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for the FIC
in The Netherlands

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WHO Family of International Classifications (FIC)

NEWSLETTER

National cause-of-death data in the English- and Dutch-speaking Caribbean

A quality assessment for the period 2000 – 2010

The quality of mortality data is a potential weakness in any national mortality surveillance system and affects both high and low income countries. The Caribbean Public Health Agency (CARPHA) maintains a regional database of cause-of-death data, which is populated by data received annually from 23 of its member states.

Determining data quality

The usefulness of cause-of-death data and its ability to guide public health planning and inform policy can be greatly constrained by data quality. This reduced quality can be a result of several factors including the level of completion of the medical certificates of death by physicians and the selection practices for the underlying cause of death. One of the ways in which CARPHA can assess the quality of national cause-of-death data submitted by its member states is to quantify the proportion of deaths that can be attributed to uninformative or ill-defined causes. Such causes have been termed garbage codes (GCs) by Naghavi and colleagues (2010; 1).

Percentage of deaths attributed to garbage codes

A review of available data from 21 CARPHA member states for the 11-year period 2000-2010, shows that the proportion of deaths attributed to GCs varies widely by country and over time (Table 1). This proportion ranges from 11-49%. Of the 212 country-years of data analyzed, 75 country-years (35%) have less than 20% of ... (continues on page 2)

Table 1 - Proportion of Deaths attributed to Garbage Codes by CARPHA Member Country, 2000-2010

| | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 |
|--------------------------|------|------|------|------|------|------|------|------|------|------|------|
| Anguilla | 31% | 48% | 32% | 39% | 17% | 16% | 21% | 15% | 16% | 13% | 12% |
| Antigua/ Barbuda | 22% | 28% | 24% | 27% | 24% | 32% | 30% | 19% | 25% | 23% | |
| Aruba | 41% | 32% | 29% | 27% | 32% | 27% | 31% | 27% | 31% | 28% | 27% |
| Bahamas | 15% | 17% | 26% | 17% | 15% | 16% | 16% | 17% | 16% | 15% | 17% |
| Barbados | 27% | 29% | 28% | 30% | 35% | 31% | 23% | 21% | 24% | 23% | 22% |
| Belize | 30% | 29% | 24% | 26% | 26% | 23% | 22% | 25% | 21% | 15% | 15% |
| Bermuda | 14% | 17% | 13% | 13% | 13% | 15% | 19% | 18% | 16% | 21% | 21% |
| British Virgin Islands | 41% | 29% | 29% | 29% | 35% | | 38% | | 36% | 38% | 22% |
| Cayman Islands | 19% | 31% | 21% | 15% | 15% | | 28% | 30% | 23% | 30% | 19% |
| Dominica | | 37% | 38% | 36% | 33% | 19% | 15% | 23% | 21% | 21% | 20% |
| Grenada | 21% | 31% | 27% | 31% | 27% | 22% | 24% | 23% | 29% | 24% | 19% |
| Guyana | 13% | 19% | 17% | 14% | 16% | 14% | 16% | 17% | 17% | 22% | 20% |
| Jamaica | 25% | 31% | 34% | 25% | 20% | 22% | 15% | 15% | 16% | | |
| Montserrat | 22% | 33% | 29% | 21% | 41% | 29% | 21% | 39% | 18% | 25% | 13% |
| Netherlands Antilles | 24% | | | | | | | | | | |
| St. Kitts/ Nevis | 39% | 46% | 35% | 36% | 38% | 26% | 20% | 15% | 14% | 16% | 14% |
| St. Lucia | 27% | 24% | 28% | 27% | 26% | 34% | 31% | 27% | 28% | 17% | 22% |
| St. Vincent/ Grenadines | 19% | 21% | 19% | 19% | 16% | 19% | 12% | 13% | 22% | 29% | 21% |
| Suriname | 26% | 23% | 23% | 21% | 25% | 24% | 19% | 20% | 21% | 20% | 21% |
| Trinidad/ Tobago | 12% | 13% | 11% | 11% | 12% | 12% | 13% | 14% | 14% | | |
| Turks and Caicos Islands | 31% | 41% | 30% | 43% | 45% | 43% | 45% | 49% | 45% | 21% | |

Number of countries targeted by CARPHA initiatives

| | | | | | | | | | | |
|---|---|---|---|---|----|---|----|---|---|----|
| 0 | 0 | 0 | 0 | 0 | 13 | 3 | 18 | 4 | 4 | 20 |
|---|---|---|---|---|----|---|----|---|---|----|

Notes: Blank squares indicate missing cause-of-death data

Legend: Proportion of deaths attributed to GCs
0% 50%

Editorial

Season's Greetings everyone! At the end of the year it is kind of a tradition to look back at the year behind us. For ICD-11 it has been a very important year; this newsletter contains an overview of progress made in 2015. Also in this newsletter a meeting report from the Washington Group on Disability Statistics' 15th meeting in Copenhagen with an overview of activities over the past year, and a contribution by the Caribbean Public Health Agency focusing on cause-of-death data quality, and finally a report from an ICF conference in Poland. This issue also contains contributions that look ahead, more or less: an Australian contribution that highlights the need for an integrative measure of functioning, a contribution from the Netherlands on geriatric cardiac rehabilitation interventions and a Belgian contribution on the ICF-Lab. Regarding some other members of the family (e.g. ICHI) we (still) unfortunately do not have enough news for the time being. As always, the last pages are filled with new ICF literature references, added to our ICF literature database.

Needless to say, of course, that the WHO-FIC Newsletter can only be produced when you share your news with us, and we will be happy to report on it for you in the next issue of this newsletter. So, please share your thoughts and experiences on using WHO classifications with us, and send us your contributions! Please also feel free to send us your feedback on newsletter articles should you feel compelled to do so. Enjoy reading and let us know your WHO-FIC news!

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National cause-of-death data in the English- and Dutch-speaking Caribbean (continued)

...deaths attributed to GCs while 46 country-years (22%) have 30- 50% of deaths being attributed to GCs. Furthermore, for the period 2000-2004, 32% of the reported annual data had between 30-50% garbage codes; the proportion of reported annual data with 30-50% garbage codes reduced to 12% for the period 2005-2010. This reduction coincides with CARPHA training initiatives which began in 2005.

Improving cause-of-death data

From 2005 to present CARPHA has prioritized the improvement of mortality surveillance in its member states. Routine workshops are conducted in mortality coding and member states are provided with software developed to support the coding process. Additionally, workshops and training videos were developed for physicians on the correct completion of medical cause-of-death certificates (2). These initiatives seem to have had an impact on the quality of the

reported data. However, there remains a need for concerted effort and drive by CARPHA to continue to assist its member states in reducing the proportion of deaths attributed to GCs.

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2. Caribbean Epidemiology Centre (CAREC/PAHO). Caribbean Public Health Agency (CARPHA). [Online].; 2007 [cited 2015 May 19]. Available from: <http://carpha.org/What-We-Do/Training>.

Latest News

The dates for the **WHO-FIC Network meeting 2016 in Japan** have been set: **8-