruments operationalized the concept of participation differently, as was confirmed by the Pearson correlation coefficient (all < 0.70). To enable a full comparison of instruments measuring participation, the content and the aspects of the items related to participation should be standardized.[15]

Our results correspond to those reported in a study[8] in which the content of 122 measurement instruments was compared with the ICF. The concept of participation in that study was operationalized almost similarly to our study, namely by operationalizing participation in the ICF chapters d7, d8 and d9. The result of that study showed that only 25% of the items of the measurement instruments addressed participation and that the other items failed to do so.[8]

The variables personal factors, body functions, and activities contributed significantly to all (or almost all) regression equations, environmental factors contributed to only one equation. Similar findings to ours were reported in a study in stroke patients.[41] That study found that body functions and activities were the most influential variables for predicting participation. The Impact on Participation and Autonomy outdoors and social relations explained 67% and 42% of the variance, respectively. A study in patients with multiple sclerosis found that higher levels of activities (exercises) were predictive for fewer restrictions in participation measured with the RAND-36 scales.[42]

However, contrary to our results, a study in people with myotonic dystrophy[43] and a study in people with knee pain[44] found environmental factors predictive for participation measured with the Life Habits Measurement Instrument.[11] Additionally, a study in spinal cord injury patients[45] found that the sense of coherence measured with the 13-item Sense of Coherence questionnaire was not predictive for participation measured by the Reintegration to Normal Living Index.[46] An explanation for these differences could be that the Life Habits Measurement Instrument and the Reintegration to Normal Living Index, similar to the component participation of the Neuromuscular Disease Impact Profile questionnaire, have operationalized participation by including some other items from the ICF than the category d660 and the chapters d7, d8 and d9.

Our study has some limitations. The first limitation concerns the selection of the measurement instruments included in our study. We chose instruments that used an operationalization of participation closely related to the ICF category d660 and the ICF chapters d7, d8, and d9. However, the component participation of the Neuromuscular Disease Impact Profile questionnaire also includes some items that are related to the ICF chapters d3-d6. Also, the Impact of Participation and Autonomy questionnaire lacks items related to the ICF chapter d8.

Furthermore, despite the fact that the Neuromuscular Disease Impact Profile questionnaire operationalizes the predictor variables body functions and activities properly in accordance with the ICF components, items related to the environmental factors are missing for the ICF chapters e1, e2 and e4. Additionally, personal factors are not included in the Neuromuscular Disease Impact Profile questionnaire, nor classified in the ICF. The content of these factors is not clear.[47] We chose the 13-item Sense of Coherence questionnaire, despite the fact that this questionnaire presents personal factors in a specific perspective and that it lacked certain items.

Although our choice of measurement instruments obviously influenced the results, at the same time they confirmed the aim of our research, which was not to assess the best instrument for measuring participation, but rather to explore the consequences of different operationalizations of participation.

The second limitation of our study concerns the difference in age between responders and non-responders. It is likely that younger patients who are diagnosed with a neuromuscular disorder will want to live as normally as possible and may not want to spend time on things that confront them with their illness, such as completing a questionnaire. However, we believe that the difference in age between responders and non-responders was clinically small and therefore not very relevant for the interpretation of our results. Although age was a variable we controlled for, our study showed that personal characteristics, including age, did not significantly contribute to the prediction of participation or to the explained variance. This finding is in keeping with results from other studies that predicted participation.[41,43,48-50]

The strengths of our study include the sample size of the population, the large response rate of 69% (677 patients), and the design, which utilized several measurement instruments related to participation at the same time and in the same population.

Our findings indicate that when selecting an instrument to measure participation, close attention should be paid to the operationalization of the concept of participation employed by that particular instrument.[49] For example, if participation is measured using the Neuromuscular Disease Impact Profile questionnaire, the outcomes suggest that health professionals should focus on activities and environmental factors to enhance participation. In contrast, if participation is measured using the RAND-36 role limitations-emotional, the outcomes suggest that health professionals should focus on body functions to improve participation. Although the concept of participation itself has gained widespread acceptance, consensus on its definition and on its operational measurement instruments is still lacking.[19]

In conclusion, our study shows that the outcomes of prediction models vary greatly due to the different operationalizations of participation, making participation an ambiguous concept in research. However, it is encouraging for the conceptualization and the operationalization of participation that the ICF has provided a definition, chapters and categories relating participation to the performance of roles in a social context. Future studies should consider using the ICF as reference terminology to conceptualize and operationalize participation in an unambiguous and standard way. This will enable comparisons of outcomes related to participation that address the effectiveness of interventions that can assist policy-makers in making evidence-based decisions directed at enhancing participation.

References

1. Stucki G and Sigl T. Assessment of the impact of disease on the individual. *Best Practice & Research in Clinical Rheumatology* 2003; 17(3): 451-473.
2. van Brakel W, Anderson A, Mutatkar R, Bakirtzief Z, Nicholls P, Raju M, et al. The Participation Scale: Measuring a key concept in public health. *Disabil Rehabil* 2006; 28(4): 193-203.
3. World Health Organization. *International Classification of Functioning, Disability and Health: ICF.* 1st ed. Geneva: World Health Organization, 2001.
4. Wilkie R, Peat G, Thomas E and Croft P. Factors associated with participation restriction in community-dwelling adults aged 50 years and over. *Quality of Life Research* 2007; 16(7): 1147-1156.
5. Hemmingsson H and Jonsson H. An occupational perspective on the concept of participation in the International Classification of Functioning, Disability and Health - Some critical remarks. *American Journal of Occupational Therapy* 2005; 59(5): 569-576.
6. Resnik L and Plow MA. Measuring participation as defined by the International Classification of Functioning, Disability and Health: an evaluation of existing measures. *Arch Phys Med Rehabil* 2009; 90(5): 856-866.
7. Noonan VK, Kopec JA, Noreau L, Singer J, Chan A, Masse LC, et al. Comparing the content of participation instruments using the International Classification of Functioning, Disability and Health. *Health and Quality of Life Outcomes* 2009; 7: 93.
8. Eyssen IC, Steultjens MP, Dekker J and Terwee CB. A systematic review of instruments assessing participation: challenges in defining participation. *Arch Phys Med Rehabil* 2011; 92(6): 983-997.
9. Wilkie R, Peat G, Thomas E, Hooper H and Croft P. The Keele Assessment of Participation: a new instrument to measure participation restriction in population studies. Combined qualitative and quantitative examination of its psychometric properties. *Quality of Life Research* 2005; 14(8): 1889-1899.
10. Gignac MAM, Backman CL, Davis AM, Lacaille D, Mattison CA, Montie P, et al. Understanding social role participation: what matters to people with arthritis? *J Rheumatol* 2008; 35(8): 1655-1663.
11. Fougeyrollas P, Noreau L, Bergeron H, Cloutier R, Dion S and St-Michel G. Social consequences of long term impairments and disabilities: conceptual approach and assessment of handicap. I*nternational Journal of Rehabilitation Research* 1998; 21(2): 127-141.
12. Andre M, Hagelberg S and Stenstrom C. The juvenile arthritis foot disability index:

development and evaluation of measurement properties. *J Rheumatol* 2004; 31(12): 2488-2493.

13. Whiteneck GG, Dijkers MP, Heinemann AW, Bogner JA, Bushnik T, Cicerone KD, et al. Development of the participation assessment with recombined tools-objective for use after traumatic brain injury. *Arch Phys Med Rehabil* 2011; 92(4): 542-551.
14. Davis AM, Palaganas MP, Badley EM, Gladman DD, Inman RD and Gignac MA. Measuring participation in people with spondyloarthritis using the social role participation questionnaire. *Ann Rheum Dis* 2011; 70(10): 1765-1769.
15. Heinemann AW, Lai J, Magasi S, Hammel J, Corrigan JD, Bogner JA, et al. Measuring participation enfranchisement. *Arch Phys Med Rehabil* 2011; 92(4): 564-571.
16. Dijkers MP. Issues in the conceptualization and measurement of participation: an overview. *Arch Phys Med Rehabil* 2010; 91(9): S5-S16.
17. Magasi S and Post MW. A comparative review of contemporary participation measures' psychometric properties and content coverage. *Arch Phys Med Rehabil* 2010; 91(9): S17-S28.
18. Perenboom R and Chorus A. Measuring participation according to the International Classification of Functioning, Disability and Health (ICF). *Disabil Rehabil* 2003; 25(11-2): 577-587.
19. Whiteneck G and Dijkers MP. Difficult to measure constructs: conceptual and methodological Issues concerning participation and environmental factors. *Arch Phys Med Rehabil* 2009; 90(11): S22-S35.
20. Wilkie R, Jordan JL, Muller S, Nicholls E, Healey EL and van der Windt DA. Measures of social function and participation in musculoskeletal populations Impact on Participation and Autonomy (IPA), Keele Assessment of Participation (KAP), Participation Measure for Post-Acute Care (PM-PAC), Participation Objective, Participation Subjective (POPS), Rating of Perceived Participation (ROPP), and The Participation Scale. *Arthritis Care & Research* 2011; 63(11): S325-S336.
21. Piskur B, Daniels R, Jongmans MJ, Ketelaar M, Smeets RJ, Norton M, et al. Participation and social participation: are they distinct concepts? *Clin Rehabil* 2014; 28(3): 211-220.
22. van der Mei SF, Dijkers MPJM and Heerkens YF. Participation as an outcome measure in psychosocial oncology: content of cancer-specific health-related quality of life instruments. *Quality of Life Research* 2011; 20(10): 1617-1627.
23. Verhagen AP, Scholten-Peeters GGGM, van Wijngaarden S, de Bie RA and Bierma-Zeinstra SMA. Conservative treatments for whiplash. *Cochrane Database of Systematic Reviews* 2007; (2): CD003338.

24. Colver A, Thyen U, Arnaud C, Beckung E, Fauconnier J, Marcelli M, et al. Association between participation in life situations of children with cerebral palsy and their physical, social, and attitudinal environment: a cross-sectional multicenter European study. *Arch Phys Med Rehabil* 2012; 93(12): 2154-2164.
25. Rowland LP and McLeod JG. Classification of neuromuscular disorders. *J Neurol Sci* 1994; 124 Suppl(S): 109-130.
26. World Health Organization. *International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10).* 10th ed. Geneva: World Health Organization, 1992.
27. Bos I, Middel B, Kuks JBM and Wynia K. The Neuromuscular Disease Impact Profile, development and testing psychometric properties of an ICF-based health measure. *Journal Of Rehabilitation Medicine* 2013; (submitted).
28. Hays R and Morales L. The RAND-36 measure of health-related quality of life. *Ann Med* 2001; 33(5): 350-357.
29. Cardol M, de Haan R, de Jong B, van den Bos G and de Groot I. Psychometric properties of the impact on participation and autonomy questionnaire. *Arch Phys Med Rehabil* 2001; 82(2): 210-216.
30. Antonovsky A. The Structure and Properties of the Sense of Coherence Scale. *Soc Sci Med* 1993; 36(6): 725-733.
31. Antonovsky A. *Unraveling the Mystery of Health. How People Manage Stress and Stay Well.* 1st ed. San Francisco, CA: Jossey-Bass, 1987.
32. Bos I, Stallinga HA, Middel B, Kuks JBM and Wynia K. Validation of the ICF core set for neuromuscular diseases. *Eur J Phys Rehabil Med* 2013; 49(2): 179-187.
33. Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustun B and Stucki G. ICF linking rules: an update based on lessons learned RID F-6994-2011. *J Rehabil Med* 2005; 37(4): 212-218.
34. *van der Zee K and Sanderman R.* Het meten van de algemene gezondheidstoestand met de RAND-36: een handleiding. 2012; 2nd revised version(1).
35. van der Zee K, Sanderman R, Heyink J and de Haes H. Psychometric qualities of the RAND 36-item health survey 1.0: a multidimensional measure of general health status. *Int J Behav Med* 1996; 3(2): 104-122.
36. Ware J and Sherbourne C. The Mos 36-Item Short-Form Health Survey (SF-36) .1. Conceptual-Framework and Item Selection. *Med Care* 1992; 30(6): 473-483.
37. Hays R and Morales L. The RAND-36 measure of health-related quality of life. *Ann Med* 2001; 33(5): 350-357.
38. Cardol M, de Haan R, van den Bos G, de Jong B and de Groot I. The development of

a handicap assessment questionnaire: the Impact on Participation and Autonomy (IPA). *Clin Rehabil* 1999; 13(5): 411-419.

39. Antonovsky A. *Health, Stress and Coping: New Perspectives on Mental and Physical Well-being.* 1st ed. San Francisco: Jossey-Bass, 1979.
40. Field A. *Discovering statistics Using SPSS.* 3rd ed. London: Sage Publications, 2009.
41. Fallahpour M, Tham K, Joghataei MT and Jonsson H. Perceived participation and autonomy: aspects of functioning and contextual factors predicting participation after stroke. *J Rehabil Med* 2011; 43(5): 388-397.
42. Turner AP, Kivlahan DR and Haselkorn JK. Exercise and quality of life among people with multiple sclerosis: looking beyond physical functioning to mental health and participation in life. *Arch Phys Med Rehabil* 2009; 90(3): 420-428.
43. Gagnon C, Mathieu J, Jean S, Laberge L, Perron M, Veillette S, et al. Predictors of disrupted social participation in myotonic dystrophy type 1. *Arch Phys Med Rehabil* 2008; 89(7): 1246-1255.
44. Wilkie R, Peat G, Thomas E and Croft P. Factors associated with restricted mobility outside the home in community-dwelling adults ages fifty years and older with knee pain: an example of use of the International Classification of Functioning to investigate participation restriction. *Arthritis Rheum* 2007; 57(8): 1381-1389.
45. Geyh S, Nick E, Stirnimann D, Ehrat S, Michel F, Peter C, et al. Self-efficacy and self-esteem as predictors of participation in spinal cord injury - an ICF-based study. *Spinal Cord* 2012; 50(9): 699-706.
46. Wood-dauphinee S, Opzoomer A, Williams J, Marchand B and Spitzer W. Assessment of Global Function - the Reintegration to Normal Living Index. *Arch Phys Med Rehabil* 1988; 69(8): 583-590.
47. Simeonsson RJ, Lollar D, Björck-Åkesson E, Granlund M, Brown SC, Zhuoying Q, et al. ICF and ICF-CY lessons learned: Pandora's box of personal factors. *Disabil Rehabil* 2014 03/07.
48. Gadidi V, Katz-Leurer M, Carmeli E and Bornstein NM. Long-term outcome poststroke: predictors of activity limitation and participation restriction. *Arch Phys Med Rehabil* 2011; 92(11): 1802-1808.
49. Jette A, Keysor J, Coster W, Ni P and Haley S. Beyond function: predicting participation in a rehabilitation cohort. *Arch Phys Med Rehabil* 2005; 86(11): 2087-2094.
50. van de Port ,I.G.L., van den Bos ,G.A.M., Voorendt M, Kwakkel G and Lindeman E. Identification of risk factors related to perceived unmet demands in patients with chronic stroke. *Disabil Rehabil* 2007; 29(24): 1841-1846.

> **“Artsen wilden haar een nieuwe heup geven, een kunsthartklep implanteren en haar ogen opereren. Zelf vond ze alleen dat laatste nodig: als zij gewoon haar krantje kon lezen, en haar kleinkinderen kon zien zou ze heel gelukkig zijn.”**

NRC Handelsblad, 22 december 2014, Machteld Huber.

4

Validation of the ICF Core Set for Neuromuscular Diseases

Isaäc Bos

Hillegonda A. Stallinga

Berrie Middel

Jan B.M. Kuks

Klaske Wynia

European Journal of Physical and Rehabilitation
Medicine 2013; 49(2): 179-187

Abstract

Background: Understanding of the consequences of a neuromuscular disease (NMD) can improve when a valid sample of disease-specific categories based on the International Classification of Functioning, Disabilities, and Health (ICF) is available.
Objective: To examine the content validity of the initial ICF Core Set for neuromuscular diseases (NMDs). The initial ICF Core Set was developed for three chronic neurological diseases.
Design: A qualitative method.
Methods: To examine the content validity of the initial ICF Core Set for NMD, concepts in established disease-specific health-related Quality of Life Questionnaires (HRQOL) were compared with ICF categories. Next, the selected ICF categories were linked to the ICF categories in the initial ICF Core Set.
Results: All concepts in the HRQOL questionnaires, except one body function concept, were covered by the initial ICF Core Set. However, the NMD Core Set reflects a broader scope concerning health problems than the concepts in the HRQOL questionnaires do, especially concerning the ‘participation’ and ‘environmental factors’ components.
Conclusion: The NMD Core Set, as well as a measurement based on this Core Set, can contribute to a better understanding of the consequences of NMDs and can also serve as a basis for clinical practice, research, social security systems, and educational programs.
Clinical rehabilitation impact: The newly developed NMD Core Set can be a basis for enhancing the development of rehabilitation interventions and improving overall health care for patients with a NMD.

4.1 Introduction

A neuromuscular disease (NMD) is a chronic and progressive neurological disorder that affects the muscle and/or the peripheral nervous system. Neuromuscular diagnoses may be classified into four major NMD groups: 1) motor neuron disorders (MND); 2) muscle disorders (MD); 3) nerve-muscle junction disorders (NMJD); and 4) peripheral nerve disorders (PND).[1] Patients with a MND suffer from progressive muscle weakness and muscle atrophy; eventually most patients will die as a result of problems with swallowing and breathing (2-4). Patients with a MD suffer from chronic and progressive muscle weakness leading to an insidious decline in mobility;[2-5] the clinical course in these diseases varies greatly in different patients and different diseases. Patients with a NMJD may suffer from droopy eyelids, double vision, swallowing and speech problems, and a limb-girdle weakness. Symptoms fluctuate and stabilize or even improve over the course of time.[6] Finally, patients with a PND may suffer from impaired sensory feeling, muscle twitching, cramping, numbness, tingling, and a host of other symptoms. Symptoms are, in most cases, slowly progressive.[7]

Symptoms of NMDs can lead to vulnerability, with a considerable impact on general health status and everyday life, and with possible limitations in terms of tasks or participation in social life with regard to housing, work, and income. The impact of these symptoms may increase with the progressive course of most of the NMDs.[8,9]

Due to better diagnostics, an increasing number of NMD patients is identified and receiving medical treatment. Therefore, life expectancy for patients with a NMD has increased.[10]

In order to reduce the patient's vulnerability and to improve his or her independent daily functioning, it is important for health care professionals and researchers to deepen the knowledge of a patient's actual functioning and disability. Health-status measuring instruments can be helpful tools.

Over the last two decades many health-measuring instruments have been developed for the use in both, clinical practice as well as in research. There are generic HRQOL instruments, for example, the 36-item Short Form Health Survey Questionnaire (SF-36).[11] In addition, there are generic and domain specific measuring instruments to assess activities of daily living, for example, GARS (Groningen Activity Restriction Scale)[12] or to assess participation in life situations, for example, the IPAQ (Impact on Participation and Autonomy Questionnaire).[13] An example of a disease specific HRQOL instrument with a broad scope concerning the consequences of a NMD is the Individual Neuromuscular Quality of Life Questionnaire (INQOL).[14]

Due to the prolific development and the increasing use of health-measuring instruments, there are now ‘competing’ instruments in many areas, and there is no consensus about which components are important and how to measure these components.[15] Furthermore, comparisons of health status across chronic diseases are problematic; the differences in aspects contributing to the content of physical, emotional, or social functioning constructs is a good example of this. Consequently, it is opportune to develop an internationally accepted frame of reference in order to measure functioning, disability, and health in patients with a MND.

Since HRQOL can be defined as an individual’s perceptions of health and health-related domains of well-being, the ICF categories can serve as the basis for the operationalization of HRQOL.[16] These ICF categories systematically describe all aspects of functioning and health. Health domains are classified in the ‘body functions and structures’ component and in the ‘activity and participation’ component. Since an individual’s functioning and disability occurs in a context, the ICF also includes a list of ‘environmental factors’.[17]

However, the ICF in its original form with about 1500 categories is hardly practicable and lacks feasibility.[18] Therefore, Stucki et al.[19,20] have suggested defining short lists – so-called Core Sets – of ICF categories which are relevant for specific conditions (e.g. stroke)[21] or multiple sclerosis.[22,23] An example of a measuring instrument based on a selection of ICF categories, and reflecting the broad scope of consequences of multiple sclerosis is the Multiple Sclerosis Impact Profile (MSIP).[24]

For the development of an assessment tool reflecting the broad range of the most important consequences of NMDs, the initial ICF Core Set for patients with a chronic neurological disorder[23] provides a good basis. Because this initial ICF Core Set was a consensus set for three neurological diseases and therefore not NMD-specific, we decided to further examine the content validity of the initial ICF Core Set with the goal to obtain an NMD Core Set.

The objective of this study is to develop an ICF Core Set for NMDs and to evaluate the content validity.

4.2 Materials and methods

4.2.1 Design

To examine the content validity of the initial ICF Core Set, we used a qualitative method. We systematically linked the concepts in the questions belonging to the domains and scales of three established disease-specific HRQOL measuring instruments with the categories appraised as relevant for neurological diseases in the initial ICF Core Set.[23]

4.2.2 Procedure

Linking the HRQOL concepts to the categories in the initial ICF Core Set was performed in three steps, namely: 1) meaningful concepts in the questions of the selected disease-specific questionnaires were identified by the two experts; 2) these concepts were linked to the categories of the full version of the ICF employing the ICF linking-rules;[25,26] and; 3) the matched ICF categories were compared with the categories in the initial ICF Core Set. Newly identified ICF categories were included in the final NMD Core Set when this category was found in at least two of the three measuring instruments.

The linking procedure was performed by two health care professionals: one professional with expertise in ICF (HAS: member of the Dutch WHO-FIC collaborating center) and one professional with expertise in NMDs (IB: Nurse Practitioner NMDs). These experts worked independently within the steps of the linking procedure.

Categories were included in the sample when both investigators unequivocally considered the selected category to be appropriate for analysis. Differences were resolved through discussion with reference to a third and fourth reviewer (JBMK, KW) if necessary.[26]

4.2.3 The initial ICF Core Set

The initial ICF Core Set was developed to indicate relevant categories of functioning and health for patients with a chronic neurological disorder such as multiple sclerosis, Parkinson’s disease, and neuromuscular disease. Therefore, a written Delphi study was performed using three disease-specific panels composed of patients and proxies, and medical and non-medical health care professionals (*n* = 98). The panels were asked to make a selection from among the 1500 categories found in the ICF reflecting relevant disease-specific health problems. As a result, sixty-eight ICF categories were considered to be the most relevant and they belonged to the ICF components: ‘body functions and structures’ (20 categories), ‘activities’ (21 categories), ‘participation’ (17 categories), and ‘environmental factors’ (10 categories). No significant differences were found between the appraisal of categories by patients/proxies and health care professionals. Agreement across the disease panels appeared to be very strong.[23]

4.2.4 Disease-specific HRQOL measuring instruments

We searched for HRQOL measuring instruments that at least covered the dimensions of ‘physical functioning’, ‘psychological functioning’, and ‘social functioning’, and represented at least one of the four groups in the classification of NMD according to Rowland and McLeod.[1]

We searched the Medline, Embase, Psychinfo, and Pubmed databases from 2000 until 2010 using the following keywords: 1) neuromuscular disease; 2) quality of life; 3) disability; and 4) outcome assessment. No measurement was found for the peripheral nerve disorder group.

We found the following instruments used for analysis:

Individualized Neuromuscular Quality of Life Questionnaire

The Individualized Neuromuscular Quality of Life Questionnaire (INQOL) is a measurement developed to assess HRQOL among patients with muscle disorders[14] and consists of 42 questions within ten domains. Four of the domains focus on the impact of key muscle disease symptoms (weakness, locking, pain, and fatigue), five of the domains concern the impact on particular areas of life (e.g. independency, relationships, body image), and one domain concerns the effects of treatment. The test-retest reliability demonstrated good stability[14] in eight subscales. In an Italian study, the Cronbach’s alpha was estimated twice in the test-retest sample. In both cases its values were high, varying from 0.88 to 0.95.[27]

Amyotrophic Lateral Sclerosis Assessment Questionnaire

The Amyotrophic Lateral Sclerosis Assessment Questionnaire (ALSAQ-40) is a measurement developed to assess HRQOL among patients with amyotrophic lateral sclerosis, a disease within the motor neuron disorder group.[28] The ALSAQ-40 consists of 40 questions within five domains, namely: 1) Eating and Drinking; 2) Communication; 3) ADL/Independence; 4) Physical Mobility; and 5) Emotional Well-being. The internal reliability coefficients of the five ALSAQ-40 dimensions at both administrations were all above the 0.91.[28] In an Italian study, the ASLSAQ40 scales showed good internal consistency (Cronbach's alpha > 0.86).[29]

Myasthenia Gravis Quality of Life 60

The Myasthenia Gravis Quality of Life 60 (MGQOL-60) is a measurement developed to assess HRQOL among patients with a junction disorder. The MGQOL-60 consists of 60 questions derived from interviews with experts and patient focus groups. Items were grouped into seven domains: 1) Mobility, with nine items, Cronbach's alpha = 0.89; 2) Symptoms, with eight items, Cronbach's alpha = 0.74; 3) Emotional Well-being, with eleven items, Cronbach's alpha = 0.88; 4) General contentment, with seven items, Cronbach's alpha = 0.74; 5) Thinking and Fatigue, with four items, Cronbach's alpha = 0.91; 6) Family/social well-being, with nine items, Cronbach's alpha = 0.72; and 7) Additional concerns, with twelve items, Cronbach's alpha = 0.60.[30]

4.3 Results

4.3.1 Linking procedure

We identified 142 concepts in the three HRQOL measurements: 42 concepts were derived from the INQOL, 40 concepts from the ALSAQ-40, and 60 concepts from the MGQOL-60.

Results of the linking procedure are provided in Tables 4.1 - 4.4, showing the content of the ICF components of 'body function and structures', 'activities', 'participation', and 'environmental factors', respectively.

4.3.2 Newly identified ICF categories not covered by the initial ICF Core Set

The initial ICF Core Set did not cover seven concepts. One newly identified ICF category was found in two measuring instruments (INQOL and MGQOL-60): Muscle endurance functions (b740).

From the MGQOL-60, three other concepts could not be linked to categories in the initial ICF Core Set: Functions of structures adjoining the eye (b215), Driving (a475), and Friends (e320). From the ASLSAQ-40, three concepts could be linked to the ICF categories: Voice functions (b310), Fluency and rhythm of speech functions (b330), and Climbing (a4551).

Table 4.1 The number of categories belonging to the component of 'body function and structures' associated with INQOL, MGQOL-60 and ALSAQ-40 items.

ICF category		INQOL	MGQOL-60	ALSAQ-40
	Mental functions			
b1300	Energy level	-*	4	-
b134	Sleep functions	-	1	-
b140	Attention functions	-	-	-
b144	Memory functions	-	-	-
b152	Emotional functions	3**	19	12
b160	Thought functions	-	1	-
	Sensory functions and pain			
b210	Seeing functions	-	-	-
b280	Sensation of pain	4	-	1
	Voice and speech functions			
b320	Articulation functions	-	1	2
	Functions of cardiovascular and respiratory systems			
b455	Exercise tolerance functions	4	1	1
	Ingestion functions			
b5105	Swallowing	-	-	1
b525	Defecation functions	-	-	-
	Genitourinary and reproductive functions			
b620	Urination functions	-	-	-
b640	Sexual functions	-	-	-
	Muscle and movement functions			
b730	Muscle power functions	4	2	-
b735	Muscle tone functions	4	-	-
b740	***Muscle endurance functions***[#]	3	3	-
b760	Control of voluntary movement functions	-	-	-
b765	Involuntary movements functions	-	-	-
b770	Gait pattern functions	-	-	-
b780	Sensations related to muscle and movement functions	-	1	-

[#]Newly added ICF category; *a dash indicates the ICF category is not addressed by the HRQOL measurement concept; **a digit indicates the frequency at which an ICF category was addressed by an HRQOL measurement concept.

4.3.3 Measurement concepts not covered by the ICF

Six concepts could not be linked to an ICF category. Three concepts from the INQOL: 1) 'Independency' (in the question 'Your independence'); 2) 'Appearance' (in the question 'The way you look'); and 3) 'All kinds of activities' (in the question 'Things you do'); and three concepts from the MGQOL-60: 1) 'Bedridden' (in the question 'I am forced to spend time in bed'); 2) 'I am satisfied with my sex life'; and 3) 'I am proud of how I am coping with my illness'.

Table 4.2 The number of categories belonging to the component of 'activities' associated with INQOL, MGQOL-60, and ALSAQ-40 items.

ICF category		INQOL	MGQOL-60	ALSAQ-40
	Communication			
a330	Speaking	-*	-	1
a350	Conversation	-	-	-
a360	Using communication devices and techniques	-	-	-
	Mobility			
a410	Changing basic body position	-	-	3
a415	Maintaining a body position	-	-	-
a420	Transferring oneself	-	-	-
a440	Fine hand use	-	-	2
a445	Hand and arm use	-	-	2
a450	Walking and moving	-	1	5
a465	Moving around using equipment	-	-	-
a470	Using transportation	-	-	-
	Self-care			
a510	Washing oneself	-	-	1
a520	Caring for body parts	-	1	1
a530	Toileting	-	-	-
a540	Dressing	-	-	1
a550	Eating	-	1	2
a560	Drinking	-	-	1
a570	Looking after one's health	-	1	-
	Domestic life			
a630	Preparing meals	-	-	-
a640	Doing housework	-	-	1
	Community, social and civic life			
a920	Recreation and leisure	1**	-	-

*a dash indicates the ICF category is not addressed by the HRQOL measurement concept; **a digit indicates the frequency in which an ICF category was addressed by an HRQOL measurement concept.

4.3.4 Categories in the initial ICF Core Set not covered by the measurement concepts

In total 58 categories of the initial ICF Core Set were not covered by the concepts in the INQOL: fifteen categories for the 'body function and structures' component, twenty categories for the 'activities' component, fourteen categories for the 'participation' component, and nine categories for the 'environmental factors' component.

In total 51 categories of the initial ICF Core Set were not covered by the concepts in the ASLSAQ-40: fifteen categories of the 'body functions and structures' component, ten categories of the 'activities' component, sixteen categories of the 'participation' component, and ten categories for the 'environmental factors' component.

Table 4.3 The number of categories belonging to the component of 'participation' associated with INQOL, MGQOL-60, and ALSAQ-40 items.

ICF category		INQOL	MGQOL-60	ALSAQ-40
	Communication			
p350	Conversation	-*	-	1
p360	Using communication devices and techniques	-	-	-
	Mobility			
p465	Moving around in different locations	-	-	-
p470	Using transportation	-	-	-
	Self-care			
p510	Washing oneself	-	-	-
p520	Caring for body parts	-	-	-
p530	Toileting	-	-	-
p540	Dressing	-	-	-
p570	Looking after one's health	-	-	-
	Domestic life			
p610	Acquiring a place to live	-	-	-
p630	Preparing meals	-	-	-
	Interpersonal interactions and relationships			
p750	Informal social relationships	5**	-	-
p760	Family relationships	3	1	-
p770	Intimate relationships	-	-	-
	Major life areas			
p850	Remunerative employment	1	1	-
	Community, social and civic life			
p910	Community life	-	1	-
p920	Recreation and leisure	-	1	-

*a dash indicates the ICF category is not addressed by the HRQOL measurement concept; **a digit indicates the frequency in which an ICF category was addressed by an HRQOL measurement concept.

In total 49 categories of the initial ICF Core Set were not covered by the concepts in the MGQOL-60: twelve categories of the 'body functions and structures' component, seventeen categories of the 'activities' component, thirteen categories of the 'participation' component, and seven categories of the 'environmental factors' component.

Table 4.4 The number of categories belonging to the component of 'environmental factors' associated with INQOL, MGQOL-60, and ALSAQ-40 items

ICF category		INQOL	MGQOL-60	ALSAQ-40
	Products and technology			
e115	Products and technology for personal use in daily living	-*	-	-
e120	Products and technology for personal indoor and outdoor mobility and transportation	-	-	-
e125	Products and technology for communication	-	-	-
e155	Design, construction and building products and technology of buildings for private use	-	1	-
	Support and relationships			
e310	Immediate family	-	6	-
e340	Personal care providers and personal assistants	-	-	-
	Services, systems and policies			
e5400	Transportation services	-	-	-
e5700	Social security services	-	-	-
e5702	Social security policies	-	-	-
e580	Health services, systems and policies	7**	6	-

*a dash indicates the ICF category is not addressed by the HRQOL measurement concept;
**a digit indicates the frequency in which an ICF category was addressed by an HRQOL measurement concept.

4.3.5 Final NMD Core Set

As a result the ICF category, 'Muscle endurance function' (b740) was added to the 'body functions and structures' component of the initial ICF Core Set. The final NMD Core Set now consists of 69 'very relevant' categories, belonging to the ICF components: 'body functions and structures' (21 categories), 'activities' (21 categories), 'participation' (17 categories), and 'environmental factors' (10 categories).

4.4 Discussion

The objective of this study was to examine the content validity of the initial ICF Core Set for the NMDs.

Based on our findings, we can conclude that the initial ICF Core Set covered all the relevant health problems of NMDs except for one 'body function' category. The final NMD Core Set consists of 69 ICF categories that belonged to all ICF components.

In comparison with concepts in the disease-specific HRQOL measurement instruments, the NMD Core Set has a broader scope, especially for the ‘participation’ and ‘environmental factors’ components. The under representation of ‘environmental factors’ in the three HRQOL measurements was also found in comparable studies using an HRQOL measurement for stroke,[31] and multiple sclerosis measurement.[23]

As a result of this study, we were able to add an important category to complete the NMD Core Set: ‘Muscle endurance functions’ (b740). Furthermore, in clinical practice this is an important and recognizable issue. Fatigue and muscle weakness have a major impact on the functioning of NMD patients.

Some concepts belonging to ‘Personal Factors’ – such as ‘Independency’, ‘Appearance’, ‘Coping’, and ‘Satisfaction’ – could not be linked to ICF categories, because ‘Personal Factors’ have not been classified in the ICF up until now.

We decided to use HRQOL measuring instruments for the validation of the initial ICF Core Set because of the expected broad scope of these questionnaires. However, it turned out that these instruments were few in number. Furthermore, we found that each of these measuring instruments mainly focused on one specific ICF component. For example, the ASLSAQ-40 has a strong focus on the ‘activity’ component, while the INQOL gears its focus towards the ‘body functions’ component, and the MGQOL-60 mainly focuses on the ‘body functions’ component. These findings further justify our intention to develop a new ICF-based functional health-status measurement with a broad and balanced scope that includes all ICF components.

We think the methods and procedures applied contributed in a positive way to the results of our study. There are reasons for assuming this. First, because we validated the initial ICF Core Set that was meticulously developed in a Delphi study, in which the ICF categories were selected by a varied and extensive Delphi panel. Second, we applied a proven method to evaluate the content validity of this initial ICF Core Set by linking concepts from established disease specific measuring instruments, representing three of the four NMD-classification groups, to the items in the initial ICF Core Set. Finally, a reliable linking procedure was carried out by experts in NMDs and ICF so that all relevant expertise was present.

As a consequence of the meager number of disease-specific measuring instruments with a broad scope available, one potential limitation of this study is that we could not find an established measurement for the NMD peripheral nerve disorders group. Therefore, we were not able to validate the initial ICF Core Set for this group of NMDs. However, considering our findings for the other three groups, we think that no essential items are missing in our final NMD Core Set.

In the ICF, the 'activity' and 'participation' components are listed together. In this context the NMD Core Set does not consist of 69 but of 59 ICF categories, because ten categories are listed in both components. For example, for the 'Recreation and Leisure' category d920, we made a distinction between a920, 'Can you participate in recreation and leisure'? (capacity) and p920, 'Do you take part in recreation and leisure'? (performance).

We decided to apply the distinction between both components (Table 4.2 and Table 4.3) with respect to the participants in the Delphi study and the initial ICF Core Set.[23] Furthermore, Jette et al.[32] identified distinct concepts within physical functioning that conformed to the components 'activity' and 'participation' as proposed in the ICF. Another important reason for our decision was that the distinction between these components is common in HRQOL measuring instruments and is reflected in the domains of physical and social functioning. This distinction is also relevant for the development of the next step, an ICF-based questionnaire.

Our choice for the biomedical classification of Rowland[1] could provide a potential limitation because of its medical focus. Therefore, this classification may not accurately portray the consequences of the disease, namely, functioning and disabilities. However, based on our findings, we can now conclude that the NMD Core Set is a consensus set for functioning and disabilities for all NMDs.

The ICF proved to be a useful classification for the linking of the concepts in the HRQOL questionnaires.[26] The ICF categories concerning mobility and muscles are goals of nursing interventions both in specialized rehabilitation nursing as well as in general health care.[17] The newly developed NMD Core Set can be a basis for enhancing the development of rehabilitation interventions and improving overall health care for patients with an NMD.

Based on our findings, we can conclude that the NMD Core Set is a valid selection of categories reflecting a broad scope of functioning and disabilities related to NMD, one that is broader than the established disease-specific HRQOL measuring instruments, especially in terms of the components of ‘participation’ and ‘environmental factors’. Therefore, the NMD Core Set provides a solid basis for the development of a health-status measuring instrument reflecting the most relevant aspects of functioning and health for patients with NMDs.

4.5 Conclusions

In conclusion, the NMD Core Set as well as a measurement based on this Core Set can contribute to a better understanding of the NMDs and can also serve as a basis for clinical practice, research, social security systems, and educational programs.

References

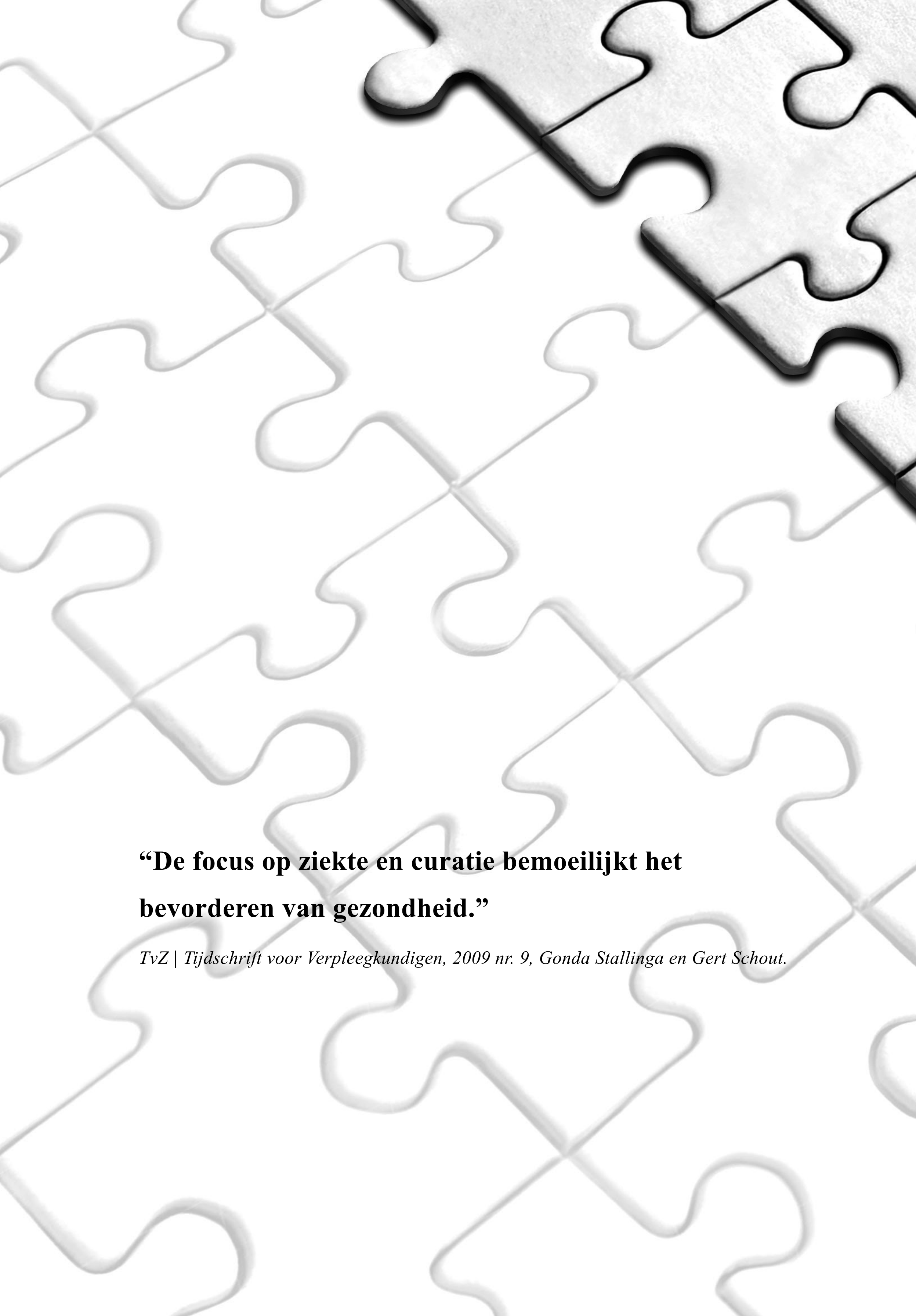
1. Rowland LP and McLeod JG. Classification of neuromuscular disorders. *J Neurol Sci* 1994; 124 Suppl(S): 109-130.
2. Hardiman O. Management of respiratory symptoms in ALS. *J Neurol* 2011; 258(3): 359-365.
3. Mathus-Vliegen LMH, Louwerse LS, Merkus MP, Tytgat GNJ and Vianney de Jong JM. Percutaneous endoscopic gastrostomy in patients with amyotrophic lateral sclerosis and impaired pulmonary function. *Gastrointest Endosc* 1994; 40(4): 463-469.
4. Mitsumoto H and Norris FT,Jr, editors. *Amyotrophic Lateral Sclerosis: A Comprehensive Guide to Management.* 10th ed. 1994. p.1-20.
5. Graham CD, Rose MR, Grunfeld EA, Kyle SD and Weinman J. A systematic review of quality of life in adults with muscle disease. *J Neurol* 2011; 258(9): 1581-1592.
6. Beekman R, Kuks JBM and Oosterhuis HJGH. Myasthenia gravis: diagnosis and follow-up of 100 consecutive patients. *J Neurol* 1997; 244(2): 112-118.
7. Marchettini P, Lacerenza M, Mauri E and Marangoni C. Painful peripheral neuropathies. *Current Neuropharmacology* 2006; 4(3): 175-181.
8. Carter GT, Han JJ, Abresch RT and Jensen MP. The importance of assessing quality of life in patients with neuromuscular disorders. *Am J Hosp Palliat Care* 2006; 23(6): 493-7.
9. Shi L, Stevens GD, Lebrun LA, Faed P and Tsai J. Enhancing the measurement of health disparities for vulnerable populations. J*ournal of public health management and practice 2*008; 14 Suppl: S45-52.
10. Eagle M, Baudouin SV, Chandler C, Giddings DR, Bullock R and Bushby K. Survival in duchenne muscular dystrophy: improvements in life expectancy since 1967 and the impact of home nocturnal ventilation. *Neuromuscular Disorders* 2002; 12(10): 926-929.
11. Ware J and Sherbourne C. The Mos 36-Item Short-Form Health Survey (Sf-36) .1. Conceptual-Framework and Item Selection. *Med Care* 1992; 30(6): 473-483.
12. Kempen GIJM, Miedema I, Ormel J and Molenaar W. The assessment of disability with the Groningen Activity Restriction Scale. Conceptual framework and psychometric properties. *Soc Sci Med* 1996; 43(11): 1601-1610.
13. Cardol M, de Haan R, van den Bos G, de Jong B and de Groot I. The development of a handicap assessment questionnaire: the Impact on Participation and Autonomy (IPA). *Clin Rehabil* 1999; 13(5): 411-419.
14. Vincent KA, Carr AJ, Walburn J, Scott DL and Rose MR. Construction and validation of a quality of life questionnaire for neuromuscular disease (INQoL). *Neurology* 2007;

68(13): 1051-1057.

15. Stucki G, Cieza A, Ewert T, Kostanjsek N, Chatterji S and Ustun TB. Application of the International Classification of Functioning, Disability and Health (ICF) in clinical practice. *Disabil Rehabil* 2002; 24(5): 281-282.
16. Cieza A and Stucki G. The International Classification of Functioning Disability and Health: its development process and content validity. *European Journal of Physical and Rehabilitation Medicine* 2008; 44(3): 303-313.
17. Boldt C, Brach M, Grill E, Berthou A, Meister K, Scheuringer M, et al. The ICF categories identified in nursing interventions administered to neurological patients with post-acute rehabilitation needs RID D-1875-2010. *Disabil Rehabil* 2005; 27(7-8): 431-436.
18. Ustun TB, Chatterji S, Kostansjek N and Bickenbach J. WHO's ICF and functional status information in health records. *Health Care Financ Rev* 2003; 24(3): 77-88.
19. Stucki G, Ewert T and Cieza A. Value and application of the ICF in rehabilitation medicine. *Disabil Rehabil* 2003; 25(11-12): 628-634.
20. Stucki G, Ustun TB and Melvin J. Applying the ICF for the acute hospital and early post-acute rehabilitation facilities. *Disabil Rehabil* 2005; 27(7-8): 349-352.
21. Geyh S, Cieza A, Schouten J, Dickson H, Frommelt P, Omar Z, et al. ICF core sets for stroke RID F-6994-2011. *J Rehabil Med* 2004; 36: 135-141.
22. Coenen M, Cieza A, Freeman J, Khan F, Miller D, Weise A, et al. The development of ICF Core Sets for multiple sclerosis: results of the international consensus conference. *J Neurol* 2011; 258(8): 1477-1488.
23. Wynia K, Middel B, Van Dijk JP, De Ruiter H, Lok W, De Keyser JH, et al. Broadening the scope on health problems among the chronically neurologically ill with the International Classification of Functioning (ICF). *Disabil Rehabil* 2006; 28(23): 1445-1454.
24. Wynia K, Middel B, van Dijk JP, de Ruiter H, de Keyser J and Reijneveld SA. The Multiple Sclerosis Impact Profile (MSIP). Development and testing psychometric properties of an ICF-based health measure. *Disabil Rehabil* 2008; 30(4): 261-274.
25. Cieza A, Brockow T, Ewert T, Amman E, Kollerits B, Chatterji S, et al. Linking health-status measurements to the International Classification of Functioning, Disability and Health. *J Rehabil Med* 2002; 34(5): 205-210.
26. Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustun B and Stucki G. ICF linking rules: an update based on lessons learned RID F-6994-2011. *J Rehabil Med* 2005; 37(4): 212-218.
27. Sansone VA, Panzeri M, Montanari M, Apolone G, Gandossini S, Rose MR, et al. Italian

validation of INQoL, a quality of life questionnaire for adults with muscle diseases. *European Journal of Neurology* 2010; 17(9): 1178-1187.

28. Jenkinson C, Fitzpatrick R, Brennan C and Swash M. Evidence for the validity and reliability of the ALS assessment questionnaire: The ALSAQ-40. *Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders* 1999; 1(1): 33-40.
29. Palmieri A, Soraru G, Lombardi L, D'Ascenzo C, Baggio L, Ermani M, et al. Quality of life and motor impairment in ALS: Italian validation of ALSAQ. *Neurol Res* 2010; 32(1): 32-40.
30. Mullins LL, Carpentier MY, Paul RH and Sanders DB. Disease-specific measure of quality of life for myasthenia gravis. *Muscle Nerve* 2008; 38(2): 947-956.
31. Teixeira-Salmela LF, Neto MG, Magalhaes LC, Lima RC and Faria CDCM. Content comparisons of stroke-specific quality of life based upon the International Classification of Functioning, Disability and Health. *Quality of Life Research* 2009; 18(6): 765-773.
32. Jette A, Haley S and Kooyoomjian J. Are the ICF activity and participation dimensions distinct? *J Rehabil Med* 2003; 35(3): 145-149.



“De focus op ziekte en curatie bemoeilijkt het bevorderen van gezondheid.”

TvZ | Tijdschrift voor Verpleegkundigen, 2009 nr. 9, Gonda Stallinga en Gert Schout.

5

Functioning assessment versus conventional medical assessment: a comparative study on health professionals' clinical decision-making and the fit with patient's own perspective of health

Hillegonda A. Stallinga
Petrie F. Roodbol
Coby H. Annema
Gerard J. Jansen
Klaske Wynia

Journal of Clinical Nursing 2013; 23(7-8): 1044-1054

Abstract

Aims and objectives: To compare a functioning assessment based on the International Classification of Functioning, Disability and Health (ICF) with a conventional medical assessment, in terms of their respective consequences for health professionals' clinical decision-making and on the fit with patient's own perspective of health.

Background: In chronic diseases, pathogenic-oriented health care falls short in generating all the information required for determining health care provision to improve health. A broader, so-called salutogenic approach, by using the ICF, focussing on how to stay healthy, rather than what causes diseases, seems more appropriate.

Design: A cross-sectional comparative study using data from a randomised controlled trial.

Method: Data about patient problems and professional health care activities were collected from a total of 81 patients with severe multiple sclerosis who were randomly assigned to one of two groups: the ICF group, assessed with a functioning assessment (n = 43), and the medical group, assessed with a conventional medical assessment (n = 38). Data were analyzed statistically using descriptive and inferential statistics.

Results: A functioning assessment resulted in registration of significantly more patient problems in the health components 'participation' and 'environmental factors', as well as significantly more professional health care activities befitting these components. The ICF group had a significant positive correlation between registered problems by health professionals and patients' self-reported problems whereas the medical group had several negative correlations.

Conclusion: A functioning assessment resulted in a care plan which was not only broader and more complete but which also reflected the patients' self-reported problems more closely than a medical assessment, without a loss of focus on medical problems.

Relevance to clinical practice: This study has shown that some health problems remain unnoticed by a medical assessment alone, which is especially important for the chronically ill. A functioning assessment provides a strong foundation for identifying all relevant information related to health.

5.1 Introduction

Historically, communicable, infectious diseases with a high mortality risk have been the main concern of our health care system. Consequently, the medical disease model with its pathogenic orientation has occupied centre stage in the health care system. Together with early medical diagnoses and improved medical technology, this model has resulted in great medical progress in many areas. But, on the other side, this model has also led to an increase of survivors and patients with non-communicable, chronic diseases such as cardiovascular diseases, neurological disorders, diabetes, and cancer.[1]

With the pathogenic model came the definition of health as 'a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity'.[2] Despite the psychological and social dimensions of this definition, the requirement of a 'state of complete well-being' labels persons with chronic diseases and disability as definitively ill. Furthermore, this stringent definition would leave most of us unhealthy for most of the time.[3] Although a disease or disability impacts one's health, it does not define one's health.[4] This is why a new definition of health has recently been proposed: 'health is the ability to adapt and self-manage in the face of social, physical, and emotional challenges'.[3] In this broader, so-called salutogenic view of health, a strong emphasis lies on 'ability', which allows for a focus on how to stay healthy,[5] rather than on what causes disease.

Following this concept of health, the central question for health care provision, especially for the chronically ill, can be formulated as follows: 'How can this person become healthier, while at the same time he stays more or less ill'?[6,7] A medical assessment that focuses solely on the biological medical aspects falls short in generating all the information required for determining health care provision;[8] moreover, effective health care requires a good fit with patients own perspective of health.[4]

While clinical practice is experiencing a shift from acute disease to chronic disease and the health opinion is broadening its scope to include 'ability', clinical practice is still using tools and skills based on the pathological medical model,[9] focusing on diseases and disability.

To describe health, ability, and disability, the WHO has published the International Classification of Functioning, Disability and Health (ICF).[10] The ICF represents the biopsychosocial model, which covers all aspects of health and well-being operationalized in terms of human functioning in the health components ‘body functions and structures’, ‘activities’, and ‘participation’. Ability and disability are presented in a single spectrum as different manifestations of the same domains of functioning.[11] The ICF complements the International Statistical Classification of Disease and Related Health Problems (ICD-10)[12] which represents the medical model. A dynamic interaction takes place between functioning and disease, as well as between functioning and the ‘environmental factors’ and ‘personal factors’.[10] Using both the medical status (ICD-10) and the status of functioning (ICF) can provide a more complete picture of the patients’ health status and a more solid base for determining individual treatment and health care provision.[13-15]

Until now, few studies have focused on the added value of using tools and skills centred on the status of functioning. We have found one study[16] that evaluated the use of information on the status of functioning in addition to medical information. They found that adding information on the status of functioning in the health components ‘activities’ and ‘participation’ resulted in a statistically significant difference in scores on assessed work limitations compared with medical information alone. Physicians who used a functioning assessment felt they possessed more relevant information than physicians who had access to only medical information. The results of Spanjer et al.[16] are grounded on a laboratory situation, whereas the physicians’ assessments were based on written patient cases.

Our research is primarily motivated by the discrepancy between the current pathogenic-oriented health care tools and skills and a growing number of chronically ill patients for whom a broader and salutogenic approach seems more appropriate.[17,18] A general assessment tool is needed in order to acknowledge the views, experiences, and perspectives of the patients themselves and all the multidisciplinary team members involved in the health care process.[19] Due to its general terminology, the ICF can be used in determining health care provision in a multidisciplinary health care process. Concurrently, the ICF terminology also reflects discipline-specific terms[20] relevant for discipline-specific health care in the subsequent phases of the health care process.

We conducted our study in order to explore a status of functioning tool as a general assessment tool. The purpose was to examine the differences between a functioning assessment (ICF) and a conventional medical assessment in terms of their respective consequences for health professionals' clinical decision-making and the fit with patient's own perspective of health.

5.2 Methods

5.2.1 Study design

The current cross-sectional comparative study is a secondary analysis of data from a randomised controlled trial. The randomised controlled trial was conducted to examine the effects of a Dutch patient advocacy case management model compared with health care as usual applied to patients with severe multiple sclerosis (MS). The study protocol of the randomised controlled trial has been published.[21] In the randomised controlled trial, patients were randomly assigned to one of two groups: experimental (in this study the ICF group) or control (in this study the medical group). Patients in the ICF group received case management from a nurse practitioner who used the ICF functioning assessment. Patients in the medical group received care as usual from a neurologist who used the conventional medical assessment. The current study focuses on a comparison between the two types of assessment based on health professionals' clinical decision-making and on the fit with patient's own perspective of health. Clinical decision-making is defined operationally as the number and kind of patient problems and professional health care activities registered in patient records by health professionals as a consequence of the assessment. Patient's own perspective is defined as a severity score on the self-report functioning assessment tool completed by patients. The fit is expressed by the correlation between the frequency of the health problems registered by the health professionals and the severity score of the self-reported problems. In contrast to previous studies[16] that used data based on laboratory research, we used data from a randomised controlled trial. Consequently, our results are grounded in actual clinical practice.

5.2.2 Participants and procedure

Patients with MS known to the MS Centre of a university hospital in the north of the Netherlands were invited to participate in the randomised controlled trial. The inclusion criteria for eligible patients were to be diagnosed with severe MS, living independently in the community and at least 18 years old. To define the severity of the MS, the neurological classification system Expanded Disability Status Scale (EDSS) was used. The EDSS is a commonly used medical measure instrument for MS with a scoring scale ranging from 0 (no problem) to a maximum score of 10 (death due to MS). The severity of MS in this study was defined as having a score ranging from 4.5 to 8.5. A score of 4.5 indicates experiencing some mild neurological dysfunctions and being able to walk about 300 meters without aid or rest. A score of 8.5 indicates having severe neurological dysfunctions and being mostly restricted to a wheelchair.[22] The EDSS score was assessed by the neurologist and registered in the patient's medical record. All eligible patients with the diagnosis MS and a suitable EDSS score (n = 227) were invited to participate in the study. Informed consent to participate in the study was given by 102 patients with MS. Between respondents and nonrespondents, there were no differences in age (t-test p-value 0.332) and gender (chi-square test p-value 0.374).

After the inclusion criteria were checked, a total of 99 patients were included and randomly assigned to the ICF group or the medical group. To control for the characteristics of the participants, the following blocking variables were included in the randomization process: wheelchair dependency (yes/no), having a partner or caregiver (yes/no), educational level (low/middle/high level), having children living at home (yes/no), and performing paid work (yes/no). The computerized randomization program assigned 51 patients to the ICF group and 48 patients to the medical group. Sample size calculations were targeted on a relevant clinical change in quality of life, the primary outcome measure. If each research group would consist of 30 subjects, a power of 0.82 would be reached.

At the start of the study, both groups (the ICF group and the medical group) were asked to answer background questions and to complete the self-report functioning assessment. The background data are shown in Table 5.1. There were no significant statistical differences between patients in the ICF group and in the medical group; they all had similar background characteristics, similar disease related variables, and similar self-reported states of functioning (Table 5.2). During the study, patients in both groups were lost to follow-up for similar reasons (admission to a nursing home, death). Ultimately, 43 patients in the ICF group and 38 patients in the medical group completed the study and were included in the analysis.

See the flow diagram of the study in Figure 5.1.

Table 5.1 Background data of the patients.

Variable	ICF	Medical	Total
N	43	38	81
Gender			
Female (%)	26 (61)	25 (66)	51 (63)
Age			
Mean (SD)	54 (11.6)	57 (11.3)	56 (11.4)
Marital status			
Married / in partnership (%)	35 (81)	29 (76)	64 (79)
Children			
Yes (%)	35 (81)	32 (84)	67 (83)
Mean (SD)	2 (1.3)	2 (1.1)	2 (1.2)
Educational level			
Primary school (%)	8 (19)	3 (8)	11 (14)
Secondary/vocational school (%)	22 (51)	20 (53)	42 (52)
High school/ University (%)	13 (30)	14 (37)	27 (33)
EDSS (scale: 0–10)			
Mean (SD)	6.3 (1.4)	6.6 (1.3)	6.5 (1.3)
Years since MS diagnosis			
Mean (SD)	14.8 (6.9)	15.8 (8.1)	15.3 (7.5)

Table 5.2 Severity scores of the self-reported functioning assessment at the start of the study.

ICF domains (MSIP scales) and -categories ordered in health components	*n*	ICF total patients *N* = 43 Median*(IQR#)	*n*	Medical total patients *N* = 38 Median*(IQR#)	*p*-value†
Body Functions and structures					
Muscle and movement	35	31.25 (25)	31	37.50 (19)	.421
Excretion and reproduction	35	33.33 (33)	28	41.67 (35)	.277
Mental	32	25.00 (17)	33	25.00 (17)	.330
Speech	43	0.00 (25)	36	0.00 (25)	.742
Seeing	42	25.00 (25)	36	25.00 (50)	.791
Fatigue	42	50.00 (6)	37	50.00 (25)	.292
Pain	43	25.00 (25)	38	25.00 (50)	.727
Activities					
Basic movement	40	46.67 (38)	37	40.00 (53)	.553
Daily living	43	45.83 (37)	37	45.83 (52)	.824
Participation	42	25.00 (34)	36	25.00 (32)	.813
Environmental factors	-	-	-	-	-

*Severity score: score 0 = no problem; score 100 = very serious problems; #Inter Quartile Range; †Mann-Whitney U test. Note: Pending validation of the 'environmental factors' scale, this component was not yet included in the MSIP tool at the start of the study period. Therefore in this study we do not have data on the 'environmental factors' of the patients in the self-reported status of functioning.

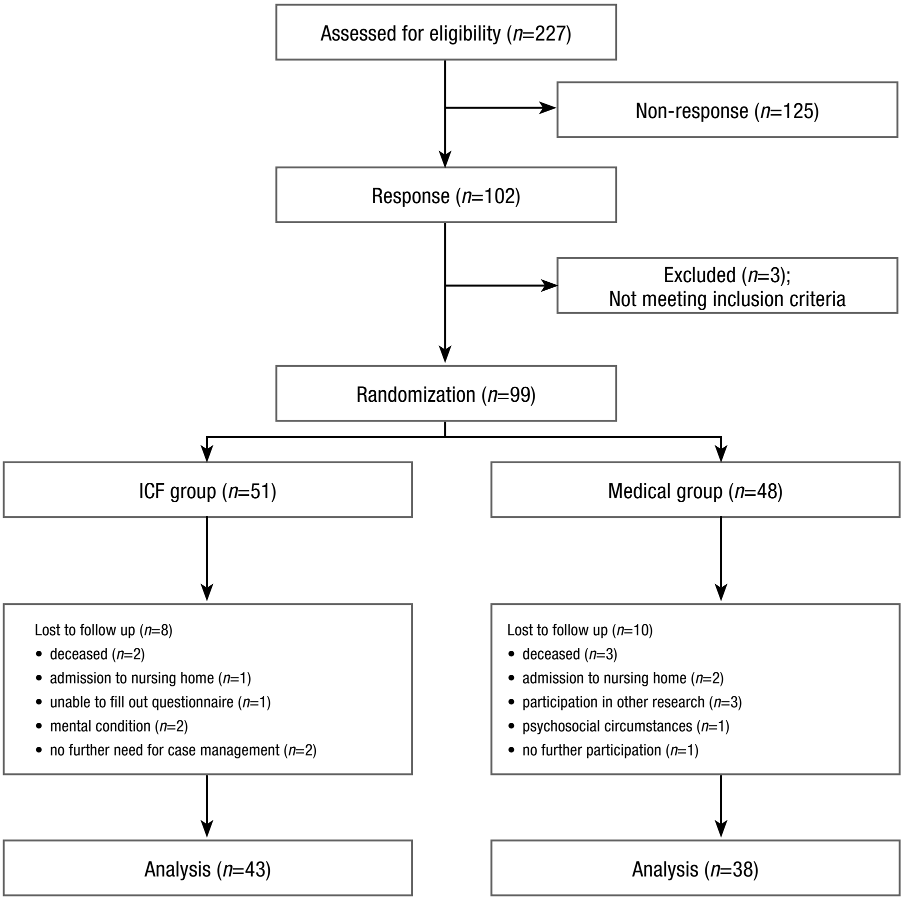


Figure 5.1 Flow diagram of the study.

During the study period of 15 months (between September 2006 and January 2008), the nurse practitioner used the filled-out functioning assessment in the ICF group. Patients in the ICF group were not consulted by the neurologist. The patients in the medical group were assessed with the conventional medical assessment by the neurologist. Patients in the medical group were not consulted by the nurse practitioner and the filled-out functioning assessment was not known to or used by the neurologist.

5.2.3 The functioning assessment

The status of functioning was assessed using the Multiple Sclerosis Impact

Profile (MSIP). The MSIP is a recently developed and validated self-report assessment tool based on an ICF Core Set for patients with MS. The internal consistency tests showed good levels of internal consistency with Cronbach's alphas = 0.80/0.90 for most scales, and sufficient and weak Cronbach's alphas for mental functioning (0.62/0.65) and the environmental factors (0.49/0.50).[23,24] An ICF Core Set identifies the most typical and relevant ICF categories in the health components 'body functions and structures', 'activities', 'participation', and 'environmental factors' for patients with a specific disease or health condition.[25] The MSIP consists of 36 ICF categories, distributed over seven scales and four single items. There are three scales in the health component 'body functions and structures' (muscle and movement functions, excretion, reproductive functions, and mental functions), two scales in the health component 'activities' (basic movement and daily living), one scale in the health component 'participation', and one scale in 'environmental factors'. The four single items all belong to the health component 'body functions and structures' (speech functions, seeing functions, fatigue, and pain). Scoring options, which are discrete, range from 0 (no disability) to 3 or 4 (complete disability). These scores express the severity of the disability. For reasons of comparability, the scores are standardized by dividing the individual sum scores in each scale/single item by the maximum score of each scale/single item, and multiplying it by a hundred to obtain a result ranging from 0 to 100.

Patients in both groups filled out the self-report functioning assessment at the start of the study period. To determine the fit between the assessment and patient's own perspective of health, the frequency of the health problems registered by health professionals were correlated with the severity scores of the self-reported problems. This is based on the assumption that the more severe the problems indicated by the patient himself, the higher will be the frequency of the registration of these problems by health professionals and vice versa. The functioning assessment was used in the ICF group, in which health problems and required health care was assessed by two nurse practitioners specialized in patients with MS. They were trained in using the functioning assessment and were also authorized to perform medical neurological examinations. Medical aspects of patients in the ICF group were discussed with the neurologists during the biweekly multidisciplinary consultation or in between these meetings when necessary. During the

15-month study period, the nurse practitioners consulted the patients at their homes three times: at the start, halfway through, and at the end. The nurse practitioners used the functioning assessment to identify the patients' health problems and related professional health care activities required. These problems and professional health care activities were registered in the patient's record.

In this study, the nurse practitioner was in the same professional position as the neurologist. This means that the nurse practitioner had the same authority as the neurologist to assess all the health problems and required professional health care activities for the patients with MS. Patients in the medical group were not consulted by the nurse practitioners, and patients in the ICF group were not consulted by the neurologists. In this way we minimized potential bias of the type of health care provider on the outcomes of the assessments.

5.2.4 The medical assessment

The medical assessment was used in the medical group, in which health problems and required professional health care activities as usual was assessed by two neurologists specialized in care for patients with MS. The medical assessment includes an examination of the functions of the body in general and the neurological functions in specific.

During the 15-month study period, patients in the medical group were consulted by their neurologist three times in the hospital. This is the usual frequency for these consultations at the Groningen MS Centre. The neurologist used the medical (neurological) assessment to identify the patients'
health problems and the related professional health care activities required. These problems and professional health care activities were registered in the patient's record.

5.2.5 Classifying health problems and related professional health care activities

The MSIP scales/single items, categorized by the health components 'body functions and structures', 'activities', 'participation', and 'environmental factors', were used to classify the broad range of health problems registered in both groups, so as to make these data accessible for statistical analysis.

The class ‘other’ was added for classification of problems which did not belong to one of the mentioned MSIP scales/single items (e.g. nutritional problems or skin afflictions). Health problems were characterized as follows: they were either new (problem identified in a consultation), continuous (problem existed before the first consultation) or recurrent (problem identified in a previous consultation and still going on). The ‘recurrent’ problems were excluded from the analysis since they were already included in the classes of ‘new’ and ‘continuous’ problems.

The professional health care activities were summarized and classified into seven classes based on inductively developed general features of professional health care activities performed by both types of health professionals, the nurse practitioner and the neurologist. The following classes were distinguished: ‘giving information/advice’, ‘gathering information/consultation of professionals’, ‘medical referral’, ‘nonmedical referral’, ‘adjusting medication’, ‘arranging additional support/obtaining assisting products’, and ‘arranging temporary admission/day treatment’. The class ‘other’ was added to accommodate those activities that did not belong to one of the existing classes (for example professional health care activities such as monitoring or observing). Two researchers independently classified all registered problems and professional health care activities in the most appropriate class. These researchers were familiar with the health problems and professional health care activities associated with patients with MS. Differences of opinion between the researchers were resolved through discussion and if necessary, by referring to a third researcher. Data were analyzed at the end of the study period of 15 months.

5.2.6 Ethics

The randomised controlled trial was approved by the medical ethical committee of the hospital (Reference M06.040514) and was registered in the Dutch Trial Register. Trial ID: NTR 762.

5.2.7 Analysis

Data were analysed using PASW 18.0 for Windows (SPSS Inc., Chicago, IL, USA). First, descriptive statistics, such as frequencies, percentages, means, standard deviations, median, minimum, and maximum, were computed for background variables, categories, and scales. Second, inferential statistics were used for several comparisons. The independent sample *t*-test was used to compare the continuous variables in the patient characteristics between the two groups and for the mean number of registered health problems and professional health care activities for each patient. The Pearson's chi-square test and, where appropriate, the difference of proportions test[26] were used for the nominal variables in the patient characteristics. The latter test was also used to compare the registered health problems and professional health care activities between the two groups. The Mann-Whitney *U*-test was used for group comparison in the self-reported status of functioning as the variables were not normally distributed. The correlation between the severity of the self-reported problems by patients and the frequency of the registered problems by health professionals was established by a Spearman's coefficient. This coefficient is used to test the relationship between ordinal data or between numerical and ordinal data. It also takes on values from –1 – 1, ranging between negative correlation (–1), uncorrelated (0), and positive correlation (1); *p*-values of ≤ 0.05 were considered statistically significant.

5.3 Results

5.3.1 Registered health problems

The mean number of registered health problems per patient was significantly higher in the ICF group: 6.8 SD 4.2 versus 3.2 SD 2.7 for patients with MS in the medical group; *p*-value < 0.001.

Within both groups most of the registered health problems were listed in the health component 'body functions and structures' (65% in the medical group versus 55% in the ICF group) (Table 5.3). The number of health problems in the health component 'body functions and structures' did not differ significantly between the two groups.

A comparison of the proportions of the problems registered by the health professionals in the two groups shows that in the ICF group significantly more problems were found in the health components 'participation' (10% versus 3% in the medical group) and 'environmental factors' (19% versus 6% in the medical group). Participation problems included social isolation and difficulties with preserving jobs and relationships. Problems with respect to the 'environmental factors' were, for example, inadequate or lack of domestic help or adjustments in the patient's home.

Table 5.3 Frequency registered health problems at the end of the study.

ICF-domains (MSIP scales) and -categories ordered in health components	**ICF *N* = 43 *n* (%)**	**Medical *N* = 38 *n* (%)**	**95% CI***
Body Functions and structures	162 (55)	79 (65)	-1.09 to 19.97
Muscle and movement	34 (12)	14 (12)	-8.04 to 6.62
Excretion and reproduction	47 (16)	23 (19)	-5.06 to 2.14
Mental	27 (9)	8 (7)	-4.42 to 8.00
Speech	11 (4)	5 (4)	-3.65 to 6.36
Seeing	2 (1)	9 (7)	2.47 to 13.38
Fatigue	25 (9)	8 (7)	-5.06 to 7.24
Pain	16 (5)	12 (10)	-1.20 to 11.88
Activities	19 (7)	14 (12)	-1.01 to 12.85
Basic movement	5 (2)	3 (2)	-2.31 to 6.02
Daily living	14 (5)	11 (9)	-1.08 to 11.54
Participation	30 (10)	3 (3)	1.78 to 12.39
Environmental factors	54 (19)	7 (6)	5.23 to 18.69
Other	27 (9)	18 (15)	-1.28 to 14.05
Total health problems	*292 (100)*	*121(100)*	

N = number of patients; *n* = total number of problems of all patients together; *difference of proportions test.

5.3.2 Registered professional health care activities

Again, the mean number of registered professional health care activities per patient was significantly higher in the ICF group: 5.1 SD 4.3 versus 2.2 SD 2.9 for patients with MS in the medical group; *p*-value < 0.001(Table 5.4).

Table 5.4 Frequency registered professional health care activities at the end of the study.

Classes	**ICF *N* = 43**	**Medical *N* = 38**	**95% CI***
	$n^{\#}$ (%)	**$n^{\#}$ (%)**	
Giving information/advice	54 (25)	10 (12)	2.04 to 21.44
Gathering information/ consultation of professionals	57 (26)	1 (1)	16.62 to 31.51
Medical referral	11 (5)	20 (24)	9.50 to 29.79
Non-medical referral	24 (11)	7 (8)	-6.70 to 9.57
Adjusting medication	16 (7)	27 (32)	14.25 to 36.38
Arranging additional support/ obtaining assisting products	40 (18)	6 (7)	1.60 to 18.47
Arranging temporary admission/day treatment	7 (3)	7 (8)	-0.72 to 13.94
Other	9 (4)	6 (7)	-2.67 to 11.60
Total professional health care activities	*218 (100)*	*84 (100)*	

N = number of respondents; $^{\#}n$ = total number of professional health care activities of all patients together; *difference of proportions test.

In the ICF group most professional health care activities were registered in the classes ‘gathering information/consultation of professionals’ (26% versus 1% in the medical group), ‘giving information/advice’ (25% versus 12% in the medical group), and ‘arranging additional support/obtaining assisting products’ (18% versus 7% in the medical group). A comparison of the proportions of the registered professional health care activities in the two groups shows that the differences in these classes were significant. Professionals consulted included the social security services to provide income support or the health services to provide care support.

In the medical group most professional health care activities were registered in the classes ‘adjusting medication’ (32% versus 7% in the ICF group) and ‘medical referral’ (24% versus 5% in the ICF group). ‘Medical referral’ consisted of referrals to, amongst others medical specialists. A comparison of the proportions of registered professional health care activities between the two groups shows that the differences in these two classes were also significant.

5.3.3 Self-reported problems compared with the registered problems

The self-reported status of functioning (Table 5.2) showed that in both groups the most severe problems were in the health components ‘body functions and structures’ and ‘activities’. ‘Fatigue’ was the most severe problem, directly followed by limitations in the domains ‘basic movement’ and ‘daily living’ in the health component ‘activities’. Impairments in the health component ‘body functions and structures’ in the domains ‘excretion and reproduction’ (e.g. constipation and incontinence problems) and ‘muscle and movement’ were the third severe problems.

The Spearman’s correlation tests showed two significant correlations: the severity of the self-reported problems in the domain ‘basic movement’ and the frequency of the health problems registered in that domain had a coefficient of 0.37 ($p < 0.05$) in the ICF group. In the medical group the severity of the self-reported problems in the domain ‘daily living’ and the frequency of the problems registered in that domain had a negative coefficient of –0.51 ($p < 0.05$). Moreover, there were two other negative correlations in the medical group: the severity of the self-reported problems in the component ‘participation’ and the frequency of the health problems registered in that component had a coefficient of –0.34; the severity of the self-reported problems in the domain ‘basic movement’ and the frequency of the health problems registered in that domain had a coefficient of –0.29. This means that the high severity scores in these domains, as scored by the patients themselves, are disproportionate with the low number of problems identified and registered in the medical group.

5.4 Discussion

The purpose of this study was to examine the differences between a functioning assessment (ICF) and a conventional medical assessment in terms of their respective consequences for health professionals’ clinical decision-making and the fit with patient’s own perspective of health.

Our results show that a functioning assessment results in significantly more registered problems within the health components ‘participation’ and ‘environmental factors’. These results are consistent with a previous report which showed that if health care professionals are offered a tool that enables them to assess patients in a broader health perspective, they identify problems in all health components.[16] It may seem only logical to focus on broader health components rather than just the medical components in patients with a chronic disease. But without a specific tool with which these health components are explicitly examined, they are left out of formal health care provision. Due to the fact that the measures and tools used in the medical pathogenic approach are disease-specific and focused on pathophysiology,[27] the biopsychosocial orientation needs tools that are specific for the other health components and which also take into account both patient’s ability and their own perspective of health. Moreover, the results of our study show that using the biopsychosocial perspective does not detract attention from the medical status. To illustrate this: the health problems registered in the component ‘body functions and structures’, which represents the medical status of disease-related problems, were similar in the ICF group and the medical group.

With respect to professional health care activities, the most important difference was that the functioning assessment in the ICF group led to the registration of significantly more professional health care activities in the classes ‘giving information/advice’, gathering information/consultation of professionals’, and ‘arranging additional support/obtaining assisting products’ when compared to the medical group. The medical assessment, by contrast, resulted in the registration of significantly more professional health care activities in the classes ‘medical referral’ and ‘adjusting medication’. This difference between the two groups can be explained as being the result of the differences in the assessed health problems between both groups. The professional health care activities in the classes ‘giving information/advice’, ‘gathering information/consultation of professionals’, and ‘arranging additional support/obtaining assisting products’ seem appropriate given the high prevalence of registered problems in the health components ‘participation’ and ‘environmental factors’ and are focused on supporting patients ability. Furthermore, in the medical group the professional health care activities in the classes ‘medical referral’ and ‘adjusting medication’ also seem appropriate considering the relatively high prevalence of registered problems in the health component ‘body functions and structures’.

At the start of the study period, the self-reported status of functioning of the patients was the same in the two groups. The severity of disability was found to be the highest in the health components ‘body functions and structures’ and ‘activities’. The use of the medical assessment led to a disproportionate focus on the component ‘body functions and structures’, with very limited attention to the problems in the other health components. In contrast, while the use of the functioning assessment also led to a strong focus on the problems in the health component ‘body functions and structures’, the other health components nevertheless received sufficient attention. Two significant correlations were identified between the severity of the self-reported problems by patients and the frequency of the health problems registered by health professionals. First, a positive correlation was found in the ICF group in the domain ‘basic movement’. This means that the severity of the self-reported problems in that domain is proportionate with the identification and registration of these problems by the health professional. Second, a negative correlation was found in the medical group related to the domain ‘daily living’. This means that the severity of the problems as scored by the patients themselves is disproportionate with the number of problems in that domain identified and registered by the health professional. The results of this study indicate that the clinical decision-making of health professionals according to the functioning assessment had a more closely fit with the self-reported problems by patients when compared to the clinical decision-making according to the medical assessment.

Finally, we pointed out that the differences in professional health care activities compared to the similarity in health problems in the component 'body functions and structures' mean that for the same health problems different professional health care activities will be performed for the two groups. For example 'adjusting medication' was the health care activity in the medical group for the health problem 'fatigue', where in the ICF group also 'additional support' and 'giving advice or information' were applied. Assessing the health status from the medical perspective only, generates unilateral (medical) interventions. In contrast, a broader health perspective results in multilateral health care, which is far more appropriate for supporting patients' ability to adapt and self-manage the social, physical, and emotional challenges they face.

5.4.1 Limitations

This study has some limitations. Firstly, the data are derived from a randomised controlled trial of a nonpharmacological intervention. In this design the effect of a given treatment can be biased due to differential expertise of the health care providers.[28] In our study the health care professionals involved had different expertise, but they each conducted an assessment method that reflected their own expertise. The nurse practitioners used the functioning assessment based on the biopsychosocial perspective and the neurologists used the medical assessment based on the medical model. The biopsychosocial perspective is central to the education of nurses, and the same can be said about the medical perspective with respect to the education of neurologists. If both types of professionals were obliged to use both the experimental (ICF) assessment and control (medical) assessment, the restricted expertise and experience could have compromised the validity of the results.[29] The skill set needed to perform the functioning assessment requires training and experience. By only performing the assessment in which health professionals have expertise, the problem of the differential expertise might just have been avoided in our study.

Secondly, the patients in the ICF group were consulted by the nurse practitioner at their homes, whereas the patients in the medical group were consulted by the neurologist in the hospital. At home, the health components 'participation' and 'environmental factors' are of course more salient than in the hospital. However, the strength of this study, apart from its design, is that the ICF group and the medical group were similar with respect to all patient characteristics and with respect to the self-reported status of functioning. This means the differences between the two groups can be explained by the difference in the assessment method used.

Finally this study represents patients with MS. Hence, the results might not be generalisable to other patient populations. However, the study design itself can be used for evaluating a functioning assessment as a general assessment in other patient groups.

5.5 Conclusion

The current study shows that the functioning assessment results in a treatment and care plan for patients that is not only broader (all health components) and more complete (including the components ‘participation’ and ‘environmental factors’) but which also reflects patients’ self-reported problems more closely when compared to the medical assessment alone. The health components ‘activities’, ‘participation’, and ‘environmental factors’ offer the opportunity to improve the health of patients with MS. At the same time the functioning assessment does not neglect the medical problems represented in the component ‘body functions and structures’. Due to its terminology, which is not discipline specific, the ICF functioning assessment can be used as a general assessment at the start of the health care process. This is important in order to acknowledge the views, experiences, and perspectives of the patients themselves and all the multidisciplinary team members involved in the health care process. Next, clinical decisions can be made in a multidisciplinary way and the required discipline-specific interventions can be performed. Concurrently, the ICF can also reflect discipline-specific terms.

The functioning assessment is a suitable general assessment tool to determine health care provision to improve health. It meets the growing chronically ill patient population in which the central question is: ‘How can this person become healthier, while at the same time he stays more or less ill’? Further research into the use of a functioning assessment and its consequences for clinical outcomes is required to confirm our conclusions. Relevant outcome parameters could be, for instance, the association with patient outcomes such as quality of life, and the effects of specific professional health care activities in the health components ‘activities’, ‘participation’, and ‘environmental factors’.

5.6 Relevance to clinical practice

This study has shown that health problems related to the health components ‘participation’ and ‘environmental factors’ remain unnoticed by a medical assessment alone. A functioning assessment based on the formalized and systematic construction of the ICF provides a strong foundation for identifying ability and disability in all health components without a loss of focus on medical problems. Nursing is the discipline that is pre-eminently involved with patients’ status of functioning. In addition nurses have the skills to respond to (dis)ability in the health components ‘activities’, ‘participation’, and ‘environmental factors’. Further research into the key role nurses can play with respect to the patients’ status of functioning is required.

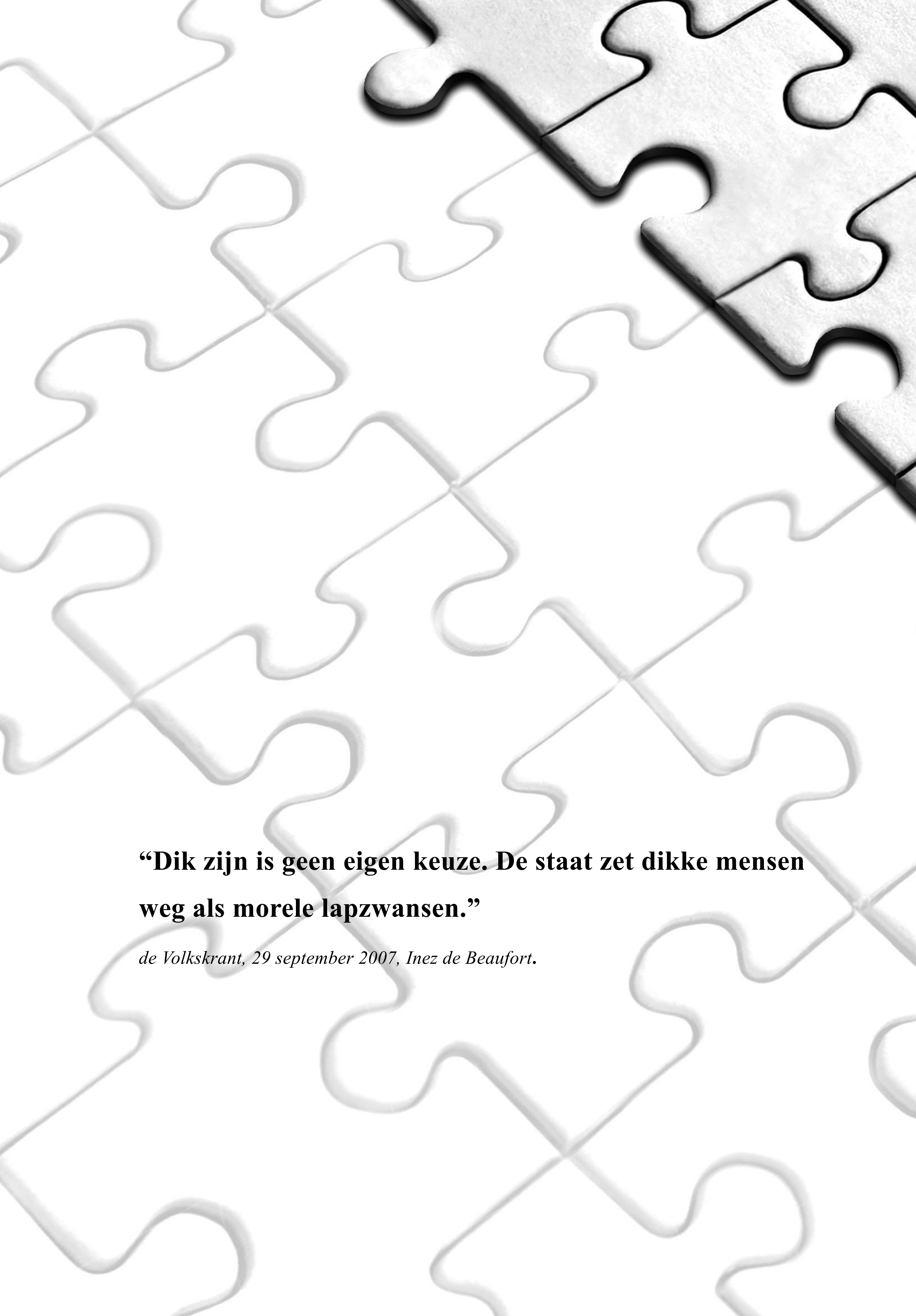
References

1. Magnusson RS. Rethinking global health challenges: towards a ‘global compact’ for reducing the burden of chronic disease. *Public Health* 2009; 123: 265-274.
2. *World Health Organization. Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference.* Official Records of the World Health Organization, no. 2, p. 100; World Health Organization, New York; 1948.
3. Huber M, Knottnerus JA, Green L, van der Horst H, Jadad AR, Kromhout D, et al. How should we define health? *Br Med J* 2011; 343: d4163.
4. Wade D and Halligan P. New wine in old bottles: the WHO ICF as an explanatory model of human behaviour. *Clin Rehabil* 2003; 17(4): 349-354.
5. Antonovsky A. *Unraveling the Mystery of Health. How People Manage Stress and Stay Well.* first ed. San Francisco, CA: Jossey-Bass; 1987.
6. Zeyer A. Salutogenesis and pathogenesis - a change of paradigm viewed from the standpoint of modern physics. *Sozial-Und Praventivmedizin* 1997; 42(6): 380-384.
7. Bengel J, Strittmatter R and Willmann H. *What Keeps People Healthy? The Current State of Discussion and the Relevance of Antonvsky’s Salutogenetic Model of Health.* th ed. Germany: Federal Centre for Health Education (FCHE); 1998.
8. Ustun TB, Chatterji S, Bickenbach J, Kostanjsek N and Schneider M. The International Classification of Functioning, Disability and Health: a new tool for understanding disability and health. *Disabil Rehabil* 2003; 25(11-2): 565-571.
9. Pruitt S and Epping-Jordan J. Preparing the 21st century global healthcare workforce. *Br Med J* 2005; 330(7492): 637-639.
10. World Health Organization. *International Classification of Functioning, Disability and Health: ICF.* 1st ed. Geneva: World Health Organization, 2001.
11. Kostanjsek N. Use of The International Classification of Functioning, Disability and Health (ICF) as a conceptual framework and common language for disability statistics and health information systems. *BMC Public Health* 2011; 11 Suppl 4: S3.
12. World Health Organization. *International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10).* 10th ed. Geneva: World Health Organization, 1992.
13. 13. Chen H, Katz PP, Eisner MD, Yelin EH and Blanc PD. Health-related quality of life in adult rhinitis: the role of perceived control of disease. *J Allergy Clin Immunol* 2004; 114(4): 845-850.
14. Lollar DJ and Simeonsson RJ. Diagnosis to function: classification for children and youths. *Journal of Developmental and Behavioral Pediatrics* 2005; 26(4): 323-330.

15. Sharma L, Cahue S, Song J, Hayes K, Pai YC and Dunlop D. Physical functioning over three years in knee osteoarthritis - Role of psychosocial, local mechanical, and neuromuscular factors. *Arthritis Rheum* 2003; 48(12): 3359-3370.
16. Spanjer J, Krol B, Popping R, Groothoff JW and Brouwer S. Disability Assessment Interview: the Role of Detailed Information on Functioning in Addition to Medical History-Taking. *J Rehabil Med* 2009; 41(4): 267-272.
17. Antonovsky A. Health, *Stress and Coping: New Perspectives on Mental and Physical Well-being.* 1st ed. San Francisco: Jossey-Bass; 1979.
18. Lindstrom B and Eriksson M. Salutogenesis. *J Epidemiol Community Health* 2005; 59(6): 440-442.
19. Steiner W, Ryser L, Huber E, Uebelhart D, Aeschlimann A and Stucki G. Use of the ICF model as a clinical problem-solving tool in physical therapy and rehabilitation medicine. *Phys Ther* 2002; 82(11): 1098-1107.
20. Segal R, Mandich A, Polatajko H and Cook J. Stigma and its management: a pilot study of parental perceptions of the experiences of children with developmental coordination disorder. *American Journal of Occupational Therapy* 2002; 56(4): 422-428.
21. Wynia K, Annema C, Nissen H, De Keyser J and Middel B. Design of a Randomised Controlled Trial (RCT) on the effectiveness of a Dutch patient advocacy case management intervention among severely disabled Multiple Sclerosis patients. *BMC Health Services Research* 2010; 10:142-142.
22. Kurtzke JF. Rating neurologic impairment in multiple-sclerosis - an expanded disability status scale (EDSS). *Neurology* 1983; 33(11): 1444-1452.
23. Wynia K, Middel B, van Dijk JP, De Ruiter H, De Keyser J and Reijneveld SA. The Multiple Sclerosis Impact Profile (MSIP). Development and testing psychometric properties of an ICF-based health measure. *Disabil Rehabil* 2008; 30(4): 261-274.
24. Wynia K, Middel B, De Ruiter H, van Dijk JP, De Keyser JHA and Reijneveld SA. Stability and relative validity of the Multiple Sclerosis Impact Profile (MSIP). *Disabil Rehabil* 2008; 30(14): 1027-1038.
25. Ewert T, Fuessl M, Cieza A, Andersen C, Chatterji S, Kostanjsek N, et al. Identification of the most common patient problems in patients with chronic conditions using the ICF checklist. *J Rehabil Med* 2004; 36: 22-29.
26. Newcombe RG and Altman DG. Proportions and their differences. In: Altman DG, Machin D, Bryant TN and Gardner MJ, editors. *Statistics with confidence.* 2nd ed. Bristol: British Medical Journal Books; 2005. p. 45-56.
27. Stucki G, Reinhardt JD and Grimby G. Organizing human functioning and rehabilitation research into distinct scientific fields. Part II: conceptual descriptions and domains for

research. *J Rehabil Med* 2007 ; 39(4): 299-307.

28. Boutron I, Moher D, Altman DG, Schulz KF and Ravaud P. Extending the CONSORT statement to randomized trials of nonpharmacologic treatment: explanation and elaboration. *Ann Intern Med* 2008; 148(4): 295-309.
29. Devereaux PJ, Bhandari M, Clarke M, Montori VM, Cook DJ, Yusuf S, et al. Need for expertise based randomised controlled trials. *Br Med J* 2005; 330(7482): 88-91.



“Dik zijn is geen eigen keuze. De staat zet dikke mensen weg als morele lapzwansen.”

de Volkskrant, 29 september 2007, Inez de Beaufort.

6

Nurse practitioners' focus on health care in terms of cure and care: analysis of graduate theses using the International Classification of Functioning, Disability and Health

Hillegonda A. Stallinga
Gerard J. Jansen
Marijke C. Kastermans
Albert Pranger
Pieter U. Dijkstra
Petrie F. Roodbol

Submitted

Abstract

Aim: To explore the focus of nurse practitioners on health care in terms of cure and care.
Background: Nurse practitioners are expected to act on the intersection of cure and care. However, in clinical practice and education, a clear model covering this area is lacking; therefore, it is unknown to what extent nurse practitioners are focused on this specific area. Graduate theses may reflect the focus of nurse practitioners.
Design: Sequential-exploratory mixed-method.
Methods: In total 413 published abstracts of graduate theses of the Master of Advanced Nursing Practice (MANP) (2000-2015) were analyzed using the International Classification of Functioning, Disability and Health (ICF). Data source included aim, question, and outcome of each thesis, as well as graduates' characteristics. A qualitative deductive approach was used for the analyses. Theses were classified as focused on cure, care, or on the intersection of cure and care.
Results: A small majority of 53% (*n* = 219) of the graduate theses addressed patient's health status and could be classified in the ICF. Of the classified theses, 48% were focused on cure, 39% on the intersection of cure and care, and 13% on care. While the percentage of theses addressing health status increased significantly over the 15-year period, the percentage of theses focused on cure, care and on the intersection of cure and care remained the same.
Conclusion: The graduate theses reflected that nurse practitioners are increasingly oriented toward patients' health status. However, their focus is predominantly on cure rather than on the intersection of cure and care.

6.1 Introduction

In the debate about the roles of health care professionals, physicians are associated with cure, whereas nurses and allied health care professionals are associated with care.[1] Nurse practitioners[a] are unique in this respect, because they act on the intersection of cure and care, combining medical and nursing competencies.[2-4] This specific area is known for its unique blending of medicine and nursing.[5,6] However, a clear scope or model of practice that adequately covers this specific area of cure and care is lacking for both clinical practice and graduate education.[2,7-11]

Advanced nursing practice[b] finds its origins in the task substitution and delegation of certain medical activities from physicians to nurses.[12] As a result, the professional development of advanced nursing practice reflects an *extended* nursing practice rather than an *advanced* nursing practice.[13] This primarily economic and instrumental perspective has dominated the nurse practitioners' professional development to date and has failed to capture the nature of what it means to be a nurse practitioner.[4,14]

Our study aims to explore the health care focus (cure, care, or the intersection of cure and care) of advanced nursing practice by analyzing graduate theses of students of a Dutch Master of Advanced Nursing Practice (MANP).

The International Classification of Functioning, Disability and Health (ICF) was used as a reference tool for determining cure, care, and the intersection.

6.1.1 Background

The World Health Organization (WHO) published the ICF as the international standard terminology for functioning and environmental factors, together with the conceptual model of health[15] (Figure 6.1). The conceptual model is based on the biopsychosocial model and represents the components of the health status in which functioning has been conceptualized as a result of a dynamic

---

[a] The International Council of Nurses (2008) defines a nurse practitioner as a "registered nurse who has acquired the expert knowledge base, complex decision-making skills and clinical competence for expanded nursing practice, the characteristics of which are shaped by the context and/or country in which she/he is credentialed to practice. A Masters degree is recommended for entry level".[41]

[b] Advanced nursing practice is defined as the expert practice within a regulated nursing scope.

interaction between a health condition (disease or disorder) and contextual factors (environmental and personal factors). Functioning encompasses the components body functions and structures, activities, and participation. Diseases or disorders (i.e. health conditions) are included in the conceptual model, but they are classified in the International Classification of Diseases and Related Health Problems (ICD).[16] The ICF and the ICD are complementary; both classifications have to be used to describe an individual's health status[15] (Figure 6.1).

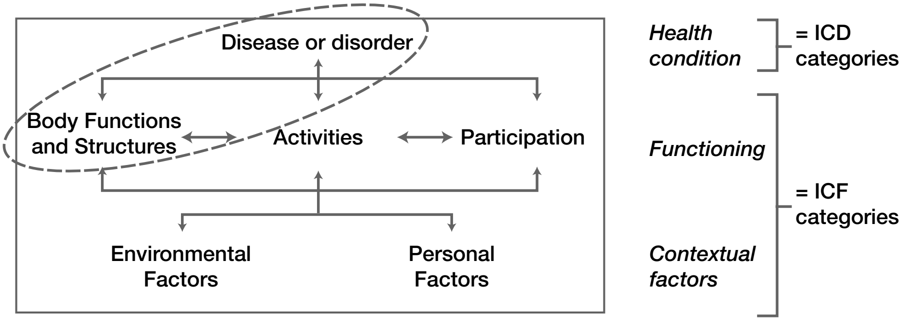


Figure 6.1 WHO's conceptual model of health representing the interactions between the components (disease, body functions and structures, activities, participation, environmental and personal factors) of the health status.[15] The partial perspective of health (oval) based on the biomedical model representing cure vs the comprehensive perspective of health (rectangle) based on the biopsychosocial model representing the intersection of cure and care.[40] ICD: International Classification of Diseases; ICF: International Classification of Functioning, Disability and Health. Note: activities and participation are distinguished in the conceptual model but combined in the standard terminology of the ICF.

Both cure and care aim to improve the health status of individuals. When expressed in the conceptual model of health, cure is primarily focused on the biomedical aspects, including disease and disorders in body functions and structures, whereas care is primarily focused on aspects related to functioning[17] (Figure 6.1). Although cure and care can be distinguished from one another, they should not be seen as separate units in health care provision but as a continuum in which both can be considered as endpoints.[1,18] By recording information related to the health status in the components of the conceptual model, a clinical decision model emerges that can be used in health care provision regarding cure and care.

The MANP started in the Netherlands in 1998. The program, which was designed with the aim to provide more efficient health care, was motivated by a shortage of doctors and growing health care costs. The curriculum of the MANP ($N = 9$) in the Netherlands is similar to that of the MANP in the United States.[4] Being a registered nurse is an entry requirement for the MANP. Following the general competency profiles, students have to integrate cure and care.[19] In addition, the so-called cure competencies, which are competencies aimed at biomedical aspects of health such as prescribing medication, ordering of diagnostic tests, and referral to specialists, are required for the granting of nurse practitioner status.[13] However, a clear model of practice that demonstrates how to integrate cure and care does not exist. It was actually expected that MANP students would automatically integrate cure competencies with care competencies because of their nursing background.

Writing graduate thesis gives students the opportunity to study a specific topic of their own choice related to clinical practice. In this context, graduate theses reflect the contribution of the MANP and the perception of the field o

6.2 The study

6.2.1 Aim

The aim of this study was to explore the focus of nurse practitioners on health care in terms of cure and care by analyzing MANP graduate theses using the WHO's conceptual model of health, including the ICF and the ICD, as a reference tool. The current trends with respect to the focus on health care reflected in the graduate theses can help establish guidelines for the MANP's curriculum in order to meet the competency profiles for nurse practitioners regarding the integration of cure and care.
The following research questions were answered:

- To what extent are graduate theses focused on cure, care, or on the intersection of cure and care?
- What is the content of graduate theses and how can this content be coded in the components of the WHO's conceptual model of health using the ICD and the ICF?

6.2.2 Design

A sequential exploratory mixed- methods design was employed in which textual data were collected. First, data were analyzed in a qualitative content analysis, using a deductive approach. This approach was appropriate as the aim was to map existing qualitative data in a new context with predefined categories.[21] The conceptual model, including the chapters and categories of the ICD and the ICF, provided for the predefined categories. Next, a quantitative analysis was performed using an algorithm derived from the conceptual model of health. The algorithm enabled the classification of graduate theses as cure-focused (= theses coded in disease (ICD) and not in activities and participation (ICF)), care-focused (= theses coded in activities and participation (ICF) and not in disease (ICD)) and intersection of cure- and care-focused (= theses coded in disease (ICD) and in activities and participation (ICF)).

6.2.2 Sample

The sample consisted of published abstracts (n = 413) of theses of MANP graduates of a Dutch University of Applied Sciences, written between March 2000 and September 2014. The sample represents 16% of the total number of graduated and registered nurse practitioners (N = 2 573)[22] of the MANPs (N = 9) in the Netherlands.

6.2.4 Data collection

The abstracts were obtained from internally published graduate theses and the website of the University of Applied Sciences (www.hanze.nl/kopstukken). These abstracts were written by the graduates themselves and published by the University. Three independent research assistants extracted the research question, the research goal, and the research conclusion from each thesis abstract. Graduate characteristics, such as age, gender, graduation year, and field of activity were obtained from the administration office of the MANP involved. Three lecturers of the MANP (GJJ, MCK, AP), trained in using the conceptual model including the ICD and the ICF, coded the research question, the research goal and the research conclusion of the graduate theses. Each of the three encoders independently coded two-thirds of the graduate theses. As a result, each thesis was coded twice. An independent expert (HAS) in using the conceptual model and linking meaningful concepts to the ICD and the ICF checked all codes and acted as a gold standard. Discordant opinions were discussed until consensus was reached. If consensus was not reached, the expert had the final say.

6.2.5 Ethical considerations

Informed consent was not obtained from graduates as the data were anonymized and it was not possible to link specific features of the abstracts to individual graduates.

6.2.6 Data analysis

Qualitative content analysis

A qualitative content analysis was conducted on the total sample of 413 graduate theses. A detailed manual and coding scheme were developed based on the established linking rules,[23] The manual and coding schema specifically aimed to indicate the classification of the meaningful concepts of the master theses into the components of the conceptual model of health and the chapters and categories of the ICD and the ICF. First, the topic of each thesis was assessed. A graduate thesis was coded health status-oriented if the topic of the thesis reflected components of the conceptual model (Figure 6.1) i.e. disease (classified in the ICD), and/or body functions and structures, and/or activities and participation (classified in the ICF). Environmental factors do not determine the focus on cure or care and were therefore not included in this first step. Personal factors are included in the conceptual model but not classified in the ICF and were therefore excluded from coding in this study. In the second step, the health status-oriented theses were coded into one or more components of the conceptual model and chapters and categories of the ICD and the ICF. Environmental factors are included in this coding procedure in order to describe the content of the graduate theses.

The first 10% of the coded graduate theses were discussed between the three encoders and the ICF expert. Subsequently, the expert modified and reinforced the manual and the coding scheme with examples of how specific meaningful concepts should be coded. The agreement between the encoders was calculated using Cohen's kappa (κ) and interpreted as follows: < 0.20 indicated slight agreement; 0.21–0.41 fair agreement; 0.42–0.60 moderate agreement; 0.61–0.80 substantial agreement; and κ > 0.80 almost perfect agreement.[24]

Quantitative analysis

Descriptive statistics were computed for characteristics of the graduates and the content of the different types of graduate theses i.e. not health status-oriented and health status-oriented and subsequent for cure-focused, care-focused, and intersection of cure- and care-focused. Differences in characteristics between graduates with not health status-oriented theses and health status-oriented theses and between cure-focused, care-focused, and intersection of cure- and care-focused theses were analyzed using chi-square test (gender and working field) and independent sample *t*-test and ANOVA (age). Effect sizes (*d* or Phi (φ)) were calculated and assessed against Cohen's criteria (*d* 0.2 or φ 0.1 = small, *d* 0.5 or φ 0.3 = medium, *d* 0.8 or φ 0.5 = large).[25] A p-value < 0.05 was considered statistically significant. Data were analyzed using IBM Statistical Package for the Social Sciences Version 22.0 for Windows (SPSS Inc., Chicago, IL, USA).

6.2.7 Validity and reliability

To increase the validity and reliability of the qualitative data, content validity was ensured by: a training of three encoders in using the conceptual model of health, including the chapters and categories of the ICD and the ICF; an extensive coding scheme and manual derived from established linking rules;[23] involvement of an coding expert (HAS) as the gold standard; and obtaining agreement between the encoders about the coding of the graduate theses. The data were analyzed in a transparent and systematic way using careful documentation, triangulation (encoder, analysis) and reassembling by means of an algorithm.

6.3 Results

6.3.1 Qualitative analysis

In the first step, a substantial to almost perfect agreement was achieved ($\kappa = 0.79$–0.98) between the encoders regarding the orientation of the graduate theses (health status-oriented or not health status-oriented). After discussions between the encoders and the expert a full agreement was achieved. Of the 413 graduate theses, 53% ($n = 219$) were health status-oriented and 47% ($n = 194$) not health status-oriented. The following research question illustrates a health status-oriented thesis: *"What is the effectiveness of secondary prevention related to fatigue and resumption of work in stroke patients at a younger age?"* This thesis was coded as follows: *stroke* was coded in the component disease; *fatigue* was coded in body functions; *resumption of* *work* was coded in activities and participation; and *secondary prevention* was coded in the environmental factors.

Thesis topics that were not health status-oriented addressed organizational issues, quality of care or the positioning of nurse practitioners. The following research topic illustrates a thesis that is not health status-oriented: *“To develop a job description for the nurse practitioner in nursing homes.”*

In the second step, regarding the coding of the 219 health status-oriented theses, κ was fair for diseases (0.52–0.63) and body functions (0.44–0.51), moderate for activities and participation (0.26–0.43) and slight to moderate for the environmental factors (0.10–0.34). After the encoders received extra training in linking rules and discussed a number of meaningful concepts, they revised their initial coding. This resulted in an almost perfect agreement (κ = 0.95–1) for all the components. After discussing the coding differences, consensus could be reached.

6.3.2 Quantitative analysis

Sample characteristics

No significant differences were found between graduates with the health status-oriented theses compared with graduates with not-health-status-oriented theses in mean age (resp. 42.0 years, SD 7.9; 40.5, 7.4) and gender (Table 6.1). Significant differences were found in working field; more graduates with health status-oriented theses worked in psychiatric care, primary care, rehabilitation, or geriatric and palliative care, compared with graduates with

Table 6.1 Comparison of characteristics of graduates with health status-oriented and not health status-oriented theses.

		Total	**Health status-oriented**	**Not health status-oriented**	***p* value**	**Effect size**
		n = 413	*n* = 219	*n* = 194		
Age (mean (SD))		41.3 (7.7)	42.0 (7.9)	40.5 (7.4)	0.055*	0.2
Gender *n* (%)	Female	326 (79)	170 (78)	156 (80)	0.488#	0.01
	Male	87 (21)	49 (22)	38 (20)		
Working field *n* (%)	A	350 (85)	174 (80)	176 (91)	0.001#	0.2
	B	63 (15)	45 (20)	18 (9)		

SD: standard deviation; A: generic hospital care; B: psychiatric care, primary care, rehabilitation, geriatric and palliative care; #Pearson chi-square and effect size Phi coefficient φ; **t*-test and effect size Cohens’*d* not-health-status-related theses ($p = 0.001$; $\varphi = 0.2$).

Female graduates and graduates working in general hospital care were predominant in both groups. A significant upward trend in the number of health status-oriented theses was found for recent years. (χ^2 (14, $n = 413$) = 109.34 $p < 0.001$, $\varphi = 0.5$) (Figure 6.2).

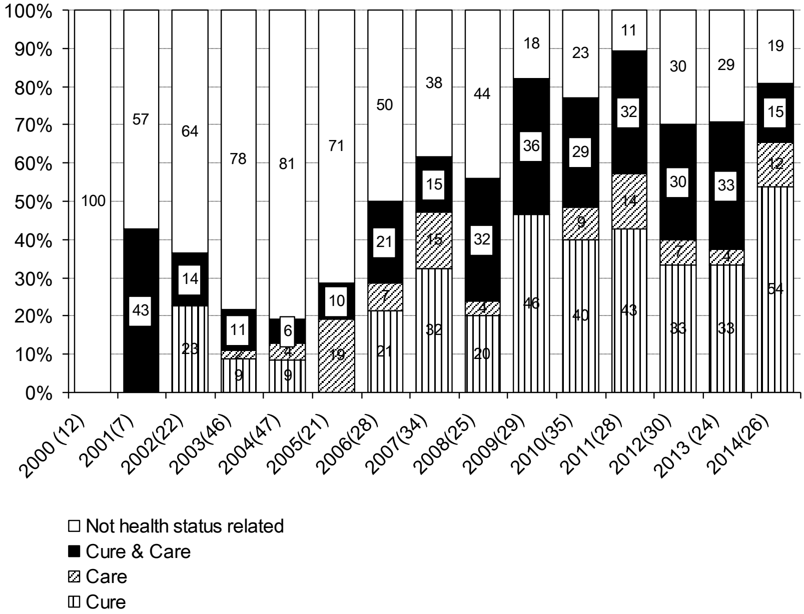


Figure 6.2 Percentage of theses with different focuses per year; between brackets the number of theses published in that year (sig. chi-square for trend p < 0.001;$\varphi = 0.5$).

Focus of the graduate theses

Of the 219 health status-oriented graduate theses, 48% ($n = 106$) were focused on cure, 13% ($n = 28$) on care, and 39% ($n = 85$) on the intersection of cure and care ($p < 0.001$; $\varphi = 1.9$). There was no statistically significant difference between the 219 graduates regarding basic characteristics, except for age ($p = 0.022$; $d = 0.04$). The graduates with theses focused on care were older compared with the graduates whose theses focused on cure or on the intersection of cure and care (Table 6.2).

Table 6.2 Comparison of characteristics of graduates with cure-focused, care-focused, and cure- and care-focused theses (total $n = 219$).

		Cure $n = 106$	Care $n = 28$	Cure and care $n = 85$	p value	Effect size
Age (mean (SD))		41.8 (7.9)	45 (6.0)	40.3 (8.0)	0.022*	0.04
Gender *n* (%)	Female	81 (76)	22 (79)	68 (80)	$0.836^{\#}$	0.0
	Male	25 (24)	6 (21)	17 (20)		
Working field *n* (%)	A	78 (74)	23 (82)	73 (86)	$0.105^{\#}$	0.1
	B	28 (26)	5 (18)	12 (14)		

SD: standard deviation; A: generic hospital care; B: psychiatric care, primary care, rehabilitation, geriatric and palliative care; $^{\#}$Pearson chi-square and effect size Phi coefficient φ; * *t*-test and effect size Cohens'*d*

Content of the graduate theses

Of the 219 health status-oriented graduate theses, 87% ($n = 191$) included a health condition (i.e. disease). Diseases related to mental and behavioral disorders (total: 20%; $n = 45$) and the circulatory system (total: 19%; $n = 41$) were the most frequently included diseases (Table 6.3).

Table 6.3 Diseases in health status-oriented theses ordered by frequency.

Diseases (ICD chapters)	**Total** ***n* (%)**	**Cure** ***n* (%)**	**Cure and care** ***n* (%)**
Mental and behavioral disorders	45 (20)	31 (29)	14 (17)
Circulatory system	41 (19)	23 (22)	18 (21)
Neoplasms	17 (8)	8 (8)	9 (11)
Nervous system	16 (7)	7 (7)	9 (11)
Endocrine, nutritional and metabolic	17 (8)	12 (11)	5 (6)
Respiratory system	15 (7)	6 (6)	9 (11)
Musculoskeletal system	11 (5)	6 (6)	5 (6)
Infectious diseases	7 (3)	2 (2)	5 (6)
Genitourinary system	6 (3)	3 (3)	3 (4)
Digestive system	5 (2)	4 (4)	1 (1)
Blood and immune mechanism	4 (2)	3 (3)	1 (1)
Skin	3 (1)	0 (0)	3 (4)
Not specified	3 (1)	1 (1)	2 (2)
Pregnancy, childbirth, puerperium	1 (1)	0 (0)	1 (1)
Total n (%) within disease	*191 (87)*	*106 (48)*	*85 (39)*

ICD: International Classification of Diseases. Note: Care-focused theses ($n = 28$; 13%) are left out because diseases were not included in these theses.

There was no significant difference in frequency of included diseases between the theses focused on cure compared to theses focused on the intersection of cure and care (χ^2 (13, $n = 191$) = 17.23, $p = 0.18$, $\varphi = 0.3$).

Diseases were not a topic of theses focused on care.

In total 52% ($n = 113$) of the health status-oriented graduate theses included activities and participation. Self-care was the most frequently included topic of the component of activities and participation (total: 19%; $n = 42$), directly followed by activities and participation not specified (total: 18%; $n = 40$) (Table 6.4). These unspecified activities and participation referred to concepts such as quality of life and psychosocial support or behavior. These concepts are too broad to be coded. Hence, they could be related to various chapters in the component activities and participation. There was no significant difference in frequency of included activities and participation between theses focused on care and theses focused on the intersection of cure and care (χ^2 (7, $n = 113$) = 8.18, $p = 0.32$, $\varphi = 0.3$). Activities and participation were not a topic of theses focused on cure.

Table 6.4 Activities and participation in health status-oriented theses ordered by frequency.

Activities and participation (ICF chapters)	**Total** ***n* (%)**	**Cure** ***n* (%)**	**Cure and care** ***n* (%)**
Self-care	42 (19)	11 (39)	31 (37)
Not specified	40 (18)	9 (32)	31 (37)
Interpersonal interactions and relationships	13 (6)	3 (11)	10 (12)
Learning and applying knowledge	11 (5)	2 (7)	9 (10)
General tasks and demands	2 (1)	2 (7)	0 (0)
Mobility	2 (1)	1 (4)	1 (1)
Domestic life	2 (1)	0 (0)	2 (2)
Major life areas	1 (1)	0 (0)	1 (1)
Communication	0 (0)	0 (0)	0 (0)
Community, social, and civic life	0 (0)	0 (0)	0 (0)
Total n (%) within activities and participation	*113 (52)*	*28 (13)*	*85 (39)*

ICF: International Classification of Functioning, Disability and Health. Note: Cure-focused theses ($n = 106$; 48%) are left out because activities and participation were not included in these theses.

In total 88% ($n = 192$) of the health status-oriented graduate theses included body functions. Body functions related to cardiovascular, hematological, immunological, and respiratory systems were the most frequently included topics, (total: 29%; $n = 62$) followed by mental functions (total: 20%; $n = 44$). The care-focused theses addressed these topics less frequently compared with the cure-focused and the intersection of cure- and care-focused theses

(Table 6.5). Graduate theses focused on care were mostly directed to various chapters of body functions, although 28% (*n* = 8) of these theses did not address any body functions.

Table 6.5 Body functions in health status-oriented theses ordered by frequency.

Body functions (ICF chapters)	**Total** ***n* (%)**	**Cure** ***n* (%)**	**Care** ***n* (%)**	**Cure and care** ***n* (%)**
Cardiovascular, hematological, immunological and respiratory	62 (29)	36 (33)	1 (4)	25 (29)
Mental	44 (20)	25 (24)	3 (11)	16 (19)
No focus on body functions	*27 (12)*	*2 (2)*	*8 (28)*	*17 (20)*
Digestive, metabolic, and endocrine	29 (13)	17 (16)	2 (7)	10 (12)
Sensory and pain	20 (9)	14 (13)	3 (11)	3 (4)
Genitourinary and reproductive	16 (7)	6 (6)	4 (14)	6 (7)
Not specified	7 (3)	2 (2)	4 (14)	1 (1)
Neuromusculoskeletal and movement-related	8 (4)	2 (2)	1 (4)	5 (6)
Skin	6 (3)	2 (2)	2 (7)	2 (2)
Voice and speech	0 (0)	0 (0)	0 (0)	0 (0)
Total n (%) within body functions	*219 (100)*	*106 (48)*	*28 (13)*	*85 (39)*

ICF: International Classification of Functioning, Disability and Health. Note: Theses with *no focus on body functions* (*n* = 27; 12%) are included.

Environmental factors were also included in 88% (*n* = 192) of the health status-oriented graduate theses. Environmental factors related to services, systems, and policies were the most frequently addressed topics (total: 65%; *n* = 142), followed by products and technology (total: 19%; *n* = 43) (Table 6.6).

Table 6.6 Environmental factors in health status-oriented theses ordered by frequency.

Environmental Factors (ICF chapters)	**Total** ***n* (%)**	**Cure** ***n* (%)**	**Care** ***n* (%)**	**Cure and care** ***n* (%)**
Services, systems, and policies	142 (65)	66 (62)	14 (50)	62 (73)
Products and Technology	43 (19)	26 (25)	3 (11)	14 (17)
No focus on environmental factors	*27 (12)*	*12 (11)*	*9 (32)*	*6 (7)*
Not specified	2 (1)	0 (0)	2 (7)	0 (0)
Attitudes	3 (1)	1 (1)	0 (0)	2 (2)
Natural environment	1 (1)	1 (1)	0 (0)	0 (0)
Support and relationships	1 (1)	0 (0)	0 (0)	1 (1)
Total n (%) within environmental factors	*219 (100)*	*106 (48)*	*28 (13)*	*85 (39)*

ICF: International Classification of Functioning, Disability and Health. Note: Theses with *no focus on environmental factors* (*n* = 27; 12%) are included.

The care-focused theses addressed products and technology less frequently compared with the cure-focused and the intersection of cure- and care-focused theses.

6.4 Discussion

This study analyzed the content of 413 graduate theses (2000-2015) of graduates of a Dutch MANP in order to explore the focus of nurse practitioners on health care in terms of cure and care. About half (*n* = 219) of the graduate theses were oriented toward patients' health status, of which 48% (*n* = 106) were focused on cure, 13% (*n* = 28) on care, and 39% (*n* = 85) on the intersection of cure and care. The number of health status-oriented graduate theses increased significantly from the period of 2000 to 2015. The percentage of theses focused on cure, care and the intersection of cure and care remained the same.

The increase of the number of health status-oriented graduate theses can be explained by the aim of the MANP at the start in 1998, which was to improve efficiency in health care practice.[4] In those early years, the professional role development of the nurse practitioners was related to the consolidation of their own role and position. In recent years, however, the professional role development of the nurse practitioners is moving toward the improvement of patients' health status.[4,26]

However, while the percentage of theses oriented to patients' health status increased significantly from the period of 2000 to 2015, the percentage of theses focused on cure, care and on the intersection of cure and care remained the same. In addition, the majority of the graduate theses were focused on cure. This may be explained by the aim of the MANP as well, for the MANP aims to legalize the transfer of medical procedures and certain medical activities from physicians to nurses.[12] Nurse practitioners have been granted direct legal authority for medical health checks and certain medical procedures within selected fields for selected patients in the Netherlands since 2012.[4] Consequently, students of the MANP are strongly focused on the medical competencies required for granting of nurse practitioners status.[13] This focus is confirmed in studies that compared the cure competencies of physicians and nurse practitioners. In general, these studies concluded that both professions are very well comparable when it comes to particular competencies related to cure.[27-30] Considering this, the over-representation of the cure-focused graduate theses in the present study might have been caused by the preceptor in clinical practice of the nurse practitioner, who is often a physician and might have influenced the choice of the topic of the student's thesis.

Despite the fact that the nurse practitioner is a health care professional who is expected to act on the intersection of cure and care, and to combine medical and nursing competencies,[2,3] the number of graduate theses that were focused on the intersection of cure and care was small. The findings did not indicate that the focus of graduate theses will shift to the intersection of cure and care in the future. Moreover, the predominance of the focus on cure over a 15-year period indicates that the integration of cure and care will come to a halt without the development of a specific model of practice covering the intersection of cure and care. Our results are consistent with studies testing health status assessments.[31,32] Their results demonstrated that only when health care professionals were offered a tool enabling them to assess patients' health status, including functioning, cure and care were integrated. This finding supports a recently published ICD-ICF joint use initiative,[33] in which health information was displayed combining the ICD and the ICF in order to guide clinical decision-making related to health care provision.

The findings of the present study indicate that type of disease or activities and participation did not define the focus of the graduate theses. There were no differences in type and number of diseases and activities and participation between the cure-focused, care-focused, and intersection of cure- and care-focused theses. Mental functions and body functions related to the cardiovascular system were the most frequently coded topics in the cure-focused as well as in the intersection of cure- and care-focused graduate theses (Table 6.3). The predominance of these topics may be explained by the predominance of nurse practitioners working in mental health care and cardiovascular care. The Dutch nurse practitioners register showed that 48% (*n* = 1 223) of nurse practitioners are registered in the category intensive care, which covers cardiovascular care, and 28% (*n* = 722) in the category mental care.[22] The predominance of diseases related to the circulatory system and mental disorders (Table 6.3) corresponded to the predominance of body functions related to the cardiovascular, hematological, immunological and respiratory system and to mental functions (Table 6.5). This finding confirmed that there is a close link between diseases and body functions, for they represent the same types of categories.[34]

The predominance of self-care activities (Table 6.4) was demonstrated in both care-focused and the intersection of cure- and care-focused theses. This finding confirmed that self-care activities are part of the core business of nursing, also in advanced nursing practice.

Our study is the first to examine MANP graduate theses in relation to the focus on health care of nurse practitioners. Other studies have analyzed MANP graduate theses in relation to educational outcomes, including graduates' research knowledge and skills, methodological approach, thematic area of research,[35,36] and the examiners' consistency in the grading of theses.[37] The results of the present study support the opinion, that it may be essential to reexamine the curriculum of MANPs to ensure that educational institutions are meeting the needs of nurse practitioners, consumers, and health care systems.[38] A clear scope or model of practice that incorporates tools representing the intersection of cure and care has to be developed. The WHO's conceptual model, which integrates health conditions and functioning, may provide such a clear scope or model and may be useful for guiding the MANP program.

6.4.1 Limitations and strengths

It can be debated whether graduate theses reflect the focus of nurse practitioners on health care. Graduate theses are primarily intended for testing research competencies, and this aim might have interfered with a focus on health care. On the other hand, graduate theses do not only reflect the graduates' focus but also the faculty's perspectives, worldviews, perception of the field, and areas of expertise.[20] In this respect, graduate theses do reflect the focus of nurse practitioners in relation to cure, care, and the intersection of cure and care. Although our results provide a reflection of advanced nursing practice in an educational context, future studies should collect data in the context of clinical practice to validate the results, for instance, by analyzing registered problems and professional health care activities by nurse practitioners in patient health records.

Another limitation concerns the coding of the graduate theses. In a number of graduate theses it was difficult to determine the topic of the study (i.e. focused on disease or one of the components of functioning) and the patient population involved. This is illustrated by the following graduate thesis topic: *The experienced participation of patients with chronic heart failure.* Although the cardiovascular patient population was involved, the focus was not primarily on the disease of heart failure itself. This graduate thesis should only be coded in the component activities and participation.

A final limitation concerns the lack of knowledge of the encoders related to the linking of meaningful concepts to the components of the conceptual model and the chapters and categories represented by ICD and ICF. This lack of knowledge can explain the moderate to fair level of agreement of the initial coding of the health status-oriented thesis. For example, the encoders did not know that *noncompliance* is classified in the ICF component activities and participation, chapter d5 self-care (category d5702 maintaining one's health) or that *diabetic alert dog* is classified in environmental factors, chapter e3 support and relationships (category e350 domesticated animals). This means that linking aspects of the health status to components of the conceptual model and categories of the ICD and ICF requires training and supervision.

The strength of the study is the large number of graduate theses conducted over a 15-year period, that were included in the study. Because they covered a substantial period of time, the field of advanced nursing practice was adequately reflected. The analysis consisted of an intensive and careful coding process using established linking rules and classifications (i.e. ICD and ICF). An expert in using the linking rules and the related classifications within the conceptual model provided supervision and additional training when necessary. Although the single center character of the study limited the generalizability of the results, almost one-fifth of all Dutch registered nurse practitioners were represented in this study. Generalization outside the Netherlands is hampered due to the large variety of professional titles and the diversity of functions, roles, and education programs related to nurse practitioners.[39]

6.5 Conclusion

Graduate theses reflected that nurse practitioners are increasingly oriented toward patients' health status. However, their focus is predominantly on cure, rather than on the intersection of cure and care. Findings from this study indicate that a clear model or scope of practice should be developed to guide the MANP to that particular area of practice. The WHO’s conceptual model of health, including the integration of disease (ICD) and functioning (ICF) represents the intersection of cure and care and can form the basis of this model. Finally, additional studies are needed to evaluate the outcomes and to validate the findings.

References

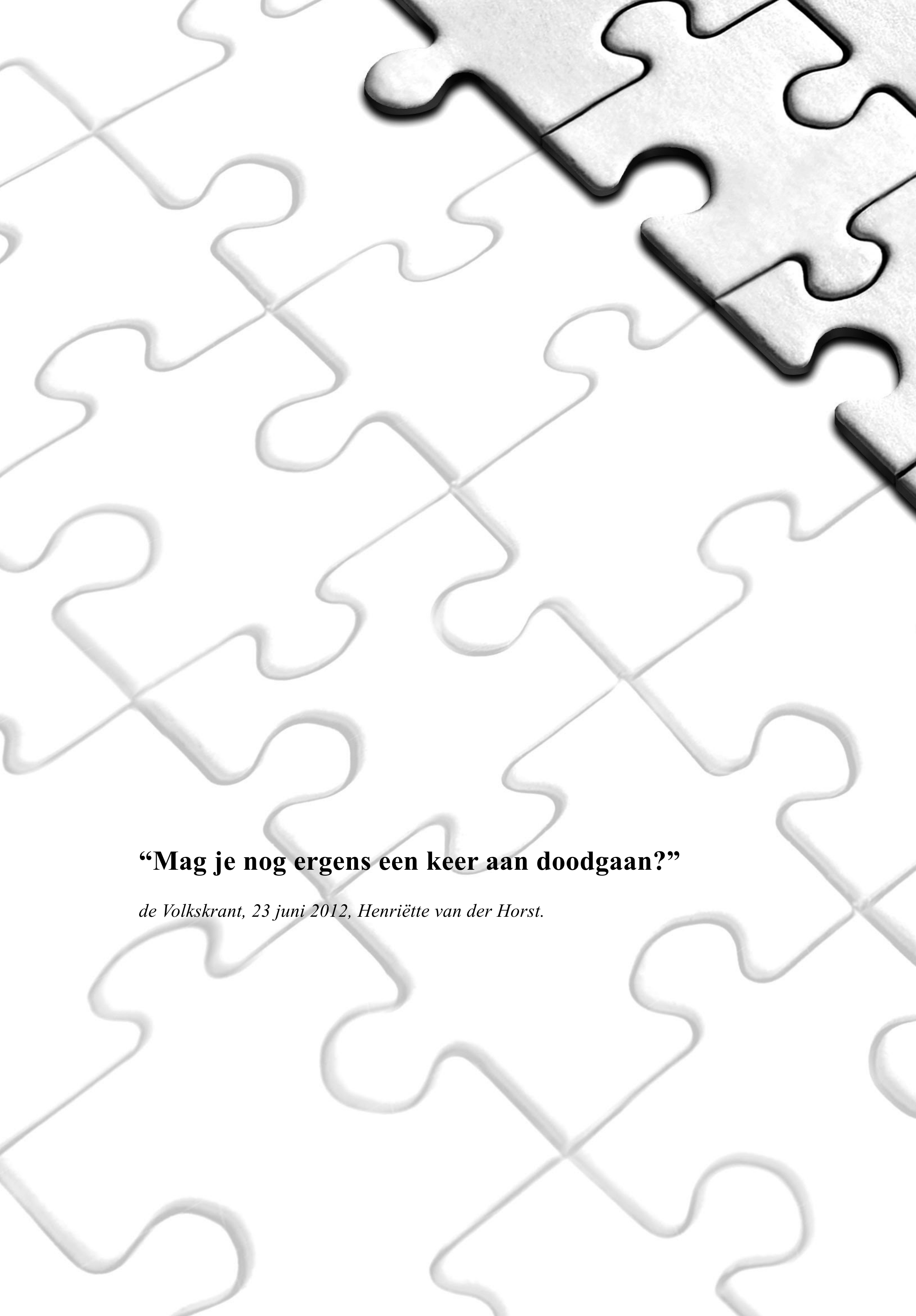
1. Baumann A, Deber R, Silverman B and Mallette C. Who cares? Who cures? The ongoing debate in the provision of health care. *J Adv Nurs* 1998; 28(5): 1040-1045.
2. Kilpatrick K, Lavoie-Tremblay M, Ritchie JA, Lamothe L and Doran D. Boundary work and the introduction of acute care nurse practitioners in healthcare teams. *J Adv Nurs* 2012; 68(7): 1504-1515.
3. Partin B. Who, if not you, will determine NP scope of practice? *Nurse Pract* 2006; 31(2): 6-6.
4. ter Maten-Speksnijder A, Grypdonck M, Pool A, Meurs P and van Staa AL. A literature review of the Dutch debate on the nurse practitioner role: efficiency vs. professional development. *Int Nurs Rev* 2014; 61(1): 44-54.
5. Brown MA and Draye MA. Experiences of pioneer nurse practitioners in establishing advanced practice roles. *J Nurs Scholarsh* 2003; 35(4): 391-397.
6. Fawcett J, Newman DM and McAllister M. Advanced practice nursing and conceptual models of nursing. *Nurs Sci Q* 2004; 17(2): 135-138.
7. Bryant-Lukosius D and DiCenso A. A framework for the introduction and evaluation of advanced practice nursing roles. *J Adv Nurs* 2004; 48(5): 530-540.
8. Bryant-Lukosius D, DiCenso A, Browne G and Pinelli J. Advanced practice nursing roles: development, implementation and evaluation. *J Adv Nurs* 2004; 48(5): 519-529.
9. McNamara S, Giguere V, St-Louis L and Boileau J. Development and implementation of the specialized nurse practitioner role: use of the PEPPA framework to achieve success. *Nurs Health Sci* 2009; 11(3): 318-325.
10. Gardner G, Chang A and Duffield C. Making nursing work: breaking through the role confusion of advanced practice nursing. *J Adv Nurs* 2007; 57(4): 382-391.
11. Lowe G, Plummer V, O'Brien AP, Boyd L. Time to clarify - the value of advanced practice nursing roles in health care. *J Adv Nurs* 2012; 68(3): 677-685.
12. Petrie F. Roodbol. *Dwaallichten, struikeltochten, tolwegen en zangsporen. Onderzoek naar taakherschikking tussen verpleging en artsen [Research on rearrangement of tasks between nurses and doctors] PhD Thesis.* Groningen: Universiteit Groningen, 2005.
13. Elsom S, Happell B and Manias E. Mental health nurse practitioner: expanded or advanced? *International Journal of Mental Health Nursing* 2005; 14(3): 181-186.
14. Rashotte J. Knowing the nurse practitioner: dominant discourses shaping our horizons. *Nurs Philos* 2005; 6(1): 51-62.
15. World Health Organization. *International Classification of Functioning, Disability and Health: ICF.* 1st ed. Geneva: World Health Organization, 2001.

16. World Health Organization. I*nternational Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10).* 10th ed. Geneva: World Health Organization, 1992.
17. Stucki G, Cieza A and Melvin J. The International Classification of Functioning, Disability and Health: a unifying model for the conceptual description of the rehabilitation strategy. *J Rehabil Med* 2007; 39(4): 279-285.
18. Webb C. Caring, curing, coping: towards an integrated model. *J Adv Nurs* 1996; 23(5): 960-968.
19. *VBOC- Nursing occupational structure and training-continuum (Verpleegkundige Beroepenstructuur en OpleidingsContinuum.* General and specific competency profiles of the nurse practitioner (Algemeen Competentieprofiel en specifieke deelprofielen Verpleegkundig Specialist). 2008.
20. Sparacino PS. Nursing research and graduate nursing student involvement. *Clin Nurse Spec* 2000; 14(3): 126-126.
21. Elo S and Kyngaes H. The qualitative content analysis process. *J Adv Nurs* 2008; 62(1): 107-115.
22. V&VN The Dutch National Professional Organization of Nurses. Verpleegkundig Specialisten Register. (Nurse specialists register). 2015; Available at: http://www.verpleegkundigspecialismen.nl/Registratie/Verpleegkundig-specialist/Aantal-Verpleegkundig-Specialisten. Accessed April 24, 2015.
23. Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustun B and Stucki G. ICF linking rules: an update based on lessons learned RID F-6994-2011. *J Rehabil Med* 2005; 37(4): 212-218.
24. Landis JR and Koch GG. Measurement of Observer Agreement for Categorical Data. *Biometrics* 1977; 33(1): 159-174.
25. Cohen J. *Statistical power analysis for the behavioural sciences.* 2nd ed. New York: Academic Press, 1988.
26. Cotterill-Walker SM. Where is the evidence that master's level nursing education makes a difference to patient care? A literature review. *Nurse Educ Today* 2012; 32(1): 57-64.
27. Hoffman LA, Tasota FJ, Scharfenberg C, Zullo TG and Donahoe MP. Management of patients in the intensive care unit: comparison via work sampling analysis of an acute care nurse practitioner and physicians in training. *American Journal of Critical Care* 2003; 12(5): 436-443.
28. Hughes DR, Jiang M and Duszak R, Jr. A comparison of diagnostic imaging ordering patterns between advanced practice clinicians and primary care physicians following

office-based evaluation and management visits. *JAMA Intern Med* 2015; 175(1): 101-107.

29. Lohr RH, West CP, Beliveau M, Daniels PR, Nyman MA, Mundell WC, et al. Comparison of the quality of patient referrals from physicians, physician assistants, and nurse practitioners. *Mayo Clin Proc* 2013; 88(11): 1266-1271.
30. Mundinger MO, Kane RL, Lenz ER, Totten AM, Tsai WY, Cleary PD, et al. Primary care outcomes in patients treated by nurse practitioners or physicians: a randomized trial. *JAMA* 2000; 283(1): 59-68.
31. Spanjer J, Krol B, Popping R, Groothoff JW and Brouwer S. Disability Assessment Interview: the Role of Detailed Information on Functioning in Addition to Medical History-Taking. *J Rehabil Med* 2009; 41(4): 267-272.
32. Stallinga HA, Roodbol PF, Annema C, Jansen GJ, Wynia K. Functioning assessment vs. conventional medical assessment: a comparative study on health professionals' clinical decision-making and the fit with patient's own perspective of health. *J Clin Nurs* 2014; 23(7-8): 1044-1054.
33. Selb M, Kohler F, Robinson Nicol MM, Riberto M, Stucki G, Kennedy C, et al. ICD-11: A comprehensive picture of health, an update on the ICD-ICF joint use initiative. *J Rehabil Med* 2014; 47(1): 2-8.
34. Tesio L. From codes to language: is the ICF a classification system or a dictionary? *BMC Public Health* 2011; 11 Suppl 4: S2-2458-11-S4-S2.
35. Dobratz MC, Primomo J and Bjorling E. Outcomes of scholarly inquiry: an analysis of Master's of Nursing students' projects/theses. *J Prof Nurs* 2006; 22(5): 296-303.
36. Garbin LM, de Castro Sajioro Azevedo AL, da Silva LT, Laus AM, Chaves LD, Gualda DM, et al. Inter-unit Doctoral Program in Nursing of the University of Sao Paulo: characterization of graduates and theses defended in a decade. *Rev Lat Am Enfermagem 2*010; 18(5): 841-848.
37. Bourke S and Holbrook AP. Examining PhD and research masters theses. *Assessment & Evaluation in Higher Education 2*013; 38(4): 407-416.
38. Gerard SO, Kazer MW, Babington L and Quell TT. Past, present, and future trends of master's education in nursing. *J Prof Nurs* 2014; 30(4): 326-332.
39. Pulcini J, Jelic M, Gul R and Loke AY. An International Survey on Advanced Practice Nursing Education, Practice, and Regulation. *Journal of Nursing Scholarship* 2010; 42(1): 31-39.
40. Stucki G and Celio M. Developing human functioning and rehabilitation research. Part II: Interdisciplinary university centers and national and regional collaboration networks. *J Rehabil Med* 2007; 39(4): 334-342.

41. International Council of Nurses. The Scope of Practice, Standards and Competencies of the Advanced Practice Nurse. *ICN Regulation Series, International Council of Nurses, Switzerland* 2008.
42. Stasa H, Cashin A, Buckley T and Donoghue J. Advancing advanced practice - clarifying the conceptual confusion. *Nurse Educ Today* 2014; 34(3): 356-361.



“Mag je nog ergens een keer aan doodgaan?”

de Volkskrant, 23 juni 2012, Henriëtte van der Horst.

7

Effects of a short training in using the International Classification of Functioning, Disability and Health (ICF) on perceived usefulness of the ICF: a randomized controlled trial in Master of Advanced Nursing Practice students

Hillegonda A. Stallinga
Pieter U. Dijkstra
Huib ten Napel
Gabriël Roodbol
Jeroen W. B. Peters
Yvonne F. Heerkens
Petrie F. Roodbol

Submitted

Abstract

Objective: To test effects of a 4-hour instructor-led training in using the International Classification of Functioning, Disability and Health (ICF) on perceived usefulness of the ICF.
Design: Randomized controlled trial.
Subjects: A total of 74 students enrolled in the Master of Advanced Nursing Practice (MANP) were randomly allocated to intervention or control group.
Methods: The intervention group received a 4-hour instructor-led training in using the ICF. The control group did not receive ICF training. Primary outcome measure was perceived usefulness of the ICF. Secondary outcome measures were ICF-related knowledge, skills and attitude. Data were collected using an ICF survey and learning assessment tool at baseline, immediately after the training, and at 3-months follow-up.
Results: Data of 56 students were included for analysis. Perceived usefulness of the ICF was significantly increased in the intervention group immediately after training ($p = 0.002$) but no longer at 3-months follow-up ($p = 0.054$). Attitude and knowledge related to the ICF were significantly increased in the intervention group at both post-training assessments ($p < 0.001$ to 0.02). Skills were not affected.
Conclusion: A short ICF training has positive influence on perceived usefulness of the ICF, which is relevant for including ICF in the MANP curriculum.

7.1 Introduction

The World Health Organization (WHO) published the International Classification of Functioning, Disability and Health (ICF) as the international standard terminology for functioning, together with the conceptual model of health.[1] Functioning encompass the components body functions and structures, activities, and participation. These components dynamically interact with one another and are influenced by contextual factors (environmental and personal factors) and health condition (Figure 7.1). Health conditions (diseases or disorders) are classified in the tenth version of the International Classification of Diseases and Related Health Problems (ICD-10).[2] The ICF and the ICD are complementary; both classifications have to be used to describe an individual's health status.[1]

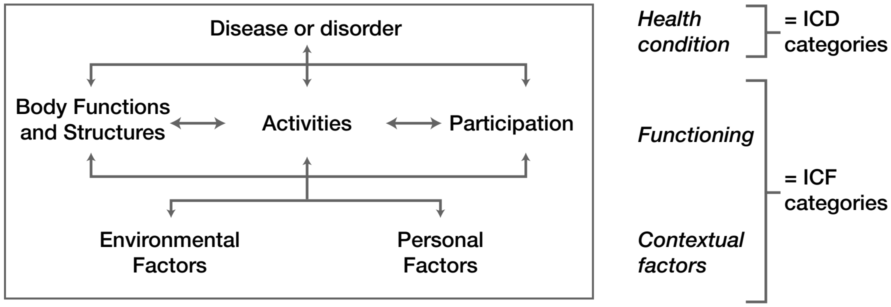


Figure 7.1 WHO's conceptual model of health representing the interactions between the components (disease, body functions and structures, activities, participation, environmental and personal factors) of the health status.[1] ICD: International Classification of Diseases; ICF: International Classification of Functioning, Disability and Health.

Health care provisions aim to improve the health status of individuals by means of cure and/or care. Within the conceptual model, cure is primarily focused on disease or disorders and body functions and structures, and care is primarily focused on activities and participation.[3] The latter is particularly relevant in the face of the ageing global population and the increasing burden of non-communicable chronic diseases.

In the debate about the role of health care professionals, cure has been associated with physicians and care with nurses and other allied health professions.[4] In this respect, nurse practitioners (NPs)[a] are unique health care professionals who operate on the intersection of cure and care and who combine medical and nursing competencies.[5,6]

The Master of Advanced Nursing Practice (MANP) educates nurses to become a NP[a], following the Dutch established competency profiles, in which the integration of cure and care is included.[7] However, a clear scope and model that adequately cover the roles and position of NPs is currently lacking.[5,8-12] The use of the conceptual model and the terminology of the ICF may be useful in the integration of cure and care. The use of this model and the including of the focus on functioning in clinical decision-making require a paradigm shift in health care provision from a pathogenetic orientation to a broader, so-called salutogenetic orientation. Following the salutogenic orientation, health care provisions focus on how to stay healthy, rather than on what causes diseases.[13-15] MANP students may not favor the introduction of the conceptual model and the use of the ICF in their curriculum, because of their focus on the pathogenically-oriented competencies, required for the granting of NP status.[16] However, by using the conceptual model of health and the ICF, the focus on cure and medical competencies is not lost.[17]

There are currently only a few ICF-related educational programs that have been tested for their effects.[18-20] In addition, MANP students may not perceive the ICF as useful, whereas a positive attitude is a prerequisite for effective cognitive and skill-based learning outcomes.[21] Therefore, this study aimed to analyze the effects of a short instructor-led ICF-training on perceived usefulness of the ICF in MANP students in a randomized controlled trial.

7.2 Methods

7.2.1 Participants and procedure

Participants were students (n = 74) enrolled in the 2-year MANP program at a University of Applied Sciences in the Netherlands. The sample represents 15% of the total student population (N = 500) of the MANPs (N = 9) in the Netherlands.

Both the ICF training and the control training were included in the schedule of the MANP program, labeled as ‘testing an educational concept’.

---

[a] The International Council of Nurses (2008) defined a nurse practitioner as “a registered nurse who has acquired the expert knowledge base, complex decision-making skills and clinical competence for expanded nursing practice, the characteristics of which are shaped by the context and/or country in which she/he is credentialed to practice”. A Masters degree is recommended for entry level.[30]

The non-disclosure of the topic of the training was necessary to prevent information bias. All students received an information letter and the consent form one month prior to the training. All students were fully informed about the research procedure immediately after the final data collection by means of a presentation of the researcher.

Data were collected using questionnaires that were handed out immediately before the training (T1, pre-test), immediately after the 4-hour training (T2, post-test), and 3 months after the training (T3, follow-up). Four independent research assistants collected and anonymized the data.

The study was approved by the Ethics Committee of the Dutch Association for Medical Education (NVMO Ethical Review Board; Dnr 2013/294).

7.2.2 Randomization

All students of the 2-year MANP program were randomized into an intervention group and 2 control groups using 2 strata with blocks of 4 by means of a blind drawing of sealed opaque envelopes. Randomization was performed by an independent research assistant. Strata were made for academic year (first year versus second year) and working field (somatic hospital care versus psychiatric care, primary care, rehabilitation care, geriatric care and palliative care). The control groups consisted of one group with a pre-test (C^+ group) and one group without a pre-test (C^- group) to analyze a testing effect of the questionnaire; the ICF survey and learning assessment tool.[18] For every 2 persons in the intervention group there was one person in the C^+ group and one person in the C^- group.

7.2.3 Intervention

The intervention was a 4-hour instructor-led discussion-based training in using the ICF. This training was part of an existing ICF training course developed and given over the past several years in the Netherlands.[22] The instructor (HAS) is a nurse as well as a teacher. The format of the training is based on the concept of meaning and application-oriented learning,[23] indicating that the training appeals to the experience of health care professionals and focuses on the practical application of the ICF in patient care. Short lectures were interspersed with group assignments and interaction between students and instructor. The goal of the present training is to provide students of the MANP with knowledge and skills related to the ICF, enabling them to learn about the ICF's practical applications and potential utilization in daily practice. The knowledge content of the course included: a conceptual overview of using the concept of functioning in health care; basic concepts related to the ICF (conceptual model of health, components, categories, and qualifiers); ICF core sets[b]; inking rules; and some simple clinical vignettes to explain what using the conceptual model and the standard terminology of the ICF entails. The skills content of the course included exercises in making clinical vignettes based on participants own professional settings. The exercises demonstrated how the application of the conceptual model and the standard terminology of the ICF can be applied throughout the health care process.

The control groups received a training in diabetes. Break times during the training were scheduled separately in order to prevent contact between the ICF group and the control groups so as to minimize information bias.

7.2.4 Measures

Data on students' learning competencies including ICF-related attitude, knowledge and skills, were collected with the ICF survey and learning assessment tool developed by Reed et al.[18] This tool consists of an attitude section, a knowledge section and a skills section.

The attitude section contains 12 statements on the construct of usefulness (2 statements) and the construct of mastery (10 statements). The level of agreement (5-point Likert scale) was summed for the 2 subscales (range: 2 to 10; 10 to 50, respectively) as well as for the total attitude scale (range 12 to 60). The knowledge section contains of 15 questions, including true/false questions and multiple choice questions. The percentage of knowledge questions answered correctly was calculated (range 0 to 15). The skills section contains 38 ICF categories classified in body functions (8 categories), activity and participation (21 categories), and external factors (9 categories), which have to be coded with qualifiers to a patient case. The percentage of agreement with a key-coding that had been established by 2 ICF experts coders (HAS and HN) was calculated for the 3 subscales separately (range 0

---

[b] An ICF core set is a selected set of categories out of the whole ICF, related to a specific health condition. This set can serve as a minimal standard for the assessment and reporting of functioning and health for that specific health condition.[31]

to 8; 0 to 21; 0 to 9, respectively) as well as for the total skills scale (range 0 to 38).

A higher score on the scales indicates a more positive attitude, more knowledge, and better skills. The ICF survey and learning assessment tool has not been tested yet for psychometric properties. A factor analysis has been performed for the items of the attitude scale, resulting in the constructs usefulness and mastery.[18]

Students in the ICF group and the C^+ group filled out the survey and learning assessment tool 3 times (T1, T2 and T3) and students of the C^- group 2 times (T2 and T3). The C^- group completed a questionnaire about diabetes at T1 (data not presented).

Questions about student characteristics such as gender, age, and working field, as well as questions about prior exposure to the ICF, were added to the first assessment of each group.

The primary outcome measure was perceived usefulness of the ICF, a subscale of the attitude scale, dichotomized into ≤ 6 or > 6. This measure is similar to the measure in the study of Reed et al.,[18] which was the first study with sample size calculation. Secondary outcome measures were knowledge, skills (total scale and 3 subscales), and attitude (total scale and 2 subscales: usefulness and mastery) as continuous variables.

7.2.5 Sample size calculation

The sample size was estimated based on the assumption that in the intervention group 29% of subjects would have changed to a score on the usefulness scale > 6, whereas this percentage would be 0% in the control group.[18] With an α value of 0.05 and 80% power, this difference results in a sample of 22 students in the intervention group and 22 students in the control group (11 C^+ group; 11 C^- group). Given the dropout rate of 15% of students in the MANP program, the non-participation rates, and the missing data, we decided to include all enrolled students (*n* = 74).

7.2.6 Statistical analysis

The data were expressed as mean values (standard deviation or 95% confidence interval) because they were normally distributed on Probability Plots and percentages. Testing effect was evaluated between the C^+ group and the C^- group. The chi-square test was applied for analysis of usefulness scores (≤ 6 or > 6). Independent-samples *t*-test was used to analyze the secondary outcome measures for the between-groups comparison and the difference in change scores between T1 and T2 and between T1 and T3. Paired *t*-test was used for the within-group analysis. Effect sizes statistics (*d* or Phi (φ)) were calculated and assessed against Cohen's criteria (*d* 0.2 or φ 0.1 = small, *d* 0.5 or φ 0.3 = medium, *d* 0.8 or φ 0.5 = large).[24] A *p*-value < 0.05 was considered statistically significant. Data were analyzed using IBM Statistical Package for the Social Sciences (v.22.0).

7.3 Results

Of the 74 students scheduled for testing an educational concept, 36 students were allocated to the experimental group (ICF group), 19 students to the C^+ group and 19 students to the C^-group. Nine students dropped out (did not attend the training) and a further nine students did not give informed consent.

Data of 56 students were included for analysis. Fifty-two out of the 56 students, completed all questionnaires. Four students completed only the first 2 questionnaires (Figure 7.2).

7.3.1 Baseline characteristics

The mean age of the participants was 40 years (SD 10). The majority were female (84%; *n* = 47); two-thirds were first-year students; and one-third were second year students (Table 7.1).

Table 7.1 Baseline characteristics of intervention group (ICF), control group with pre-test (C^+) and control group without pre-test (C^-).

	Total (n = 56)	**ICF-group (*n* = 23)**	**C^+ group (*n* = 16)**	**C^-group (*n* = 17)**	***p*-value**
Gender (female), *n* (%)	47 (84)	18 (78)	13 (81)	16 (94)	0.35*
Age, years, mean (SD)	41 (10)	38 (10)	44 (6)	40 (10)	0.18#
Academic year 1st *n* (%)	35 (63)	16 (70)	10 (63)	9 (53)	0.57*
Working field A *n* (%)	24 (43)	11 (48)	6 (38)	7 (41)	0.84*

SD: standard deviation; working field A: somatic hospital care;
*Pearson chi-square test exact; #ANOVA.

Approximately half of the participants were employed in somatic hospital care, and the other half were employed in psychiatric care, primary care, rehabilitation care, geriatric care, and palliative care. Between consent givers

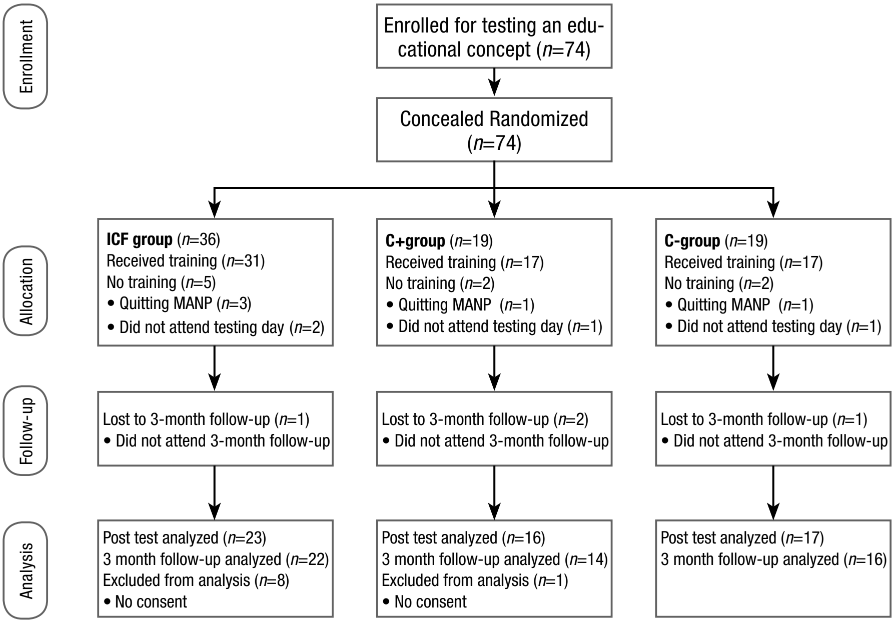


Figure 7.2 Flow chart of the randomized controlled trial. ICF, intervention group; C^+, Control group with pre-test, C^-, control group without pre-test.

(n = 56) and non-consent givers (n = 9), no statistically significant differences were found in age (p = 0.47), gender (p = 0.70), academic year (p = 0.10), and working field (p = 0.93). At baseline (T1), 55% (n = 31) of the students reported they had heard about the ICF before, 26% (n = 14) reported they had read parts of the ICF, and 3 students (6%) reported that they currently used or had used the ICF in clinical practice. No significant differences were found in baseline characteristics between the ICF-group and control groups (Table 7.1).

No testing effect was found between the C^+ group and the C^- group. Chi-square test indicated no significant difference in the primary outcome measure, the usefulness score (p = 0.18), or in the secondary outcome measures (Appendix). The control groups were therefore considered as one in the analysis. To evaluate the difference between the pre-test and the follow-up, the post-test of the C^- group was considered as pre-test.

No significant differences were found in outcome measures between the ICF group and the control group at baseline (T1), except for the skills total scale (Table 7.2). The ICF group had significantly better skills compared with the C^+ group (p = 0.04).

Table 7.2 Outcome measurements of knowledge, skills and attitude at the 3 measurement points and comparison of the change scores between the measurements over time and effect size of change between the ICF group and the Control group.

	T1= Pre-test		**T2= Post-test**		**T3= Follow up**		**Differences over time between ICF and C**			
							Change		Effect size	
Scales	ICF *n*=22	C^+ *n*=16	ICF *n*=22	C *n*=32	ICF *n*=22	C *n*=32	T1-T2	T1-T3	T1-T2	T1-T3
	mean (sd)	mean (sd)	mean (sd)	mean (sd)	mean (sd)	mean (sd)	mean (se)	mean (se)	*d*	*d*
Knowledge (range 0-15)	3.2 (3.0)	3.1 (3.4)	11.3 (1.4)	4.7 (4.3)	9.8 (2.6)	4.7 (4.3)	7.7 (0.8)*	4.7 (0.9)*	3.6	1.4
Skills (total) (range 0-38)	16.6 (5.0)	13.1 (2.7)	15.1 (3.8)	14.7 (3.8)	17.3 (4.0)	14.7 (3.8)	-2.2 (1.9)	0.4 (1.8)	-0.6	0.1
Functions (range 0-8)	3.4 (1.3)	2.6 (1.6)	3.6 (1.6)	2.3 (1.4)	3.1 (1.7)	2.3 (1.4)	-0.3 (0.6)	-0.6 (0.7)	-0.2	-0.3
Act. & Part. (range 0-21)	7.8 (2.7)	7.0 (2.3)	7.1 (2.7)	6.7 (2.3)	7.9 (2.7)	6.7 (2.3)	-1.2 (1.0)	0.3 (1.1)	-0.5	0.1
Environ. (range 0-9)	5.0 (2.6)	4.3 (2.4)	4.7 (1.8)	5.4 (1.9)	6.1 (1.2)	5.4 (1.9)	-0.4 (0.7)	0.5 (0.8)	-0.2	0.2
Attitude (total) (range 12-60)	31.2 (7.9)	32.4 (7.4)	41.7 (6.6)	30.0 (8.8)	35.7 (9.6)	30.0 (8.8)	12.1(1.9)*	5.3 (2.2)*	2.1	0.7
Usefulness (range 2-10)	6.6 (1.3)	6.3 (1.5)	7.7 (1.4)	6.31 (1.7)	7.0 (1.5)	6.31 (1.7)	1.7 (0.4)*	0.4 (0.4)	1.4	0.3
Mastery (range 10-50)	24.6 (7.5)	26.1 (6.4)	34.1 (5.8)	23.7 (7.7)	28.7 (8.6)	23.7 (7.7)	10.4(1.9)*	4.9 (2.0)*	1.9	0.7

Range scales: higher score means more knowledge, better skills or more positive attitude; ICF, intervention Group; C^+, control group with pre test; C, control group; sd, standard deviation; se, standard error; *$p < 0.05$-value (2-tailed); *d*, Cohens'*d*; Note: both control groups are presented combined the results differ with respect to Figure 7.3, in which both control groups were presented separately.

7.3.2 Primary learning outcome measure: the dichotomous variable usefulness score > 6

Between T1 and T2, 48% (*n* = 10) of the students in the ICF group changed from a score on the usefulness scale from ≤ 6 to > 6, compared with 0% in the control group (Table 7.3). At T2, significantly more students in the ICF group (86%; *n* = 19) had a usefulness score > 6 compared with the control group (47%; *n* = 15).

Between T1 and T3, 33% (*n* = 7) of the students in the ICF group changed from a score ≤ 6 to > 6, compared with 14% (*n* = 4) in the control group (Table 7.3). At T3, the differences between students scoring > 6 on usefulness in the ICF group (55%; *n* = 12) and the control group (48%; *n* = 14) were no longer significant.

Table 7.3 Comparison of the change in percentage of students in the ICF group and the Control group scoring > 6 on usefulness over time and effect size of change between groups.

	T1-T2 (*n*=36)				T1-T3 (*n*=50)			
change	**ICF group**	**C^{+} group$^{\#}$**	***p****	**effect size φ**	**ICF group**	**C group**	***p****	**effect size φ**
increase	48% (10)	0% (0)	0.002	0.6	33% (7)	14% (4)	0.054	0.3
no change	43% (9)	93% (14)			38% (8)	72% (21)		
decrease	9% (2)	7 % (1)			29% (6)	14% (4)		

T1: pre-test; T2: post-test; T3: follow-up; ICF: intervention group; C: Control group; $^{\#}$data only for control group with pre-test;**p* value (Pearson chi-square Test Exact); φ, Phi coefficient; Note: increase: from ≤ 6 to > 6; no change: remains in the same class; decrease: from > 6 to ≤ 6.

7.3.3 Secondary learning outcome measures: the continuous variables knowledge, skills, and attitude

The mean change scores (T1 to T2 and T1 to T3) of knowledge, attitude-total, and mastery differed significantly between the ICF group and the control group (*p* < 0.001 to 0.02: *d* ranging from 0.7 to 3.6) (Table 7.2).

Similar to the dichotomous results, the mean change score on usefulness differed significantly compared with the control group between T1 and T2 (*p* < 0.001; *d* = 1.4) but not significantly between T1 and T3 (*p* < 0.38; *d* = 0.3). Figure 7.3 summarizes the mean usefulness score over time for the ICF group and both control groups.

The mean change score on skills, measured with total scale as well as with subscales, did not differ significantly between the ICF group and the control group between the different measurement points.

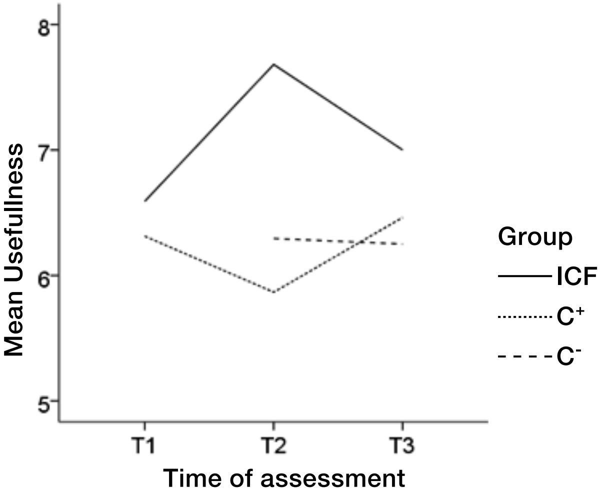


Figure 7.3 The mean usefulness score presented at baseline (T1), immediately after the intervention (T2), and at 3- months follow-up (T3). Higher scores indicate more usefulness. ICF, intervention group; C$^+$, control group with pre-test, C$^-$, control group without pre-test. Note: both control groups are presented separately; the results differ with respect to Table 7.2, in which both control groups were combined.

7.4 Discussion

The aim of this randomized controlled trial was to test the effects of a 4-hour instructor-led training in using the ICF on perceived usefulness of the ICF in MANP students. Perceived usefulness was the primary outcome measure.

Our findings demonstrated that perceived usefulness of the ICF increased significantly immediately after a 4-hour instructor-led training in using the ICF in the intervention group (ICF group) compared with the control group. At 3-months follow up, the usefulness score of the ICF group was no longer statistically significantly different from the control group. In the ICF group, the secondary outcome measures of knowledge, attitude total-scale, and mastery were significantly increased compared with the control group at both measurement points after the training. ICF-related skills were not affected by the training.

A large percentage of students in the ICF group considered the ICF to be useful immediately after the training compared with the control group. The large effect size indicates that the training positively and substantially affected students' attitude toward the ICF. If the ICF is to be incorporated successfully in the curriculum of the MANP, a positive attitude toward the ICF is important, for attitude is conditional to cognitive and skill-based learning outcomes.[21] In addition, a positive attitude toward the ICF implicates support for directing the goal of health service interventions away from disease toward a broader scope of health care provisions and involvement in life situations.[25-27]

Similar findings related to attitude were reported previously in a study showing that usefulness scores increased after an short instructor-led training to 8.2.[18] Our large training effect may be explained by the pre-test scores, in which the mean usefulness score was 6.6, compared with 7.9 in the other study. The likelihood of improvement was therefore larger in our study.

In the C^+ group a negative trend in perceived usefulness of the ICF was found at T2 (Figure 7.3). This trend may be explained by the disappointment or frustration of the students who had to fill out the ICF survey for the second time without receiving an ICF training. Another explanation might be found in the effect of the questionnaire itself. Subjects may have experienced the ICF as complex after completion of the questionnaire, which is supported by the negative trend in the C^- group between T2 and T3 (Figure 7.3). This trend corresponds to previous findings that a training in using the ICF is necessary for understanding its complexity.[18,20,25,28,29] Perceptions about the usefulness of the ICF, for example, changed from 'too complex to apply' to 'having advantages' during a 2-year implementation process.[25]

In the ICF group a negative trend in usefulness scores was found between T2 and T3. This trend may be explained by difficulties the students experienced in their attempts to use the ICF in clinical practice during the 3-month follow-up period. Support in using the ICF was absent during this period. Similar findings were seen after self-directed ICF training programs,[18,28] which showed that 29% of the students had lower scores on usefulness (≤ 6) after the training.[18] The trend of a small increase in scores on usefulness of the control group in the current study may suggest that students of the control group have spoken with students of the ICF group and were influenced by the positive attitude of the ICF group immediately after the training.

In contrast to usefulness scores, mastery scores increased significantly at both time points compared with the control group. This finding justified the 2 different constructs of the attitude scale and corresponds to previous outcomes.[18]

The significant increase in knowledge after the training with a large effect size indicates that the training was effective, even 3 months after training. The outcomes correspond to all other training programs,[18,25,27] indicating that increase in knowledge is a guaranteed outcome regardless of the type of training program. This finding can be explained by the fact that the ICF is new to health care professionals in clinical practice. Consequently, the participants have limited knowledge of the ICF prior to the training. In the control group knowledge increased to a mean of 4.7 at T3; this may suggest that students became interested in the ICF, during the follow up period, which confirmed the previously found positive attitude toward the ICF that started with gathering knowledge by reading ICF-related information.

Skills related to the ICF were not affected by the training, which could be related to the patient case used in our study: an elderly stroke patient in a primary care setting. This patient case may not have appealed to all students. Moreover, some studies have suggested that to increase skills related to the ICF a longer ICF training program of at least 2 days (12 hours) is required.[18,19]

A limitation of the current study concerns the number of students that did not give consent for using the data. This was an unexpected finding because MANP students have had high participation rates in previous studies. The non-disclosure of the topic of the training and the explicitly requested consent could explain the non-consent rate. Nevertheless, our sample size was still sufficient. Some students gave consent after the debriefing at the end of the study when the study procedure was explained, and these students were included as well.

Another limitation is that the survey tool used in the study was not fully tested for psychometric properties. When data collection began, no other assessment instruments had been published for evaluating ICF training. Only one questionnaire was found that tested knowledge and understanding of the use of the ICF.[19] In the future development of a measurement instrument for ICF training, the skills section requires special attention because of the specific requirements for a patient case which should reflect the students' clinical experiences with patients.

Finally, because we wanted to analyze test effects, samples sizes of the control group differed per measurement which prevented us from performing a repeated measures ANOVA. The strength of this study is that we have tested and measured the effect of an ICF training in a randomized controlled trial, which means that the observed effects can be attributed to the ICF training itself.

In conclusion, a 4-hour instructor-led ICF training has a positive influence on learning outcomes in MANP students. This short training program leads to a more positive attitude towards the ICF, including improved perceived usefulness of the ICF and more ICF-related knowledge. This is relevant for the implementation of the ICF in the curriculum, because a positive attitude is a prerequisite for effective cognitive and skill-based learning outcomes. To establish an increase in ICF-related skills, a comprehensive ICF training should be incorporated throughout the curriculum of the MANP. Also, additional studies are needed to evaluate extended training and to validate the findings.

Appendix Testing the effect of the ICF measurement instrument between both control groups.

Scales	**C^+ *n*=16**	**C^- *n*=17**	**Change**	**95% CI**
	mean (SD)	mean (SD)	mean (SD)	
Knowledge (range 0-15)	3.8 (3.9)	3.1 (3.6)	0.6 (1.3)	-2.0 to 3.3
Skills (total) (range 0-38)	14.2 (5.0)	13.8 (3.1)	0.4 (1.9)	-3.7 to 4.5
Functions (range 0-8)	3.2 (1.7)	3.5 (1.4)	0.4 (0.6)	-1.7 to 0.9
Act.& Part. (range 0-21)	7.2 (2.6)	6.9 (2.4)	0.2 (1.0)	-1.8 to 2.3
Environ. (range 0-9)	4.2 (2.6)	4.2 (2.0)	0.0 (0.9)	-1.9 to 2.0
Attitude (total) (range 12-60)	31.8 (8.3)	29.2 (8.7)	2.6 (3.0)	-3.6 to 8.7
Usefulness (range 2-10)	5.9 (2.0)	6.3 (1.6)	0.4 (0.6)	-1.7 to 0.9
Mastery (range 10-50)	25.9 (6.8)	22.9 (7.7)	3.0 (2.6)	-2.3 to 8.2

Range scales: higher score means more knowledge, skills, or positive attitude; C^+, control group with pre test; C^-, the control group without pre-test; CI, Confidence Interval of the difference.

References

1. World Health Organization. *International Classification of Functioning, Disability and Health: ICF.* 1st ed. Geneva: World Health Organization, 2001.
2. World Health Organization. *International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10).* 10th ed. Geneva: World Health Organization, 1992.
3. Stucki G, Cieza A and Melvin J. The international classification of functioning, disability and health: a unifying model for the conceptual description of the rehabilitation strategy. *J Rehabil Med* 2007; 39(4): 279-285.
4. Baumann A, Deber R, Silverman B and Mallette C. Who cares? Who cures? The ongoing debate in the provision of health care. *J Adv Nurs* 1998; 28(5): 1040-1045.
5. Kilpatrick K, Lavoie-Tremblay M, Ritchie JA, Lamothe L and Doran D. Boundary work and the introduction of acute care nurse practitioners in healthcare teams. *J Adv Nurs* 2012; 68(7): 1504-1515.
6. Partin B. Who, if not you, will determine NP scope of practice? *Nurse Pract* 2006; 31(2): 6.
7. *VBOC- Nursing occupational structure and training-continuum (Verpleegkundige Beroepenstructuur en OpleidingsContinuum).* General and specific competencyprofiles of the nurse practitioner (Algemeen Competentieprofiel en specifieke deelprofielen Verpleegkundig Specialist). 2008.
8. Bryant-Lukosius D and DiCenso A. A framework for the introduction and evaluation of advanced practice nursing roles. *J Adv Nurs* 2004; 48(5): 530-540.
9. Bryant-Lukosius D, DiCenso A, Browne G and Pinelli J. Advanced practice nursing roles: development, implementation and evaluation. *J Adv Nurs* 2004; 48(5): 519-529.
10. McNamara S, Giguere V, St-Louis L and Boileau J. Development and implementation of the specialized nurse practitioner role: use of the PEPPA framework to achieve success. *Nurs Health Sci* 2009; 11(3): 318-325.
11. Gardner G, Chang A and Duffield C. Making nursing work: breaking through the role confusion of advanced practice nursing. *J Adv Nurs* 2007; 57(4): 382-391.
12. Lowe G, Plummer V, O’Brien AP and Boyd L. Time to clarify - the value of advanced practice nursing roles in health care. *J Adv Nurs* 2012; 68(3): 677-685.
13. Antonovsky A. The salutogenic model as a theory to guide health promotion. *Health Promot Internation* 1996; 11(1): 11-18.
14. Zeyer A. Salutogenesis and pathogenesis - a change of paradigm viewed from the standpoint of modern physics. *Sozial-Und Praventivmedizin* 1997; 42(6): 380-384.

15. Bengel J, Strittmatter R and Willmann H. *What keeps people healthy? The current state of discussion and the relevance of Antonvsky's salutogenetic model of health.* 10 th ed. Germany: Federal Centre for Health Education - (FCHE), 1998.
16. Elsom S, Happell B and Manias E. Mental health nurse practitioner: expanded or advanced? *International Journal of Mental Health Nursing* 2005; 14(3): 181-186.
17. Stallinga HA, Roodbol PF, Annema C, Jansen GJ and Wynia K. Functioning assessment vs. conventional medical assessment: a comparative study on health professionals' clinical decision-making and the fit with patient's own perspective of health. *J Clin Nurs* 2014; 23(7-8): 1044-1054.
18. Reed GM, Dilfer K, Bufka LF, Scherer MJ, Kotze P, Tshivhase M, et al. Three model curricula for teaching clinicians to use the ICF. *Disabil Rehabil* 2008; 30(12-13): 927-941.
19. Pless M, Ibragimova N, Adolfsson M, Bjorck-Akesson E and Granlund M. Evaluation of In-Service Training in using the ICF and ICF Version for Children and Youth. *J Rehabil Med* 2009; 41(6): 451-458.
20. Leonardi M, Bickenbach J, Raggi A, Sala M, Guzzon P, Valsecchi MR, et al. Training on the International Classification of Functioning, Disability and Health (ICF): the ICF-DIN Basic and the ICF-DIN Advanced Course developed by the Disability Italian Network. *J Headache Pain* 2005; 6(3): 159-164.
21. Kraiger K, Ford J and Salas E. Application of Cognitive, Skill-Based, and Affective Theories of Learning Outcomes to New Methods of Training Evaluation. *J Appl Psychol* 1993; 78(2): 311-328.
22. *WHO Collaborating Centre for the FIC in The Netherlands.* ICF-training in the Netherlands. WHO *Familiy of International Classifications (FIC) Newsletter* 2012; (Volume 10,number 2): 7.
23. Bie dD, Gerritse J. *Onderwijs als opdracht.* 10th ed. Houten/Diegem: Bohn Stafleu Van Loghum, 1999.
24. Cohen J. *Statistical power analysis for the behavioural sciences.* 2nd ed. New York: Academic Press, 1988.
25. Pless M and Granlund M. Implementation of the International Classification of Functioning, Disability and Health (ICF) and the ICF Children and Youth Version (ICF-CY) Within the Context of Augmentative and Alternative Communication. *Augmentative and Alternative Communication* 2012; 28(1): 11-20.
26. Rauch A, Cieza A and Stucki G. How to apply the International Classification of Functioning, Disability and Health (ICF) for rehabilitation management in clinical practice. *European Journal of Physical and Rehabilitation Medicine* 2008;

44(3): 329-342.

27. Wade D and Halligan P. New wine in old bottles: the WHO ICF as an explanatory model of human behaviour. *Clin Rehabil* 2003; 17(4): 349-354.
28. Francescutti C, Fusaro G, Leonardi M, Martinuzzi A, Sala M, Russo E, et al. Italian ICF training programs: describing and promoting human functioning and research. *Disabil Rehabil* 2009; 31: S46-S49.
29. Rentsch HP, Bucher P, Dommen Nyffeler I, Wolf C, Hefti H, Fluri E, et al. The implementation of the 'International Classification of Functioning, Disability and Health'(ICF) in daily practice of neurorehabilitation: an interdisciplinary project at the Kantonsspital of Lucerne, Switzerland. *Disabil Rehabil* 2003; 25(8): 411-421.
30. International Council of Nurses. The Scope of Practice, Standards and Competencies of the Advanced Practice Nurse. *ICN Regulation Series, International Council of Nurses, Switzerland* 2008.
31. Stucki G and Grimby G. Applying the ICF in medicine. *J Rehabil Med* 2004; (44 Suppl): 5-6.

“Langer leven doen we al, nu nog beter.”

Trouw, 4 januari 2014, Marcel Levi.

8

General discussion

8.1 Introduction

The results of the studies presented in this thesis contribute toward the implementation of the concept of functioning in health care. The results are relevant to current health care provision, which faces an aging population that has one or more non-communicable chronic diseases. In this respect, a person's functioning seems the most promising target for supporting his/her well-being.[1] The concept of functioning also fits the proposed definition of health, which states that "health is the ability to adapt and self-manage in the face of social, physical, and emotional challenges".[2]

The World Health Organization (WHO) uses the term functioning as a basic concept in the International Classification of Functioning, Disability and Health (ICF).[3] The ICF was published in 2001 by the WHO as the international standard terminology for functioning and environmental factors. It was published together with the conceptual model of health (Figure 8.1), which is based on the biopsychosocial model.[4]

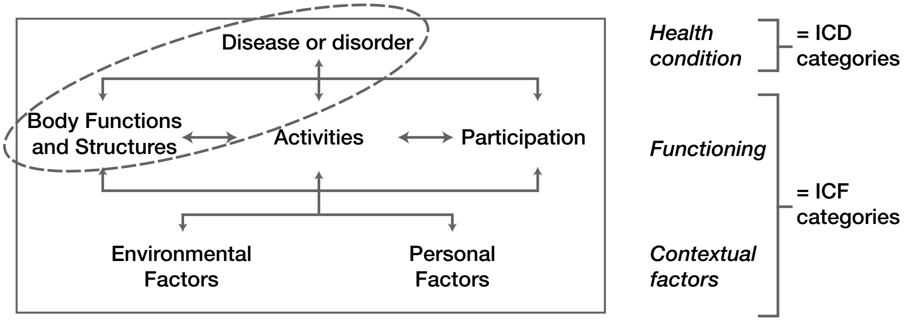


Figure 8.1 WHO's conceptual model of health representing the interactions between the components[a] of the health status.[4] Note the partial perspective of health based on the biomedical model (oval) vs the holistic perspective of health based on the biopsychosocial model (rectangle).[5] ICD: International Classification of Diseases; ICF: International Classification of Functioning, Disability and Health.

Current health care is based on the biomedical model, which focuses on diseases or disorders in body functions and structures (Figure 8.1).

---

[a] Components refer to all elements of the conceptual model including body functions and structures, activities and participation as well as environmental factors, personal factors, and health condition.

Implementation of functioning in health care means that the current *biomedical* focus on health care has to be broadened to a biopsychosocial focus. In a *biopsychosocial* model, which is based on the holistic perspective,[6,7] all components of the conceptual model of health are taken into account to reach a person's best state of health.

The aim of this thesis was to explore the inclusion of the concept of functioning as an important focus in health care by means of applying the standard terminology of the ICF and the conceptual model of health. The standard terminology aims to improve communication, and the conceptual model aims to facilitate clinical decision-making.[4] By studying these two topics as two inseparable but distinct aspects of functioning, specific information can be obtained, relevant for developing effective strategies for the implementation of the concept of functioning in health care.
To achieve this aim, three research questions were formulated:

1. To what extent does language ambiguity regarding functioning exist in clinical practice and research and what are the consequences for communication?
2. To what extent does the use of standard terminology for functioning and the conceptual model of health facilitate clinical decision-making and what are the effects on clinical practice?
3. To what extent are health care professionals focused on functioning in health care and what is their opinion on the usefulness of this concept in their clinical practice?

8.2 Main findings

To answer the first research question, two studies were conducted. The first study is a literature review that analyzed the use of ambiguous language regarding functioning in clinical practice (Chapter 2). The second study is a cross-sectional survey that analyzed the effects of different assessment tools regarding participation as an aspect of functioning in 677 patients with a neuromuscular disease (Chapter 3).

The literature review used the standard terminology of the ICF to identify aspects of functioning related to language use in clinical practice. The results demonstrated that language ambiguity regarding patients' functioning existed. However, problems related to language ambiguity were not found. The absence of problems experienced by health care professionals may explain the lack of success of many projects aimed at implementing standard terminology concerning functioning in clinical practice.[8]

The cross-sectional survey used the standard terminology of the ICF to identify the operationalizations of the concept of participation in six different assessment instruments. The conceptual model of health was used in a regression analysis in which participation was the dependent variable and the predictors were the components of disease, body functions, activities, and contextual factors. We found that participation was predicted by different components of the conceptual model depending on the operationalization of participation. To be able to compare research outcomes, consensus on the definition of the concept of participation is needed. It was concluded that participation is an ambiguous concept in research, and this ambiguity makes evidence-based decisions directed at enhancing participation difficult.

The results of these two studies demonstrated that functioning is still an ambiguous concept in clinical practice and in research. Although we did not find negative consequences of language ambiguity for clinical practice, research was hindered by language ambiguity.

To answer the second research question, two studies were conducted: a qualitative study in which the content validity of the ICF core set[b] for neuromuscular diseases (NMD) was examined (Chapter 4); and a study in which data from a randomized clinical trial in 81 patients with multiple sclerosis (Chapter 5) were analyzed regarding clinical decision-making.

The qualitative study linked concepts of existing disease-specific Health-Related Quality of Life (HRQOL) questionnaires to the ICF standard terminology and compared these with the initial ICF core set for patients with chronic neurological disorders. We found that the concepts in the existing HRQOL questionnaires were covered by the initial ICF core set. In fact, the NMD core set covered an even broader scope of health-related concepts in patients with neuromuscular disease compared with the concepts in the HRQOL questionnaires. These concepts were relevant to clinical decision-

---

[b] An ICF core set is a selected set of ICF categories, related to a specific health condition. This set can serve as a minimal standard for the assessment and reporting of functioning and health for that specific health condition.[57]

making, especially regarding participation and environmental factors.

The study described in chapter 5 investigated the effects of using the ICF core set for clinical decision-making in practice. The Multiple Sclerosis Impact Profile (MSIP),[9,10] a validated ICF core set for patients with multiple sclerosis, was used in a randomized controlled trial testing the effects of the use of a functioning assessment in combination with a biomedical assessment in 81 patients with multiple sclerosis.[11] Compared with the biomedical assessment, the combined assessment resulted in the registration of a significantly higher number of problems experienced by patients in the components participation and environmental factors and a significantly higher number of professional health care activities related to these components. Use of the functioning assessment in combination with the biomedical assessment resulted in a positive correlation between registered problems by health care professionals and patients' self-reported problems, In contrast, use of the biomedical assessment alone resulted in several negative correlations.

Based on these two studies, it can be concluded that the standard terminology of the ICF and the conceptual model of health facilitate clinical decision-making in practice and have positive effects on the promotion of patients' health, especially regarding the components participation and environmental factors.

To answer the third research question, two studies were conducted. First, an exploratory mixed-method study was performed that analyzed 413 graduate theses of Master of Advanced Nursing Practice (MANP) students. The second study concerned a randomized controlled trial that analyzed the effects of a training in using the ICF in 74 students of the MANP. The participants of both studies were nurse practitioners because they are assumed to integrate cure (disease) and care (functioning) in clinical practice.[12,13]

The mixed-method study examined the professional focus of graduates of the MANP by analyzing graduate theses in terms of cure and care (Chapter 6). The topics of the graduate theses were classified in the components of the conceptual model of health. About half of the graduate theses could be classified in the conceptual model. Of the theses that were classified in the conceptual model, approximately half were focused on cure, one-third on the intersection of cure and care, and the remaining number on care. This indicates that only a minority of the nurse practitioners were focused on the intersection of cure and care in their MANP graduate theses. Therefore, to support the assumed integration of cure and care in clinical practice by nurse practitioners, the conceptual model of health and the standard terminology for functioning should be included in their education program.

The final study (Chapter 7) explored the opinion of students enrolled in the MANP regarding the usefulness of the ICF in clinical practice. The effects of a short ICF training were studied in a randomized controlled trial. The primary outcome measure was attitude toward the ICF, for a positive attitude is a prerequisite for effective learning.[14] The perceived usefulness of the ICF was a subscale of attitude. The ICF training resulted in a significantly larger increase in perceived usefulness of the ICF immediately after the ICF training compared with the control group. At 3 months follow-up, however, there was no longer a statistically significant difference between both groups. These findings indicate that while a short ICF training increases usefulness, a more comprehensive ICF training is required to establish long-term effects.

Based on these two studies, it can be concluded that a limited number of MANP graduates were focused on functioning, which was reflected by their choice of thesis topic. Training in using the ICF, including the conceptual model of health, increases the perceived usefulness of the ICF in MANP students.

8.3 Reflections on this thesis

Functioning has been recognized and operationalized by the ICF, and numerous research projects on the application of the ICF have been conducted.[15,16] However, the inclusion of functioning as a focus in health care had yet to be explored.

Implementing functioning in health care is multidimensional. Many aspects are involved, including organization of health care, education of professionals, guidelines, tools, effects on patients, and financial issues.[17] This thesis only addresses six aspects. It builds on previous studies in which the application of the ICF was aimed at linking measurement instruments to the ICF[18,19] and at developing ICF core sets.[20] In the last decades more than 30 ICF core sets have been developed[21,22] and several instruments are linked to the ICF.[23-29] The overall conclusion of previous studies is that the ICF provides a comprehensive and complete standard terminology in a convenient structure for the description of functioning.[15,16] This conclusion formed the basis for our research, which aimed to extend the application of the ICF to the focus on the concept of functioning in health care. The exploration of the use of the standard terminology of the ICF and the use of the conceptual model of health as two distinct but inseparable topics makes this thesis unique. The implementation of the ICF in clinical practice has not been successful always.[30,31] This lack of success was confirmed in our study (Chapter 2). The results of this thesis demonstrated that making a clear distinction between the use of the standard terminology of the ICF and the use of the conceptual model is a promising approach to the implementation of the concept of functioning in health care.

A limitation of this thesis concerns the generalizability of the results. The results related to assessment tools are valid for patients with neuromuscular diseases (Chapter 4) and patients with multiple sclerosis (Chapter 5). The results related to the focus on and the opinions on functioning are valid for nurse practitioners (Chapter 6 and 7). With regard to the results on language ambiguity (Chapter 3), comparable outcomes were found in a study in patients with chronic liver failure.[32]

8.4 Synthesis of findings

This thesis addresses the distinction between use of the standard terminology and use of the conceptual model of health when focusing on functioning in health care.

Emphasizing the use of the conceptual model could be the solution for the lack of success of the implementation of ICF in clinical practice.[30] In this respect, we endorse the observation of Dahl[33] that the title of the ICF might be misleading. What exactly is meant by the use of the ICF in clinical practice? The standard terminology or the conceptual model? Furthermore, the conceptual model is not merely confined to the ICF because health conditions (the ICD) are also included. Preferably, the conceptual model of health and the standard terminology of the ICF should be separated by the WHO. Such a separation also warrants a consideration of the specific qualities of both the standard terminology of functioning and the conceptual model of health as well as their relationship.

The value of standard terminology[c] has been acknowledged for the fields of research and data aggregation[34] (Chapter 3 and 4). A well-known nursing adage states that "If we cannot name it, we cannot control it, practice it, teach it, finance it, or put it into public policy".[35] The standard terminology of functioning of the ICF provides the basis for naming, controlling, teaching and so forth.[4] For clinical practice, however, the use of unambiguous language is not a valid argument to introduce standard terminology, even when language ambiguity is present (Chapter 2).

A specific feature of the conceptual model of health concerns its fit with the biopsychosocial model. The biopsychosocial aspects are represented in the components of the conceptual model (Figure 8.1). The figure displays that the current *biomedical* model will be broadened to include the *biopsychosocial* model with the components activities and participation and contextual factors. The conceptual model is useful in clinical practice and supports the focus on functioning in health care provision (Chapter 5 and 7). To date, the biopsychosocial model is not incorporated in clinical practice despite its acknowledged relevance for health care.[7,17,36,37] A possible explanation could be the insufficient concreteness of the components of the biopsychosocial model. This holds especially true for those components related to the *psychosocial* extension of the *biomedical* model. The conceptual model of health and the terminology of the ICF can make these components more concrete. Social aspects, for example, are operationalized in the component of participation with ICF categories related to interpersonal interactions, major life areas, and community life. Both the standard terminology and the conceptual model of health are required for the implementation of functioning, i.e. the biopsychosocial model, in health care.

Clinical decisions should be the result of clinical reasoning,[38,39] which includes assessment, goal setting, interventions, and evaluation. The conceptual model of health and the standard terminology of functioning help professionals to focus on patients' biopsychosocial aspects in all these phases (chapters 5 and 7).

Finally, the mindset of health care professionals is not yet focused on functioning in health care (Chapters 4 and 6). In addition, a focus on

---

[c] A standard terminology is a selected set of terms, each with a discrete meaning, arranged in a specific structure aimed to provide unambiguous use of language with regard to a specific phenomenon.

functioning does not easily fit in with the current predominant biomedical health care system.[17,40] Health care professionals, including nurses, therapists, and physicians, deliver their care to patients by using tools and skills predominantly embedded within the biomedical model.[41] Tools (Chapters 4 and 5) and training (Chapter 7) related to functioning are therefore a prerequisite for health care professionals to be able to focus on functioning, i.e. the biopsychosocial model, in clinical practice.

8.5 Practical implications

The findings of this thesis have several implications for clinical practice, education, financing, and evaluation of health care as will be discussed below.

Clinical practice

The conceptual model of health enables health care professionals to address functioning in their clinical decision-making. In a *biopsychosocial* model, the goal setting of the patients themselves is the guiding principle, whereas disease and the related disability are the guiding principles in the *biomedical* model. The ICF enables health care providers to assess patients' goals in terms of functioning. This type of clinical decision-making requires the involvement of the patient and it gives patients the opportunity to consider, in cooperation with the health care professional, different solutions for health challenges.

Education

To implement the focus on functioning in health care, health care professionals have to be educated and trained. To make the implementation successful, a paradigm shift is needed from a biomedical orientation to a biopsychosocial orientation.[42] The education and training should include all health care professionals, not only physicians, nurses, and therapists, but also educators, politicians, administrators, and society at large. The implementation of the biopsychosocial model in clinical practice is challenging for health care professionals, especially for those who have not received training in biopsychosocial theory and its application.[43]

The main goal of the training is to provide participants with knowledge and skills that enable them to use the conceptual model and the standard terminology of the ICF as practical tools in daily practice.[44] A few training programs on the use of the ICF already exist,[43,45,46] including a program that was developed in the Netherlands.[47] This four-month training course consists of three instructor-led training days together with distance learning. Training groups consist of twelve participants and two teachers. For distance learning between the three course days (starting day, second day, and the final day), participants are assigned to one of the two teachers. The training focuses on the conceptual model and basic principles and structure of the ICF and the application of the standard terminology in different settings. Clinical cases from participants own professional settings are presented in the conceptual model using the standard terminology. Using these clinical vignettes is one of the most fruitful ways to demonstrate the differences between the *biomedical* model and the *biopsychosocial* model. Two clinical vignettes are illustrated in Figure 8.2.

Two patients with similar health conditions and impaired body functions differ in the component of participation and the environmental and personal factors. In addition, these patients differ in goal setting: the 80-year-old woman (Figure 8.2a) wants to be part of a community and keeps in touch with her children and grandchildren, whereas the 58-year-old man (Figure 8.2b) wants to be as independent as possible and to continue to work in his business. The status of functioning of these patients and their goal setting will account for the differences in the clinical decisions and the health care provision.

Financing

The main objective of adopting the conceptual model of health and the use of the standard terminology of functioning is better health related outcomes. The primary expected impact of using functioning in health care is that patients' health will improve despite their health condition. The focus on functioning relates to participation and well-being and responds to personal expectations, skills and abilities.[48]

To date, funding of health care is supported by case mix systems and models which are based on diseases (ICD) and medical interventions.[49] In the Netherlands, this model is called a DBC (Dutch: *Diagnose Behandel Combinatie*). A DBC is a predefined average care package, with a fixed price based on a specific medical diagnosis.[50] As a consequence, there is

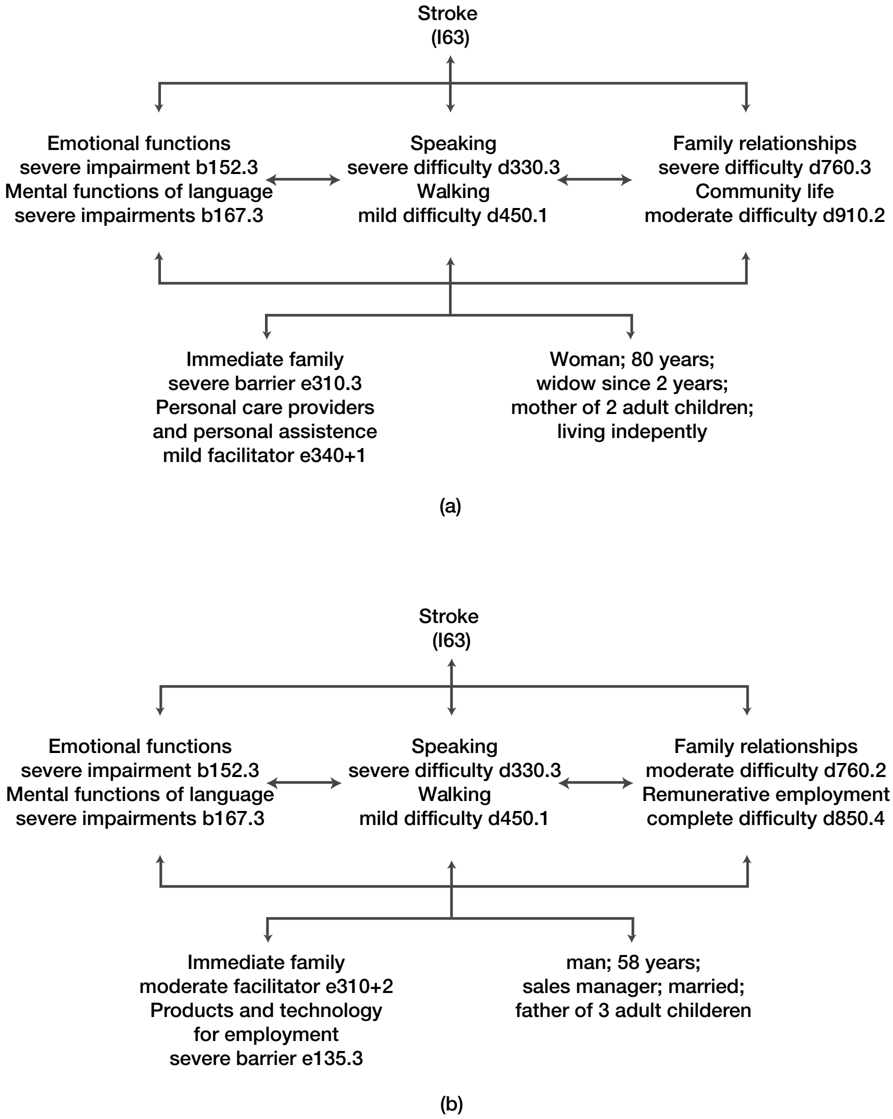


Figure 8.2 Clinical vignettes, illustrating the health status of two patients with the same health condition.

no financial incentive to achieve an improvement in functioning. To include functioning as an important focus in health care, the use of ICF categories for funding has to be explored.[49]

Evaluation of health care
While clinical practice is experiencing a shift from communicable diseases to non-communicable chronic diseases, and the health opinion is broadening its scope by focusing on ‘ability’, clinical practice is still using tools and skills based on the *biomedical* model.[41] A limitation is that the usefulness of the biopsychosocial model cannot be fully assessed until it is completely adopted and applied in clinical practice and research.[51] In order to evaluate the outcomes of this model, appropriate tools and interventions have to be developed. Decisions have to be made as to which intervention is needed to achieve a certain health status. When health care is evaluated in terms of disease, the best outcome is cure of the disease. The physician determines whether the outcome is reached. When health care is evaluated in terms of functioning, however, the best outcome depends on the patient and the goals he/she wants to achieve and has to be determined in cooperation with the patient.

8.6 Future research

This thesis contributes to the implementation of functioning as a focus in health care. Our findings have the following implications for future research:

- To improve the generalizability of our results, outcomes of a functioning assessment should be investigated and validated for other patient populations and other countries. This thesis provides evidence that functioning assessments based on ICF core sets in patients with multiple sclerosis lead to different clinical decisions compared with biomedical assessments (Chapter 5). The components of participation and environmental factors in particular were addressed. For generalization purposes, a number of the developed ICF core sets[3] should be tested for their effects on clinical decision-making in clinical practice. Future studies can use the electronic documentation forms available on the website of the ICF Research Branch (a partner of the WHO Collaborating Center for the Family of International Classifications (WHO-FIC) in Germany (at DIMDI).[52] The electronic forms facilitate the description of functioning based on ICF core sets for clinical practice. The forms are available in five languages, making international data collection possible.

- The existing core sets, including musculoskeletal core sets, cardiopulmonary core sets, and neurological core sets, are relevant to determining the influence of a given health condition on functioning. However, there are more aspects that influence functioning. The existing core sets have emerged from the *biomedical* perspective on health. New core sets should be developed that are related to other constructs relevant to functioning, for instance, dependency, employability, education level, mobility, or poverty.[53] Research on those constructs may provide a broader insight into interventions for improving a person's health from a *biopsychosocial* perspective.
- As described in the first chapter of this thesis, the salutogenetic perspective[54] on health focuses on how to stay healthy. More research is needed to identify the main factors of influence on health in relation to ability and disability. Persons who function successfully in daily life may provide additional insights. The LifeLines research performed at the University Medical Center Groningen (UMCG), for instance, offers the opportunity to research successful functioning in a heterogeneous population. Future studies should focus on environmental and personal factors in relation to successful functioning.
- The most important outcome related to the focus on functioning in health care is the effect of this focus on patients. To adequately and efficiently collect clinical data, mobile devices should be used.[55] The development of a mobile ICF application is currently in progress, and this application is expected to be implemented worldwide.[56] A mobile ICF application is very useful for collecting data related to functioning and contextual factors. Active involvement in and support of this kind of research is essential to make outcome evaluations of health improvement interventions possible.
- Education programs for health care professionals that focus on functioning have to be developed. Subsequently, their effects have to be determined. Further research is required to validate the ICF survey and learning assessment tool[45] used in this thesis. A validated measurement instrument for assessing learning outcomes is relevant to the development and evaluation of training and education programs.
- In this thesis the focus of nurse practitioners on the integration of cure and care was examined. For generalization purposes, however, the focus of other health care professionals should also be investigated. This

information is needed to make education and training programs related to functioning as comprehensive as possible.

8.7 Conclusions

This thesis explored the inclusion of functioning as a focus in health care by means of applying the ICF. It was found that use of the standard terminology of the ICF and the related conceptual model of health as two distinct but inseparable tools contributes to the implementation of the concept of functioning in health care.

Language ambiguity regarding functioning exists both in clinical practice and research. Negative consequences of language ambiguity were not found for clinical practice. However, language ambiguity has considerable consequences for research. The standard terminology of the ICF and the conceptual model of health facilitate clinical decision-making in practice and have positive effects on the promotion of patients' health, especially regarding patients' participation and environmental factors. Currently, MANP graduates are only focused on functioning to a limited extent, but a short training in using the ICF that includes the conceptual model of health increases perceived usefulness of the ICF in MANP students.

These findings have several implications for clinical practice, education, policy, and research. They offer potential ways to guide health care provision away from a narrow disease-based focus toward a broader focus that includes functioning as an aspect of health.

References

1. Madden R, Ferreira M, Einfeld S, Emerson E, Manga R, Refshauge K, et al. New directions in health care and disability: the need for a shared understanding of human functioning. *Aust N Z J Public Health* 2012; 36(5): 458-461.
2. Huber M, Knottnerus JA, Green L, van der Horst H, Jadad AR, Kromhout D, et al. How should we define health? *Br Med J* 2011; 343: d4163.
3. Bickenbach J, Cieza A, Rauch A and Stucki G editors. ICF Core Sets; manual for clinical practice. 10th ed. Göttingen, Germany: Hogrefe Publishing, 2012.
4. World Health Organization. *International Classification of Functioning, Disability and Health: ICF.* 1st ed. Geneva: World Health Organization, 2001.
5. Stucki G and Celio M. Developing human functioning and rehabilitation research. Part II: Interdisciplinary university centers and national and regional collaboration networks. *J Rehabil Med* 2007; 39(4): 334-342.
6. Engel GL. The need for a new medical model: a challenge for biomedicine. *Science* 1977; 196(4286): 129-136.
7. Engel GL. The clinical application of the biopsychosocial model. *Am J Psychiatry* 1980; 137(5): 535-544.
8. Sales AE, Bostrom A, Bucknall T, Draper K, Fraser K, Schalm C, et al. The Use of Data for Process and Quality Improvement in Long Term Care and Home Care: A Systematic Review of the Literature. *Journal of the American Medical Directors Association* 2012; 13(2): 103-113.
9. Wynia K, Middel B, Van Dijk JP, De Ruiter H, De Keyser J and Reijneveld SA. The Multiple Sclerosis Impact Profile (MSIP). Development and testing psychometric properties of an ICF-based health measure. *Disabil Rehabil* 2008; 30(4): 261-274.
10. Wynia K, Middel B, De Ruiter H, Van Dijk JP, De Keyser JHA and Reijneveld SA. Stability and relative validity of the Multiple Sclerosis Impact Profile (MSIP). *Disabil Rehabil* 2008; 30(14): 1027-1038.
11. Wynia K, Annema C, Nissen H, De Keyser J and Middel B. Design of a Randomised Controlled Trial (RCT) on the effectiveness of a Dutch patient advocacy case management intervention among severely disabled Multiple Sclerosis patients. *BMC Health Services Research* 2010; 10: 142-142.
12. Partin B. Who, if not you, will determine NP scope of practice? *Nurse Pract* 2006; 31(2): 6.
13. Kilpatrick K, Lavoie-Tremblay M, Ritchie JA, Lamothe L and Doran D. Boundary work and the introduction of acute care nurse practitioners in healthcare teams. *J Adv Nurs*

2012; 68(7): 1504-1515.

14. Kraiger K, Ford J and Salas E. Application of Cognitive, Skill-Based, and Affective Theories of Learning Outcomes to New Methods of Training Evaluation. *J Appl Psychol* 1993; 78(2): 311-328.
15. Jelsma J. Use of the International Classification of Functioning, Disability and Health: a Literature Survey. *J Rehabil Med* 2009; 41(1): 1-12.
16. Cerniauskaite M, Quintas R, Boldt C, Raggi A, Cieza A, Bickenbach JE, et al. Systematic literature review on ICF from 2001 to 2009: its use, implementation and operationalisation. *Disabil Rehabil* 2011; 33(4): 281-309.
17. van Dijk-de Vries A, Moser A, Mertens VC, van der Linden J, van der Weijden T and van Eijk JT. The ideal of biopsychosocial chronic care: how to make it real? A qualitative study among Dutch stakeholders. *BMC Fam Pract* 2012; 13: 14-2296-13-14.
18. Cieza A, Brockow T, Ewert T, Amman E, Kollerits B, Chatterji S, et al. Linking health-status measurements to the International Classification of Functioning, Disability and Health. *J Rehabil Med* 2002; 34(5): 205-210.
19. Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustun B and Stucki G. ICF linking rules: an update based on lessons learned RID F-6994-2011. *J Rehabil Med* 2005; 37(4): 212-218.
20. Stucki G, Cieza A, Ewert T, Kostanjsek N, Chatterji S and Ustun TB. Application of the International Classification of Functioning, Disability and Health (ICF) in clinical practice. *Disabil Rehabil* 2002; 24(5): 281-282.
21. Yen T, Liou T, Chang K, Wu N, Chou L and Chen H. Systematic review of ICF core set from 2001 to 2012. *Disabil Rehabil* 2014; 36(3): 177-184.
22. Selb M, Escorpizo R, Kostanjsek N, Stucki G, Ustun B and Cieza A. A guide on how to develop an International Classification of Functioning, Disability and Health Core Set. *Eur J Phys Rehabil Med* 2015; 51(1): 105-117.
23. Weigl M, Cieza A, Harder M, Kostanjsek N and Stucki G. Linking osteoarthritis-specific health-status measures to the International Classification of Functioning, Disability and Health (ICF). *Osteoarthritis and Cartilage* 2003; 11(7): 519-523.
24. Sigl T, Cieza A, Brockow T, Chatterji S, Kostanjsek N and Stucki G. Content comparison of low back pain-specific measures based on the International Classification of Functioning, Disability and Health (ICF). *Clin J Pain* 2006; 22(2): 147-153.
25. Stamm T, Geyh S, Cieza A, Machold K, Kollerits B, Kloppenburg M, et al. Measuring functioning in patients with hand osteoarthritis - content comparison of questionnaires based on the International Classification of Functioning, Disability and Health (ICF). *Rheumatology* 2006; 45(12): 1534-1541.

26. Teixeira-Salmela LF, Neto MG, Magalhaes LC, Lima RC and Faria CDCM. Content comparisons of stroke-specific quality of life based upon the International Classification of Functioning, Disability and Health. *Quality of Life Research* 2009; 18(6): 765-773.
27. Rat AC, Guillemin F and Pouchot J. Mapping the OsteoArthritis Knee and Hip Quality Of Life (OAKHQOL) instrument to the International Classification of Functioning, Disability and Health and comparison to five health status instruments used in osteoarthritis. *Rheumatology* 2008; 47(11): 1719-1725.
28. Velstra I, Ballert CS and Cieza A. A systematic literature review of outcome measures for upper extremity function using the International Classification of Functioning, Disability and Health as reference. *Pm&R* 2011; 3(9): 846-860.
29. Gradinger F, Glaessel A, Bentley A and Stucki A. Content comparison of 115 health status measures in sleep medicine using the International Classification of Functioning, Disability and Health (ICF) as a reference. *Sleep Medicine Reviews* 2011; 15(1): 33-40.
30. Alvarez AS. The application of the International Classification of Functioning, Disability and Health in psychiatry possible reasons for the lack of implementation. *American Journal of Physical Medicine & Rehabilitation* 2012; 91(2): S69-S73.
31. Schuntermann MF. The implementation of the International Classification of Functioning, Disability and Health in Germany: experiences and problems. *International Journal of Rehabilitation Research* 2005; 28(2): 93-102.
32. Wlodzimirow KA, Eslami S, Abu-Hanna A, Nieuwoudt M, Chamuleau RAFM. Asystematic review on prognostic indicators of acute on chronic liver failure and their predictive value for mortality. *Liver International* 2013; 33(1): 40-52.
33. Dahl TH. International Classification of Functioning, Disability and Health: an introduction and discussion of its potential impact on rehabilitation services and research. *J Rehabil Med* 2002; 34(5): 201-204.
34. Chalmers R. Health care terminology for the electronic era. *Mayo Clin Proc* 2006; 81(6): 729-731.
35. Clark J, Lang N. Nursing's next advance: an internal classification for nursing practice. *Int Nurs Rev* 1992; 39(4): 109-128.
36. Adler RH. Engel's biopsychosocial model is still relevant today. *J Psychosom Res* 2009; 67(6): 607-611.
37. Fava GA and Sonino N. The biopsychosocial model thirty years later. *Psychother Psychosom* 2008; 77(1): 1-2.
38. Higgs J JM. *Clinical reasoning in the Health Professions.* 2nd ed. New York: Butterworth Heinemann, 2000.
39. Rauch A, Cieza A and Stucki G. How to apply the International Classification of

Functioning, Disability and Health (ICF) for rehabilitation management in clinical practice. *European Journal of Physical and Rehabilitation Medicine* 2008; 44(3): 329-342.

40. de Camargo OK. Systems of care: transition from the bio-psycho-social perspective of the International Classification of Functioning, Disability and Health. *Child Care Health and Development* 2011; 37(6): 792-799.
41. Pruitt S and Epping-Jordan J. Preparing the 21st century global healthcare workforce. *Br Med J* 2005; 330(7492): 637-639.
42. Stephenson R and Richardson B. Building an interprofessional curriculum framework for health: a paradigm for health function. *Advances in Health Sciences Education* 2008; 13(4): 547-557.
43. Jones M, Edwards I, Gifford L. Conceptual models for implementing biopsychosocial theory in clinical practice. *Man Ther* 2002; 7(1): 2-9.
44. Leonardi M, Bickenbach J, Raggi A, Sala M, Guzzon P, Valsecchi MR, et al. Training on the International Classification of Functioning, Disability and Health (ICF): the ICF-DIN Basic and the ICF-DIN Advanced Course developed by the Disability Italian Network. *J Headache Pain* 2005; 6(3): 159-164.
45. Reed GM, Dilfer K, Bufka LF, Scherer MJ, Kotze P, Tshivhase M, et al. Three model curricula for teaching clinicians to use the ICF. *Disabil Rehabil* 2008; 30(12-13): 927-941.
46. Pless M, Ibragimova N, Adolfsson M, Bjorck-Akesson E and Granlund M. Evaluation of In-Service Training in using the ICF and ICF Version for Children and Youth. *J Rehabil Med* 2009; 41(6): 451-458.
47. WHO Collaborating Centre for the FIC in The Netherlands. ICF-training in the Netherlands. *WHO Familiy of International Classifications (FIC) Newsletter* 2012; (Volume 10, number 2): 7.
48. World Health Organization. Milestones in Health promotion: statements from global conferences. 2015; Available at: http://www.who.int/healthpromotion/en/. Accessed April 18, 2015.
49. Madden R, Marshall R and Race S. ICF and casemix models for healthcare funding: use of the WHO family of classifications to improve casemix. *Disabil Rehabil* 2013; 35(13): 1074-1077.
50. DBC Onderhoud. 2015; Available at: http://www.dbconderhoud.nl/. Accessed April 12, 2015.
51. Pincus T, Kent P, Bronfort G, Loisel P, Pransky G and Hartvigsen J. Twenty-five years with the biopsychosocial model of low back pain-is it time to celebrate? A report from

the twelfth international forum for primary care research on low back pain. *Spine (Phila Pa 1976)* 2013; 38(24): 2118-2123.

52. Bickenbach J, Cieza A, Rauch A and Stucki G. ICF Core Sets. Manual for clinical practice. The creation of an ICF based documentation form. 2013; Available at: http://www.icf-core-sets.org/. Accessed April 12, 2015.
53. Tesio L. From codes to language: is the ICF a classification system or a dictionary? *BMC Public Health* 2011; 11 Suppl 4: S2-2458-11-S4-S2.
54. Antonovsky A. The salutogenic model as a theory to guide health promotion. *Health Promot Internation* 1996; 11(1): 11-18.
55. Labrique AB, Vasudevan L, Kochi E, Fabricant R and Mehl G. mHealth innovations as health system strengthening tools: 12 common applications and a visual framework. *Glob Health Sci Pract* 2013; 1(2): 160-171.
56. Snyman S, Kraus de Camargo O and Zhuxi Gong J. The mICF Collaborators group - A worldwide initative. Poster presented at WHO-Family of International Classifications Network Annual Meeting Barcelona. 11-17 October 2014. 2015; Available at: http://www.who.int/classifications/network/WHOFIC2014_Poster_Booklet.pdf?ua=1. Accessed April 12, 2015.
57. Stucki G and Grimby G. Applying the ICF in medicine. *J Rehabil Med* 2004; (44 Suppl): 5-6.

“Niemand krijgt betaald om de patiënt gezond te hóuden.”

de Volkskrant, 25 oktober 2008, Sara de Sloover.

9

Summary

Summary

The concept of functioning pertains to how people function in everyday life, in the performance of activities, and in the areas of life in which they participate. This thesis aimed to explore the inclusion of the concept of functioning as an important focus in health care. Functioning is currently increasingly recognized as being crucial to the concept of health as its scope has extended in the last decade beyond curing diseases to the prevention of diseases and the promotion of well-being. The recently proposed definition of health as “the ability to adapt and self-manage in the face of social, physical and emotional challenges”[a], can be placed in the perspective of this changing health care.

The WHO[b] published the ICF[c] in 2001 as the international standard terminology for functioning together with the conceptual model of health. The latter represents health as the interaction between disease, functioning and contextual factors. Implementation of functioning in health care means that the focus of current health care, which is predominantly based on the *biomedical* model, has to be broadened to include the *biopsychosocial* model. In the latter model, all components of the conceptual model of health (Figure 9.1) are taken into account in order to achieve a person’s best state of health. Functioning is expressed in terms of abilities and disabilities.

In this thesis, the standard terminology for functioning and the conceptual model of health were studied as two inseparable but distinct applications in order to obtain specific information that is relevant to developing effective strategies for the implementation of the concept of functioning in health care. The standard terminology for functioning aims to improve communication (Chapters 2, 3 and 4), and the conceptual model of health (Chapters 5, 6 and 7) aims to facilitate clinical decision-making.

---

[a] Huber M, Knottnerus JA, Green L, van der Horst H, Jadad AR, Kromhout D, et al. How should we define health? Br Med J 2011; 343:d4163.

[b] WHO = World Health Organization.

[c] ICF = International Classification of Functioning, Disability and Health.

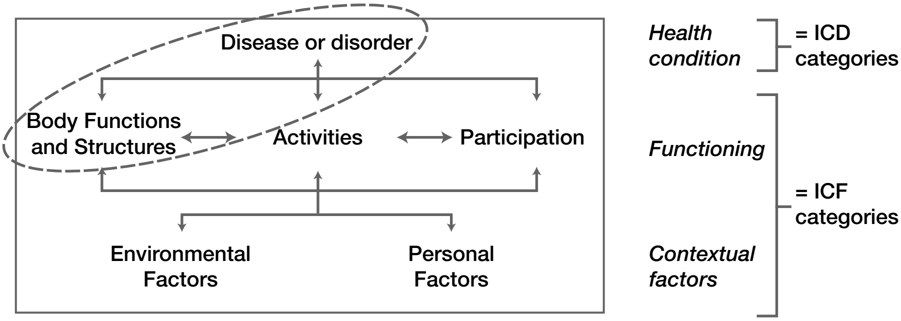


Figure 9.1 WHO's conceptual model of health representing the interactions between the components (disease, body functions and structures, activities, participation, environmental and personal factors) of the health status. Note the partial perspective of health based on the biomedical model (oval) vs the holistic perspective of health based on the biopsychosocial model (rectangle). ICD: International Classification of Diseases; ICF: International Classification of Functioning, Disability and Health.

In Chapter 1, the general introduction to this thesis is presented. Functioning is described in relation to health and current health care provision, which faces an aging population that has one or more non-communicable chronic diseases. The conceptual model of health and the standard terminology for functioning are explained.
The following research questions are answered in this thesis:

1. To what extent does language ambiguity regarding functioning exist in clinical practice and research and what are the consequences for communication?
2. To what extent does the use of standard terminology for functioning and the conceptual model of health facilitate clinical decision-making and what are the effects on clinical practice?
3. To what extent are health care professionals focused on functioning in health care and what is their opinion on the usefulness of this concept in clinical practice?

In Chapter 2, the use of ambiguous language regarding functioning in clinical practice is explored in an integrative literature review. The standard terminology of the ICF was used to identify aspects of functioning related to language use in clinical practice. Two databases were searched, and 17 out of 767 relevant papers were included in the review and synthesis. Because of the paucity of published research on the use of language ambiguity in written patient information concerning functioning, an integrative review of the literature was performed. An integrative review allows for the merging of data from empirical and theoretical literature to gain insight into a specific topic.

The use of ambiguous language in written information concerning patients' functioning was demonstrated. Problems resulting from the use of ambiguous language in clinical practice were not identified. However, several potential problems were suggested, including hindered clinical decision-making and limited research opportunities. It was concluded that the absence of problems experienced by health care professionals may explain the lack of success of many projects aimed at introducing standard terminology concerning functioning in clinical practice. Standard terminology is mainly aimed at the aggregation and reuse of data from electronic patient records for several purposes, such as multidisciplinary decision-making and research. If these issues become important to clinical practice, the likelihood of a successful introduction of standard terminology concerning patients' functioning is greatly increased. Language ambiguity alone is not a valid argument to justify the introduction of standard terminology.

In Chapter 3, the consequences of ambiguous language use in the assessment of patients' participation, as an aspect of functioning, are explored. In a survey in 677 patients with a neuromuscular disease, the standard terminology of the ICF was used to identify the operationalizations of the concept of participation in different assessment instruments. These included the Neuromuscular Disease Impact Profile questionnaire, the RAND-36 Item Health Survey (social functioning, role limitations-physical, role limitations-emotional), and the Impact on Participation and Autonomy questionnaire (autonomy outdoors, social relations). The conceptual model of health was used in a regression analysis in which participation was the dependent variable and the predictors were the components of disease (i.e. type of neuromuscular disease), body functions, activities, contextual factors (all measured with the Neuromuscular Disease Impact Profile), and personal factors (measured with the 13-item Sense of Coherence questionnaire).

Participation was predicted by different components of the conceptual model depending on the operationalization used for participation. Body functions and activities were predictors in five out of six operationalizations of participation. Sense of coherence (personal factors) predicted participation in all operationalizations. The explained variance of the different regression models ranged from 25% (RAND-36 role limitations-emotional) to 65% (Neuromuscular Disease Impact Profile). It was concluded that participation is an ambiguous concept in research, and this ambiguity makes evidence-based decisions directed at enhancing participation difficult. It is recommended that consensus on the definition of the concept of participation is reached in order to be able to compare research outcomes.

In Chapter 4, the content validity of the initial ICF core set[d], which was developed for a number of chronic neurological disorders, is examined for the application in neuromuscular diseases (NMD). Concepts in established disease-specific Health-Related Quality of Life questionnaires (HRQOL) were compared with ICF categories, and the selected ICF categories were linked to the ICF categories in the initial ICF core set. Newly identified ICF categories were included in the NMD core set when this category was found in at least two of the three measuring instruments.

All concepts in the HRQOL questionnaires were covered by the initial ICF core set, except for one body function concept. However, the NMD core set reflects a broader scope of health problems compared with the concepts in the HRQOL questionnaires, especially with regard to the components of participation and environmental factors. It was concluded that the NMD core set can contribute to a better understanding of the consequences of NMD and can also serve as a basis for clinical practice, research, social security systems, and educational programs.

In Chapter 5, the effects of using the ICF core set for clinical decision-making in practice are investigated. The Multiple Sclerosis Impact Profile (MSIP) was used in a randomized controlled trial that included 81 patients with multiple sclerosis. The MSIP is a validated self-report instrument based on the ICF that measures functioning of patients with multiple sclerosis. In the intervention group the MSIP was used as a functioning assessment combined with the biomedical assessment. In the control group the conventional biomedical

---

[d] An ICF core set is a selected set of categories out of the whole ICF, related to a specific health condition. This set can serve as a minimal standard for the assessment and reporting of functioning and health for that specific health condition.

assessment was used. The outcomes of the assessments in both groups were compared regarding their respective consequences for health professionals' clinical decision-making and their fit with patient's own perspective of health.

Compared with the biomedical assessment, the functioning assessment resulted in the registration of a significantly higher number of problems registered by health care professionals in the components participation and environmental factors and in the identification of a significantly higher number of professional health care activities related to these components. The functioning assessment resulted in a positive correlation between registered problems by health care professionals and patients' self-reported problems. In contrast, use of the biomedical assessment resulted in several negative correlations. It was concluded that the functioning assessment resulted in a care plan that was not only broader and more complete but which also reflected the patients' self-reported problems more closely than a medical assessment alone, without a loss of focus on medical problems. Further research on the use of a functioning assessment and its consequences for clinical outcomes is recommended.

In Chapter 6, the focus on health care of graduates of the Master of Advanced Nursing Practice (MANP) is studied in terms of cure and care by means of analyzing graduate theses. Following the Dutch competency profile for nurse practitioners, MANP students have to integrate cure and care. A clear model covering this area is lacking; therefore, it is unknown to what extent nurse practitioners are focused on this specific area. Graduate theses may reflect the focus of nurse practitioners. The conceptual model of health and the standard terminology for functioning (ICF) and diseases (ICD[e]) were used to classify the theses. A total of 413 published abstracts of graduate theses (2000 - 2015) were classified as focused on cure (primarily focused on disease or disorder and body functions and structures), focused on care (primarily focused on activities and participation), or focused on the intersection of cure and care (primarily focused on disease/body functions and structures, and activities/participation).

A small majority of 53% of the graduate theses could be classified in the conceptual model. Of these classified theses, 48% were focused on

---

[e] ICD = International Classification of Diseases.

cure, 39% on the intersection of cure and care, and 13% on care. While the percentage of theses addressing the health status increased significantly over the 15-year period, the percentage of theses focused on cure, care, and on the intersection of cure and care remained the same. It was concluded that nurse practitioners are increasingly oriented toward patients' health status. However, their focus is predominantly on cure rather than on the intersection of cure and care. In order to support the assumed integration of cure and care in clinical practice by nurse practitioners, it is recommended that the conceptual model of health and the standard terminology of the ICF are included in their curriculum.

In Chapter 7, a randomized controlled trial in 74 students of the Master of Advanced Nursing Practice (MANP) is presented that examined the effects of a 4-hour instructor-led training in using the ICF on perceived usefulness of the ICF as primary outcome measure. The students were assigned to either the intervention group, which received the ICF training, or the control group, which did not receive ICF training. Data about ICF-related knowledge, skills, and attitude were collected using an ICF survey and learning assessment tool at baseline, immediately after the training, and at 3-months follow-up.

Data of 56 students were included for analysis. The ICF training resulted in a significantly larger increase in perceived usefulness of the ICF immediately after the ICF training compared with the control group. At 3 months follow-up, however, there was no longer a significant difference between both groups. Positive attitude and knowledge related to the ICF were significantly increased in the intervention group immediately after the training and at 3-months follow-up. Skills were not affected. It was concluded that a short ICF training has a positive influence on perceived usefulness of the ICF, which is relevant for including the ICF in the MANP curriculum.

In Chapter 8, the main findings are summarized, the methodological considerations and a synthesis of findings are provided, and the clinical implications and directions for future research regarding the focus on functioning in health care are presented.

It is found that the standard terminology of functioning and the conceptual model of health, used as two distinct but inseparable applications, contribute to the implementation of the concept of functioning in health care.

Language ambiguity regarding functioning exists both in clinical practice and research. Negative consequences of language ambiguity were not found for clinical practice. However, language ambiguity may have considerable consequences for research.

In addition, the standard terminology of functioning and the conceptual model of health facilitate clinical decision-making in practice and have positive effects on the promotion of patients' health, especially regarding patients' participation and environmental factors.

Currently, the mindset of health care professionals is not yet focused on functioning in health care. In addition, a focus on functioning does not easily fit in with the current predominant biomedical health care system. Health care professionals, including nurses, therapists, and physicians, deliver their care to patients by using tools and skills predominantly embedded within the biomedical model. Tools and training related to functioning are therefore a prerequisite for health care professionals to be able to focus on functioning, i.e. the biopsychosocial model, in clinical practice.

The findings of this thesis have several implications for clinical practice, education, policy, and research. The most important implication is the involvement of the patient in clinical decision-making in health care. This implication requires a paradigm shift from a disease-based, biomedical focus towards a broader biopsychosocial focus on health care that affects not just health care professionals but also politicians, administrators, and society at large. Ultimately, health care provision and outcomes should be determined by all aspects of a person's health status, not just those related to disease.

“In onze ogen begint goede zorg bij het erkennen van de belangentegenstellingen tussen de patiënt, de mantelzorger, de zorgprofessional, zijn werkgever en de samenleving als geheel.”

de Volkskrant, 25 september 2013, Anne-Mei The en Antoinette Reerink.

Appendices

- Samenvatting
- Dankwoord
- About the author
- Over de auteur
- Research Institute SHARE: previous dissertations

Samenvatting

Het concept functioneren heeft betrekking op het functioneren van mensen in het dagelijkse leven, de uitvoering van activiteiten en de participatie in de maatschappij. Het doel van dit proefschrift is om het concept functioneren te verkennen als focus van zorg. Het concept functioneren wordt in toenemende mate als cruciaal gezien voor het bevorderen van gezondheid, aangezien zorg zich steeds meer uitbreidt naar het voorkomen van ziekten en het bevorderen van welzijn. De recent voorgestelde definitie van gezondheid als "het vermogen zich aan te passen en een eigen regie te voeren, in het licht van de fysieke, emotionele en sociale uitdagingen van het leven"[a] is illustratief voor deze veranderende gezondheidszorg.

De WHO[b] heeft de ICF[c] gepubliceerd in 2001 als de internationale standaardterminologie voor het menselijk functioneren, samen met het conceptuele model van gezondheid. Het conceptuele model van gezondheid representeert gezondheid als een interactie tussen ziekte, functioneren en contextuele factoren. De invoering van functioneren als focus van zorg betekent dat de huidige gezondheidszorg, die voornamelijk gebaseerd is op het *biomedische* model, verbreed wordt tot een *biopsychosociaal* model. In het laatst genoemde model worden alle componenten van het conceptuele model betrokken (Figuur 1) met als doel voor ieder individu de beste gezondheidssituatie te bereiken. Functioneren wordt in de ICF uitgedrukt in termen van mogelijkheden en beperkingen (abilities/disabilities).

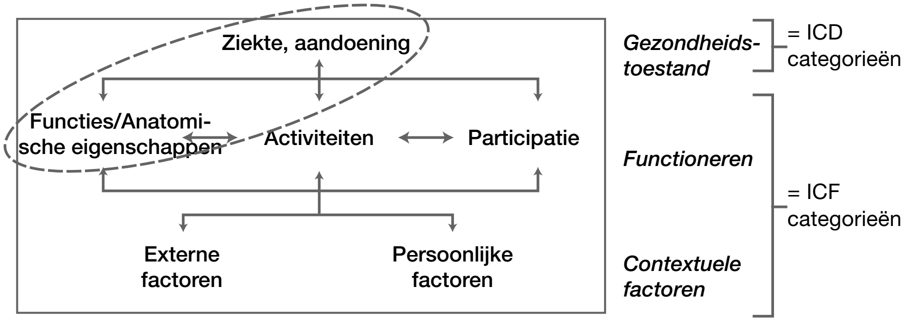
In dit proefschrift zijn de standaardterminologie van functioneren en het conceptuele model van gezondheid als twee afzonderlijke, maar onlosmakelijk met elkaar verbonden toepassingen in de zorg onderzocht om informatie te verkrijgen die relevant is voor de ontwikkeling van effectieve strategieën voor de implementatie van het concept functioneren in de gezondheidszorg. Het gebruik van de standaardterminologie voor functioneren (Hoofdstukken 2, 3 en 4) is gericht op het verbeteren van communicatie en het conceptuele model van gezondheid (Hoofdstukken 4, 5 en 6) is gericht op het ondersteunen van klinische besluitvorming.

---

[a] Huber M, Knottnerus JA, Green L, van der Horst H, Jadad AR, Kromhout D, et al. How should we define health? Br Med J 2011; 343:d4163.

[b] WHO = World Health Organization.

[c] ICF = International Classification of Functioning, Disability and Health.



Figuur 1 Het conceptuele model van gezondheid van de WHO waarin de interactie tussen de componenten (ziekte, functies/anatomische eigenschappen, activiteiten, participatie, externe en persoonlijke factoren) wordt weergegeven. Let op het perspectief van gezondheid gebaseerd op het biomedische model (ovaal) versus het biopsychosociale model (rechthoek). ICD: International Classification of Diseases; ICF: International Classification of Functioning, Disability and Health.

In Hoofdstuk 1 is een algemene inleiding op dit proefschrift gegeven. Functioneren is beschreven in relatie tot gezondheid en de huidige zorgverlening, welke zich geconfronteerd ziet met steeds ouder wordende patiënten die één of meerdere chronische ziektes hebben. Het conceptuele model van gezondheid en de standaardterminologie van functioneren zijn toegelicht. De volgende onderzoeksvragen zijn beantwoord in dit proefschrift:

1. In hoeverre is er in de klinische praktijk en in het wetenschappelijk onderzoek sprake van meerduidig taalgebruik met betrekking tot het concept functioneren en wat zijn hiervan de gevolgen voor de communicatie?
2. In hoeverre wordt klinische besluitvorming ondersteund door het toepassen van de standaardterminologie van functioneren en het conceptuele model van gezondheid en wat zijn de effecten hiervan voor de klinische praktijk?
3. In hoeverre zijn beroepsbeoefenaren in de gezondheidszorg gericht op functioneren en wat is hun mening over de bruikbaarheid van dit concept in de klinische praktijk?

In Hoofdstuk 2 is een literatuuronderzoek naar het gebruik van meerduidig taalgebruik met betrekking tot het concept functioneren in de klinische praktijk gepresenteerd. De standaardterminologie van de ICF werd gebruikt om aspecten van functioneren te kunnen identificeren. In twee databases werd naar relevante studies gezocht. Uit een totaal van 767 studies werden

17 studies geïncludeerd voor analyse. Door het gebrek aan gepubliceerd onderzoek naar meerduidig taalgebruik in schriftelijke patiënteninformatie met betrekking tot functioneren werd een zogenaamde ‘integrative review’ uitgevoerd. Een integrative review is een specifieke methode voor literatuuronderzoek waarin data samengevoegd kunnen worden uit zowel emipirische als theoretische studies waardoor inzicht verkregen wordt in een specifiek onderwerp.

Er was sprake van meerduidig taalgebruik in schriftelijke informatie met betrekking tot het functioneren van patiënten. Problemen in de klinische praktijk als gevolg van dit meerduidig taalgebruik werden echter niet gevonden. Wel werden potentiële problemen gevonden voor multidisciplinaire klinische besluitvorming en wetenschappelijk onderzoek ten gevolge van meerduidig taalgebruik. Op basis van deze resultaten werd geconcludeerd dat het gebrek aan succes van de vele projecten die gericht zijn op de invoering van standaardterminologie in de klinische praktijk verklaard kan worden door het ontbreken van ervaren problemen ten gevolge van meerduidig taalgebruik. Standaardterminologie heeft voornamelijk tot doel data te kunnen hergebruiken en aggregeren voor diverse doeleinden, zoals wetenschappelijk onderzoek en multidisciplinaire klinische besluitvorming. Pas als dat aan de orde is voor de klinische praktijk zal standaardterminologie succesvol geïmplementeerd kunnen worden. Meerduidig taalgebruik in de klinische praktijk is op zichzelf geen goed argument om standaardterminologie in te voeren.

In Hoofdstuk 3 zijn de gevolgen onderzocht van meerduidig taalgebruik in instrumenten die het concept participatie meten als onderdeel van functioneren. In een vragenlijstonderzoek bij 677 patiënten met neuromusculaire aandoeningen werd de standaardterminologie van de ICF gebruikt voor de operationalisaties van het concept participatie in verschillende meetinstrumenten (vragenlijsten): de Neuromuscular Disease Impact Profile, de RAND-36 Item Health Survey (sociaal functioneren, rolbeperkingen-fysiek, rolbeperkingen-emotioneel) en de Impact on Participation and Autonomy questionnaire (autonomie-buitenshuis, sociale relaties). Het conceptuele model van gezondheid werd gebruikt in regressieanalyses waarin participatie de afhankelijke variabele was en de andere componenten van het model de onafhankelijke variabelen waren, te weten: ziekte (type neuromusculaire aandoening), functies, activiteiten, externe factoren (allen gemeten met Neuromuscular Disease Impact Profile) en persoonlijke factoren (gemeten met 13-item Sense of Coherence vragenlijst).

Afhankelijk van het gebruikte meetinstrument werd participatie voorspeld door verschillende componenten van het conceptuele model.
De componenten functies en activiteiten waren voorspellend voor participatie in vijf van de zes meetinstrumenten; de Sense of Coherence (persoonlijke factoren) was voorspellend voor participatie in alle meetinstrumenten.
De verklaarde variantie van de verschillende regressiemodellen varieerde van 25% (RAND-36 rolbeperking-emotioneel) tot 65% (Neuromuscular Disease Impact Profile). Op basis van deze resultaten werd geconcludeerd dat participatie, als onderdeel van functioneren, een meerduidig begrip is in wetenschappelijk onderzoek, en dat deze ambiguïteit het nemen van evidence-based besluiten gericht op het verbeteren van participatie bemoeilijkt. Aanbevolen wordt om consensus te bereiken over de definitie van het begrip participatie om resultaten van wetenschappelijk onderzoek beter te kunnen vergelijken.

In Hoofdstuk 4 is de inhoudsvaliditeit onderzocht van een initiële ICF core set[d] die ontwikkeld is voor een aantal chronische neurologische ziekten voor toepassing bij neuromusculaire aandoeningen (NMD). Concepten uit al bestaande vragenlijsten over kwaliteit van leven (Health-Related Quality of Live (HRQOL)) werden vergeleken met ICF-categorieën en de geïdentificeerde ICF-categorieën werden vervolgens gekoppeld aan ICF-categorieën van de initiële ICF core set. De geïdentificeerde ICF-categorieën uit de HRQOL-vragenlijsten werden opgenomen in de NMD core set indien deze categorie tenminste in twee van de drie meetinstrumenten voorkwam.

Op één concept na werden alle concepten in de HRQOL-vragenlijsten gedekt door de initiële ICF core set. Echter, de NMD core set weerspiegelt een breder terrein van gezondheidsproblemen dan de concepten van de HRQOL-vragenlijsten, in het bijzonder met betrekking tot participatie en externe factoren. Op basis van deze resultaten werd geconcludeerd dat de NMD core

---

[d] Een ICF core set is een kernset van geselecteerde ICF-categorieën gerelateerd aan een specifieke ziekte of aandoening. Deze kernset kan dienen als een minimale standaard voor de assessment en rapportage van het functioneren en gezondheid voor die specifieke gezondheidssituatie.

set kan bijdragen aan een beter begrip van de gevolgen van een NMD en als basis kan dienen voor de klinische praktijk, wetenschappelijk onderzoek, sociale verzekeringsstelsels en scholingsprogramma’s.

In Hoofdstuk 5 worden de effecten van het gebruik van een ICF core set voor klinische besluitvorming in de praktijk onderzocht. In een gerandomiseerde gecontroleerde trial (RTC) werd de Multiple Sclerosis Impact Profile (MSIP) gebruikt bij 81 patiënten met multiple sclerose. De MSIP is een gevalideerde zelfrapportage meetinstrument gebaseerd op de ICF dat het functioneren meet van patiënten met multiple sclerose. De interventiegroep, waarin de MSIP als assessment[e] werd gebruikt, werd vergeleken met de controlegroep, waarin het conventionele biomedische assessment werd gebruikt. Uitkomstmaten waren de verschillen in klinische besluitvorming door de hulpverleners en de aansluiting bij het perspectief van gezondheid van de patiënt zelf.

In vergelijking met het conventionele biomedische assessment resulteerde het gebruik van de MSIP, als assessment voor functioneren, in significant meer gerapporteerde problemen ten aanzien van participatie en externe factoren en in meer gerapporteerde interventies die gericht zijn op deze componenten. Daarnaast bleek dat bij het assessment voor functioneren een positieve correlatie bestond tussen de problemen die door hulpverleners werden gerapporteerd en de problemen die door de patiënten zelf werden gerapporteerd. Het biomedische assessment liet een negatieve correlatie zien tussen het aantal problemen dat door hulpverleners werd gerapporteerd en het aantal problemen dat door de patiënt zelf werd gerapporteerd. Op basis van deze resultaten werd geconcludeerd dat vergeleken met het gebruik van het medische assessment alleen, het assessment voor functioneren resulteert in een zorgplan dat niet alleen breder en completer is, maar ook beter aansluit bij de problemen die patiënten zelf ervaren zonder dat het ten koste gaat van aandacht voor medische problemen. Aanbevolen wordt verder onderzoek te doen naar het gebruik van het assessment voor functioneren en de gevolgen daarvan voor klinische resultaten.

---

[e] Een assessment is het het systematisch verzamelen, ordenen en interpreteren van informatie.

In Hoofdstuk 6 is de focus op zorg van afgestudeerden van de Master of Advanced Nursing Practice (MANP)[f] onderzocht in termen van cure, care en integratie van cure en care door middel van het analyseren van afstudeerscripties. Volgens het Nederlandse competentieprofiel voor de verpleegkundig specialist wordt hij of zij geacht te werken op het snijvlak van cure en care. Door het ontbreken van een duidelijk model dat de integratie van cure en care weergeeft is het onbekend in welke mate verpleegkundig specialisten hierop gericht zijn. Afstudeerscripties weerspiegelen mogelijk de focus op zorg van afgestudeerde verpleegkundig specialisten. Met behulp van het conceptuele model van gezondheid en de standaardterminologie van functioneren (ICF) en ziekten (ICD[g]) werden 413 gepubliceerde abstracts van afstudeerscripties (2000 - 2015) geanalyseerd en geklasseerd als cure (gericht op ziekten, functies en anatomische eigenschappen), care (gericht op activiteiten/participatie) of integratie van cure en care (gericht op ziekte/functies en anatomische eigenschappen en activiteiten/participatie).

Iets meer dan de helft (53%) van de afstudeerscripties richtte zich op de gezondheidssituatie van de patiënt en kon worden geklasseerd in het conceptuele model. Van deze geklasseerde scripties was 48% gericht op cure, 39% op integratie van cure en care en 13% op care. Terwijl het percentage van de scripties dat gericht was op de gezondheidssituatie van de patiënt aanzienlijk toenam in deze periode van 15 jaar, bleef het percentage van de scripties dat gericht was op cure, care en integratie van cure en care gelijk. Op basis van deze resultaten werd geconcludeerd dat verpleegkundig specialisten in toenemende mate gericht zijn op de gezondheidssituatie van de patiënt. Echter, hun focus in de zorg is voornamelijk op cure en niet op de integratie van cure en care. Aanbevolen wordt om het conceptuele model van gezondheid en de standaardterminologie van functioneren op te nemen in het curriculum van de MANP om studenten een denkkader en hulpmiddel te bieden bij de integratie van cure en care in de praktijk

In Hoofdstuk 7 zijn de effecten van een 4-uur durende ICF-training onderzocht met als primaire uitkomstmaat de mening over de bruikbaarheid van de ICF. In een gerandomiseerde gecontroleerde trial (RCT) werden 74 studenten

---

[f] De MANP leidt verpleegkundigen op tot verpleegkundig specialist.

[g] ICD = International Classification of Diseases.

van de Master of Advanced Nursing Practice (MANP) random toegewezen aan de interventiegroep, die de ICF training kregen van een instructeur, of aan de controlegroep, die geen ICF training kregen. Kennis, vaardigheden en houding ten opzichte van de ICF werden gemeten voorafgaand aan de training, direct na de training, en drie maanden na de training. Hierbij werd gebruik gemaakt van een specifieke ICF-vragenlijst en -beoordelingsinstrument.

De gegevens van 56 studenten konden worden geanalyseerd. Direct na de ICF-training was de mening van de studenten in de interventiegroep over de bruikbaarheid van de ICF significant positief toegenomen in vergelijking met de controlegroep. Drie maanden na de training was er echter geen significant verschil meer tussen beide groepen. Andere metingen van kennis en houding ten opzichte van de ICF toonden zowel direct na de training als drie maanden na de training een significante positieve toename in de interventiegroep. De training had geen effect op vaardigheden met betrekking tot de ICF. Op basis van deze resultaten werd geconcludeerd dat een korte, vier uur durende ICF-training van een instructeur de mening van studenten van de MANP ten aanzien van de bruikbaarheid van de ICF positief beïnvloedt. Een positieve houding is relevant voor de implementatie van de ICF in het curriculum van de MANP.

In Hoofdstuk 8 zijn de belangrijkste bevindingen van dit proefschrift samengevat en besproken. De gevolgen voor de klinische praktijk, het onderwijs, de financiering van de zorg, de evaluatie van de zorg en toekomstig onderzoek zijn toegelicht.

Het blijkt dat het gebruik van de standaardterminologie van functioneren en het conceptuele model van gezondheid als twee afzonderlijke, maar onlosmakelijk met elkaar verbonden toepassingen bijdraagt aan de implementatie van het concept van functioneren in de gezondheidszorg.

Meerduidig taalgebruik voor functioneren bestaat zowel in de klinische praktijk als in wetenschappelijk onderzoek. Negatieve gevolgen van meerduidig taalgebruik werden niet gevonden voor de klinische praktijk. Meerduidig taalgebruik kan echter wel negatieve gevolgen hebben voor wetenschappelijk onderzoek.

De standaardterminologie van functioneren en het conceptuele model van gezondheid ondersteunen klinische besluitvorming in de praktijk en hebben een positief effect op het bevorderen van de gezondheid van de patiënten,

in het bijzonder op het gebied van participatie en externe factoren.
In de huidige gezondheidszorg zijn beroepsbeoefenaren in de gezondheidszorg niet primair gericht op functioneren als focus van zorg. Verpleegkundigen, therapeuten en artsen leveren hun zorg aan patiënten met behulp van instrumenten en vaardigheden die voornamelijk zijn ingebed in het biomedische model. Instrumenten en training met betrekking tot functioneren zijn daarom een voorwaarde voor hulpverleners om functioneren te kunnen betrekken in zorgverlening.

De resultaten beschreven in dit proefschrift met betrekking tot de implementatie van functioneren als focus van zorg hebben implicaties voor de klinische praktijk, het onderwijs, het beleid en het wetenschappelijk onderzoek. Eén van de belangrijkste implicatie is het betrekken van de patiënt als partner in klinische besluitvorming rondom zorg. Deze implicatie vraagt van zowel hulpverleners als van politici, bestuurders en de maatschappij een paradigmaverschuiving van een biomedisch georiënteerde naar een biopsychosociale georiënteerde gezondheidszorg. Niet alleen het aspect ziekte zal dan bepalend zijn voor zorgverlening en zorgresultaten, maar alle aspecten van iemands gezondheidssituatie.

Dankwoord

Toen *Loek J. Broerse,* toenmalig hoofd bureau Verpleegkundige Zaken van het UMCG, mij in 2005 voorstelde om te gaan promoveren op de ICF heb ik dat voorstel met veel ambitie en enthousiasme aangenomen. Dit was de kans om onze opgedane expertise met betrekking tot de ICF in het UMCG te behouden en te vergroten. Daarbij heb ik als verpleegkundige grote affiniteit met het onderwerp, omdat het concept functioneren werkelijk naam geeft aan dat waar de verpleegkunde zich bij uitstek op richt, op de patiënt als persoon met zijn omgeving. Loek, ik ben je nog steeds heel dankbaar voor dit voorstel. In de jaren dat je mijn leidinggevende was, heb je me de kans gegeven uit te groeien van mbo-verpleegkundige tot doctor in de wetenschap.

Terugkijkend heb ik niet geweten waar ik toen aan begonnen ben. Ik had tot dan verscheidene studies achter de rug, maar promoveren bleek één grote confrontatie met mijn eigen functioneren. Functies, activiteiten en participatie werden danig op de proef gesteld en de balans tussen wat ik kon en wat ik wilde leek soms ver te zoeken. Dat het proefschrift er is gekomen is dankzij de ondersteuning van vele mensen, of wel: ‘mijn omgevingsfactoren’. Met hen ben ik in staat gebleken om dit proefschrift tot stand te brengen. Ik wil iedereen bedanken die mij hierin heeft ondersteund maar een aantal mensen wil ik in het bijzonder noemen.

In de eerste plaats gaat mijn grote dank uit naar de leden van de begeleidingscommissie, *prof. dr. Petrie F. Roodbol, prof. dr. Pieter U. Dijkstra, prof. dr. Pieter F. de Vries Robbé en dr. Gerard J. Jansen.*

Beste Petrie, jij had de visie en daadkracht om zorgonderzoek op te zetten binnen het Wenckebach Instituut van het UMCG. Als een van je eerste promovendi mocht ik aansluiten. Inmiddels ben ik de vierde op rij die bij jou promoveert en heeft zorgonderzoek binnen het UMCG een positie verworven. Dank voor je beschikbaarheid en ondersteuning, ook op de momenten dat er tegenslag was en het zoeken werd hoe we verder konden gaan. Ik heb genoten van je betrokkenheid bij mijn onderwerp. Getuigen daarvan zijn de ingezonden brieven die je samen met mij schreef over functioneren als perspectief van zorg. Ik kijk uit naar de komende jaren waarin ik graag met je werk aan de gezondheidszorg van de toekomst en de positie van de verpleegkunde.

Beste Pieter D, halverwege mijn traject werd jij tweede promotor. Door jou heb ik de statistiek pas écht leren begrijpen. Daarbij versta je de kunst om duidelijk en met weinig woorden de kern van de boodschap weer te geven. Veel dank voor je onafhankelijke en steeds positieve insteek, ook bij je soms strenge maar altijd integere commentaar. Je humor en bovenal je aandacht voor de mens als persoon heb ik zeer gewaardeerd.

Beste Pieter dVR, vanaf het begin ben jij als promotor bij mijn traject betrokken en beslissend geweest. Startend vanuit onderzoek naar meerduidig taalgebruik met betrekking tot het concept functioneren, doorzag jij al in een vroeg stadium dat mijn hart veel meer lag bij het concept van functioneren zelf. Deze inbreng is illustratief voor jouw rol in mijn promotie. Je bewaakte zowel het onderzoek als het proces van uitvoeren. Met jouw inhoudelijke en wetenschappelijke expertise is het gelukt om de vele obstakels die we onderweg tegenkwamen te pareren. Heel veel dank daarvoor! Het is jammer dat je, met het verstrijken van je promotierecht vorig jaar na je emeritaat, nu niet formeel als promotor mag optreden, maar het is een eer als één van jouw laatste promovendi te mogen promoveren, zowaar bij de RUG, de bakermat van jouw carrière.

Beste Gerard, toen je in 2012 betrokken werd als copromotor, bezorgde ons dat een déjà vu. Tijdens mijn studie Verplegingswetenschappen stapte je ook halverwege mijn onderzoek in. En wederom heeft jouw betrokkenheid tot een succesvol resultaat geleid. Ik ben je zeer erkentelijk voor de goede en integere wijze waarop je mij hebt begeleid. Als geen ander ben je in staat om studenten en promovendi te volgen en ze te laten gedijen in hun rol van onderzoeker.

Prof. dr. Theo van Achterberg, prof. dr. Marieke J. Schuurmans en prof. dr. Adelita V. Ranchor, leden van de beoordelingscommissie, ik wil jullie hartelijk bedanken voor de bereidheid het proefschrift te beoordelen.

Beste Theo, toen ik je vertelde dat ik erover dacht om promotie-onderzoek te gaan doen, bood je mij een klankbord. Dank daarvoor, het was fijn je op de achtergrond altijd aanwezig te weten.

Beste Marieke, de krantenkop: “verpleegkundige moet zich richten op dagelijks functioneren patiënt”, is een citaat uit jouw oratie en heeft jarenlang boven mijn bureau gehangen. Dank voor je aanmoediging, het heeft me zeer gesteund.

Beste Adelita, het doet mij genoegen dat jij als expert op het gebied van aanpassing aan chronische ziekte mijn proefschrift hebt goedgekeurd. De combinatie van verschillende expertises bindt ons over de disciplines heen.

Maar ook anderen hebben een belangrijke bijdrage geleverd.
Prof. dr. Klaas Postema en dr. Klaske Wynia. Beste Klaas en Klaske, jullie wil ik bedanken voor de beginjaren van mijn onderzoek, waarin jullie bereid waren om met mij op pad te gaan. Het was moeilijk toen onze wegen scheiden, maar voor de voortgang van het onderzoek is het een goed besluit geweest.

Prof. dr. Jan H.B. Geertzen. Beste Jan, als hoofd van de afdeling Revalidatie en programmaleider van het onderzoeksprogramma EXPAND binnen SHARE heb je mij en mijn onderzoek een plek gegeven. Dank dat ik als een soort 'buiten-promovenda' deel mocht uit maken van de groep promovendi van de afdeling Revalidatie en voor je kritische bijdrage als co-auteur.

Drs. Huib ten Napel. Beste Huib, al 20 jaar trekken wij samen op in de ICF. Je hebt me de grondbeginselen van de ICF geleerd. Ik ben trots op de ICF-training die we samen ontwikkeld hebben en die we al een aantal jaren met succes in Nederland en België geven. Dank voor het delen van je kennis, je bijdrage als co-auteur en je nooit aflatende correcties als het gaat om termen en formuleringen ten aanzien van de ICF.

Drs. Isaäc Bos. Beste Isaäc, ook in jouw promotie-onderzoek neemt de ICF een centrale plaats in. Dank voor de plezierige samenwerking, de momenten dat ik met je kon sparren en je bijdrage als auteur en co-auteur. Met jouw promotie in zicht kunnen we stellen dat het project naar de toepassingsmogelijkheden van de ICF binnen de verpleegkunde in drie academische ziekenhuizen (2000-2002) zichzelf wel bewezen heeft; jij bent al de derde projectleider die op de ICF zal promoveren.

In dit kader wil ik in het bijzonder *drs. Fokje G. Hellema* noemen, drijvende kracht achter de verpleegkundige ontwikkelingen in het UMCG en initiatiefneemster van het ICF project. Beste Fokje, het was een eer om jouw werk voort te mogen zetten nadat je met pensioen ging. Dank voor alles wat je me hebt voorgedaan en meegegeven.
Drs. Marijke C. Kastermans, drs. Albert Pranger, dr. Jeroen W. B. Peters

en drs. Gabriël Roodbol. Beste Marijke, Albert, Jeroen en Gabriel, jullie wil ik bedanken voor de inbreng bij de onderzoeken die zijn uitgevoerd op respectievelijk de Hanzehogeschool Groningen en de Hogeschool van Arnhem en Nijmegen. Ik ben jullie zeer erkentelijk voor de beschikbaarheid en de ruimte die ik kreeg om de ICF op verschillende manieren toe te kunnen passen. Dank voor jullie bijdrage als co-auteur en de hartelijke en betrokken relatie, ik heb me altijd zeer welkom gevoeld. Ik kijk uit naar de toekomst waarin ik hoop deze samenwerking binnen de hogescholen te kunnen continueren.

Dr. Yvonne F. Heerkens. Beste Yvonne, jij bent voor mij het grote voorbeeld als het gaat om de implementatie en het gebruik van de ICF. Als een van de eersten in Nederland heb je vanuit het Nederlands Paramedisch Instituut de ICF toegepast in talloze onderzoeken, projecten, en trainingen. Dank voor de momenten van overleg en je waardevolle bijdrage als co-auteur. Graag trek ik de komende jaren met je op in de ontwikkelingen ten aanzien van de ICF zowel in nationaal als internationaal verband.

Mijn paranimfen *dr. Gert Schout en dr. Wiebe de Vries.*

Lieve Gert, al bijna een levenlang zijn wij vrienden. Als geen ander ken je mijn onzekerheden en twijfels. Maar ook als geen ander heb je me uitgedaagd en aangespoord om dit onderzoek te gaan doen. Wij delen een passie voor een gezondheidszorg waarin het werkelijk om de patiënt gaat. Voor jouw onvoorwaardelijke steun en vertrouwen, maar vooral voor je ‘zijn’ en nabijheid tijdens de promotie en alle voorbereidingen op weg daar naar toe wil ik je heel erg bedanken.

Lieve Wiebe, niet alleen ben ik blij dat je mijn directe steun en toeverlaat wilt zijn tijdens mijn promotie, maar ook met je meedenken in mijn onderzoek en het mede-organiseren van het congres. Wij kennen elkaar sinds 1987 van de leraren opleiding Verpleegkunde en het was gelijk duidelijk dat wij elkaar goed lagen. Ik ken niemand die zo goed in staat is om ideeën tot praktische uitvoer te brengen. Ook nu heb je dat weer bewezen, heel veel dank daarvoor.

Miranda Lip, Suzanne Bakker, Marjolein van der Ploeg en Klaudia Arends, stagiaires van de opleiding Verpleegkunde, bedankt voor jullie bijdrage aan de uitvoering van het onderzoek, het invoeren van data en het doen van de eerste analyses.

Sonja Hintzen, bedankt voor je zorgvuldige en goede manier waarop je mijn artikelen en het manuscript hebt gecorrigeerd. Door de jaren heen leerde je mijn onderwerp goed kennen en was je veel meer een editor dan enkel iemand die op Engelse taal en spelling corrigeert. Je betrokkenheid en toegankelijkheid, je snelle reactie op mail en je goede tekstvoorstellen zijn van grote waarde voor mijn promotie geweest.
Petra Ritsema, dank voor je ondersteuning bij het samenstellen van het manuscript.
Riki Nikkels, onder (oud) collega's is bekend dat als een tekst jouw kritisch oog heeft doorstaan, je pas zeker weet dat het het daglicht kan verdragen. Dank dat ik mijn Nederlandse teksten van dit manuscript daaraan mocht onderwerpen.

Drs. Coby Annema, dr. Aeltsje Brinksma, dr. Gerda Drent, drs. Yvonne ten Hoeve, dr. Gea A. Huizinga, dr. Marion J. Siebelink, dr. Esther Sulkers en drs. Astrid Tuinman, lieve collega's, wij hebben ieder ons eigen onderwerp, maar zijn met elkaar verbonden als zorgonderzoekers binnen het UMCG vanuit de verpleegkunde. Dank voor jullie collegialiteit en het delen van problemen maar ook de vreugde die we allemaal als promovenda ervaren. Het is fantastisch dat we al zoveel promoties hebben kunnen vieren en ik hoop dat we binnenkort allemaal gepromoveerd zullen zijn.

In de vijf en dertig jaar van mijn carrière, en ruim vijftig jaar van mijn leven zijn er talloze mensen aan wie ik schatplichtig ben, omdat zij mij hebben gevormd, uitgedaagd, en geïnspireerd. Docenten, studenten, leidinggevenden, collega's, maar bovenal *ouders, familie en vrienden.* Heel veel dank daarvoor, jullie hebben mij gebracht tot waar ik nu ben. Een speciaal woord van dank komt mijn moeder *Agnes Stallinga-Steevels* († 2013) toe. Lieve moeder, jij leerde mij als schipperskind niet alleen lezen en rekenen, maar vooral onafhankelijk en zelfstandig te zijn. Jammer dat je de afronding van mijn promotie niet meer mee kan maken, maar dat ik af zou ronden……….dat wist jij wel.
Nicolien van Halem, lieve vriendin, dank dat je de foto's op mijn promotie wilt maken.

Henk Stallinga, lieve broer, ik vind het een grote eer dat je de omslag van mijn proefschrift hebt gemaakt. Dank voor het beeld dat je hebt gecreëerd waarin de essentie van functioneren tot uitdrukking is gebracht: een puzzel.

Wouter, Annelies, Carolien en Marieke, jullie zijn de liefste en leukste kinderen die je je als ouder maar bedenken kan. Met een strakke planning en logistiek voor het huishouden dacht ik dat mijn passie voor mijn werk jullie niet zou opvallen. Maar met het klimmen van de jaren zagen jullie dat wel en deden juist een appèl op het wel naar buiten komen met die passie. Heel veel dank daarvoor, nooit gedacht zoveel support maar tegelijkertijd ook zoveel relativering van jullie te mogen ontvangen. Jullie betrokkenheid is fantastisch, de humor onovertroffen, en 'het mij bij de les houden in het normale leven' onverslaanbaar.

Tenslotte, maar niet in de laatste plaats, lieve *Richard,* jij bent bereid om mijn dromen waar te maken. Met het gereedkomen van dit proefschrift heb je dat weer gedaan. Dank voor al je geduld, tijd en ondersteuning maar bovenal voor je enorme optimisme en relativeringsvermogen. Er is geen man die ik zo leuk vind als jij. Ik kijk uit naar de vele 'onze uurtjes' waarin ik hoop de balans weer in evenwicht te kunnen brengen en we zowel het leven van alle dag als onze eigen en gezamenlijke dromen de revue kunnen laten passeren.

About the author

Hillegonda Alida (Gonda) Stallinga (Amsterdam, October 15, 1961) grew up as the middle child with two brothers. She and her siblings lived on a barge. After the Dutch Compulsory Education Law of 1969 was passed, the family's life on a barge came to an end. The family settled in Leeuwarden, the Netherlands, where Gonda graduated from high school (Karel Doorman MAVO) in 1977. She earned her Vocational Nursing degree in 1980.

After obtaining her degree, Gonda was employed as one of the first intermediate vocationally trained nurses, and the youngest nurse at that, at the University Medical Center Groningen (UMCG). She worked on several wards from 1980 to 1990 including Surgery, Internal Medicine, Psychiatry, and Intensive Care.

During this period, Gonda completed a middle management training at the Institute for Business Administration in Bilthoven (1982-1984), the Intensive Care training for nurses at the UMCG (1985-1986), and the Nurse Tutor Training Program at the University of Applied Sciences in Leusden (1987-1989).

In 1981, Gonda became a member of the Nursing Student Council at the UMCG. When the hospital-based training for nurses was discontinued at the UMCG, she continued the aforementioned council as the Nursing Council. Gonda also chaired this council until 1987.

After 10 years of working as a nurse, Gonda became a staff member at the Department of Nursing Affairs. She coordinated the practical training for nursing students (Vocational and Bachelor) and from 1993 to 2006 she was involved in the development, implementation, and evaluation of the nursing process, clinical reasoning, and the use of nursing standards in clinical practice.

During this period Gonda completed a postgraduate program in Professional Innovation in Health Care (1993-1995) at the University of Applied Sciences in Utrecht, after which she was sent on secondment to the Hanze

University of Applied Sciences in Groningen (1995-1997) to work as a project member at the project ‘Clinical decision-making to support job differentiation in nursing’. In 1999, she started her Master’s program in Health Sciences, at the University of Maastricht, specializing Nursing Science. She graduated in 2004, with a thesis on the validity of the mapping of problems in functioning to the ICF. While studying for her Master’s degree, Gonda was one of the leaders of the project ‘Applications of the ICF in nursing’ (2000-2002), which was carried out at three University Medical Centers in the Netherlands in cooperation with the Dutch Centre for Nursing and Care. This project inspired her to commence her PhD research in 2006 at the School of Nursing and Health of the Wenckebach Institute at the UMCG, which resulted in this thesis.

Gonda is a member of the ICF-expert team of the World Health Organization Family of International Classifications Collaborating Center (WHO-FIC-CC) in Bilthoven, the Netherlands (RIVM). She provides training in the use of the ICF and is involved in an international partnership of the WHO-FIC, which aims to develop a mobile application for using the ICF. She is also a member of the Lectureship Committee of ‘Nursing Innovation and Positioning' at the Hanze University of Applied Sciences in Groningen.

Gonda is married to Richard Verschure and they have four children: Wouter (1989), Annelies (1990), Carolien (1993) and Marieke (1995).

Over de auteur

Hillegonda Alida (Gonda) Stallinga (Amsterdam; 15 oktober 1961) groeide op als middelste kind in een gezin met twee broers op een binnenvaartschip. Met de leerplichtwet van 1969, waarbij alle kinderen verplicht werden naar school te gaan, eindigde het schippersbestaan en vestigde het gezin zich in Leeuwarden. Daar behaalde Gonda in 1977 haar middelbare school diploma (Karel Doorman MAVO) en rondde ze in 1980 met succes de Middelbare Beroepsopleiding voor Verpleegkundige af.

Daarna trad zij als één van de eerste mbo-opgeleide verpleegkundigen én als jongste verpleegkundige in dienst bij het Universitair Medisch Centrum Groningen (UMCG), destijds Academisch Ziekenhuis Groningen (AZG). Ze was van 1980 tot 1990 werkzaam in de functie van verpleegkundige op de afdelingen Chirurgie, Interne Geneeskunde, Psychiatrie en Intensive Care.

In deze periode behaalde ze het diploma ‘Management in Ziekenhuizen en Instellingen’ aan het Instituut voor Bedrijfswetenschappen te Bilthoven (1982-1984) en voltooide ze de Intensive Care opleiding voor Verpleegkundigen in het UMCG (1985-1986) en de tweedegraads Leraren Opleiding Verpleegkunde aan de Hogeschool Midden Nederland te Leusden (1987-1989).
Gonda was daarnaast actief als verpleegkundige in de leerlingenraad van het AZG. Deze raad zette ze na het opheffen van de Inservice-A opleiding voort als verpleegkundigenraad waarin ze de rol van voorzitter vervulde (1981-1987).

Na 10 jaar in de patiëntenzorg gewerkt te hebben, maakte Gonda in 1990 de overstap naar de functie van stagecoördinator (1990-1993) en later stafmedewerker (1993-2006) bij het bureau Verpleegkundige Zaken. In de laatste functie was ze betrokken bij de ontwikkeling, implementatie, evaluatie en training van methodisch werken, klinisch redeneren en het gebruik van verpleegkundige standaarden in de klinische praktijk.

In deze periode voltooide Gonda de post hbo-opleiding voor Beroepsinnovatie (1993-1995) waarna ze voor de duur van twee jaar gedetacheerd werd naar de Hanzehogeschool Groningen als projectmedewerker bij het project ‘Methodiekontwikkeling ter ondersteuning van functiedifferentiatie in de verpleging’ (1995-1997). In 1999 begon ze met de studie Gezondheidswetenschappen, afstudeerrichting Verplegingswetenschap, aan de Universiteit Maastricht. Deze studie rondde ze in 2004 af met een doctoraalonderzoek naar de validiteit van de mapping van functioneringsproblemen naar de ICF. Gedurende deze studie was ze één van de UMCG projectleiders van het project ‘Toepassingsmogelijkheden van de ICF binnen de verpleegkunde’ (2000-2002), dat werd uitgevoerd in drie UMC’s in samenwerking met het Landelijk Centrum Verpleging en Verzorging. Dit project vormde in 2006 de directe aanleiding voor de overstap naar de functie van zorgonderzoeker bij de School of Nursing and Health van het Wenckebach Instituut van het UMCG, alwaar ze startte met promotieonderzoek dat geresulteerd heeft in dit proefschrift.

Gonda is lid van het ICF expert team van de World Health Organization Family of International Classifications Collaborating Centre (WHO-FIC-CC) in Nederland (Bilthoven, RIVM). Zij verzorgt landelijke trainingen in het gebruik van de ICF. Ook is ze betrokken bij het internationale samenwerkingsverband van de WHO-FIC waarin een mobiele applicatie voor de ICF wordt ontwikkeld. Tevens is ze lid van de kenniskring van het lectoraat ‘Verpleegkundige Innovatie en Positionering’ van de Hanzehogeschool Groningen.

Gonda is getrouwd met Richard Verschure. Zij hebben samen vier kinderen: Wouter (1989), Annelies (1990), Carolien (1993) en Marieke (1995).

Research Institute SHARE: previous dissertations

This thesis is published within the Research Institute SHARE (Science in Healthy Ageing and healthcaRE) of the University Medical Center Groningen / University of Groningen. Further information regarding the institute and its research can be obtained from our internetsite: http://www.share.umcg.nl/.

More recent theses can be found in the list below.
((co-) supervisors are between brackets)

2015

Wyk, L van
Management of term growth restriction; neonatal and long term outcomes
(prof SA Scherjon, prof JMM van Lith, dr KE Boers, dr S le Cessie)

Vos FI
Ultrasonography of the fetal nose, maxilla, mandible and forehead as markers for aneuploidy
(prof CM Bilardo, prof KO Kagan, dr EAP de Jong-Pleij)

Twillert S van
Linking scientific and clinical knowledge practices; innovation for prosthetic rehabilitation
(prof K Postema, prof JHB Geertzen, dr A Lettinga)

Loo HM van
Data-driven subtypes of major depressive disorder
(prof RA Schoevers, prof P de Jonge, prof JW Romeijn)

Raat AN
Peer influence in clinical worokplace learning; a study of medical students'use of social comparison in clinical practice
(prof J Cohen-Schotanus, prof JBM Kuks)

Standaert BACGM
Exploring new ways of measuring the economic value of vaccination with an application to the prevention of rotavirus disease
(prof MJ Postma, dr O Ethgen)

Kotsopoulos N
Novel economic perspectives on prevention and treatment: case studies for paediatric, adolescent and adult infectious diseases
(prof MJ Postma, dr M Connolly)

Feijen-de Jong, EI
On the use and determinants of prenatal healthcare services
(prof SA Reijneveld, prof F Schellevis, dr DEMC Jansen, dr F Baarveld)

Hielkema M
The value of a family-centered approach in preventive child healthcare
(prof SA Reijneveld, dr A de Winter)

Dul EC
Chromosomal abnormalities in infertile men and preimplantation embryos
(prof JA Land, prof CMA van Ravenswaaij-Arts)

Heeg BMS
Modelling chronic diseases for reimbursement purposes
(prof MJ Postma, prof E Buskens, prof BA van Hout)

Vries, ST de
Patient perspectives in the benefit-risk evaluation of drugs
(prof P Denig, prof FM Haaijer-Ruskamp, prof D de Zeeuw)

Zhu L
Patterns of adaptation to cancer during psychological care
(prof AV Ranchor, prof R Sanderman, dr MJ Schroevers)

Peters LL
Towards tailored elderly care with self-assessment measures of frailty and case complexity
(prof E Buskens, prof JPJ Slaets, dr H Boter)

Vart P
Prevention of chronic kidney disease and its concequences; the role of socioeconomic status
(prof SA Reijneveld, prof U Bültmann, prof RT Gansevoort)

Mutsaerts M
Lifestyle and reproduction
(prof JA Land, prof BW Mol, dr A Hoek, dr H Groen)

Sulkers E
Psychological adaptation to childhood cancer
(prof R Sanderman, prof PF Roodbol, prof ESJM de Bont, dr J Fleer, dr WJE Tissing)

Febrianna SA
Skin problems related to Indonesian leather & shoe production and the use of footwear in Indonesia
(prof PJ Coenraads, prof H Soebono, dr MLA Schuttelaar)

2014

Schneeberger C
Asymptomatic bacteruiria and urinary tract infections in women: focus on diabetes mellitus and pregnancy
(prof RP Stolk, prof JJHM Erwich, dr SE Geerlings)

Skorvanek, M
Fatigue, apathy and quality of life in patients with Parkinson's disease
(prof JW Groothoff, prof Z Gdovinova, dr JP van Dijk, dr J Rosenberger)

Kolvek G
Etiology and prognosis of chronic kidney disease in children: Roma ethnicity and other risk factors
(prof SAReiijneveld, prof L Podracka, dr JP van Dijk, dr J Rosenberger)

Mikula P
Health related quality of life in people with multiple sclerosis; the role of coping, social participation and self-esteem
(prof JW Groothoff, prof Z Gdovinova, dr JP van Dijk, dr I Nagyova)

Amalia R
Improving a school-based dental programme through a sociodental risk group approach
(prof RMH Schaub, prof JW Groothoff, prof N Widyanti)

Christoffers WA
Hand eczema; interventions and contact allergies
(prof PJ Coenraads, dr MLA Schuttelaar)

Troquete NAC
START-ing risk assessment and shared care planning in out-patient forensic psychiatry; results from a cluster randomized controlled trial
(prof D Wiersma, prof RA Schoevers, dr RHS van den Brink)

Golea E
Functioning of young individuals with upper limb reduction deficiencies
(prof CK van der Sluis, dr RM Bongers, dr HA Reinders-Messelink)

Nguyen HT
Medication safety in Vietnamese hospitals; a focus on medication errors and safety culture
(prof K Taxis, prof FM Haaijer-Ruskamp, prof JRBJ Brouwers, dr TD Nguyen)

Lehmann V
Singlehood and partnerships in healthy people and childhood cancer survivors; a focus on satisfaction
(prof M hagedoorn, prof R Sanderman, dr MA Tuinman)

Jaarsma EA
Sports participation and physical disabilities: taking the hurdle?!
(prof JHB Geertzen, prof PU Dijkstra, dr R Dekker)

Ockenburg SL van
Psycholopgical states and physical fates; studying the role of psychosocial stress in the etiology of cardiovascular disease: a nomothetic versus an idiographic approach
(prof JGM Rosmalen, prof P de Jonge, prof ROB Gans)

For more 2014 and earlier theses visit our website

Research Institute
SHARE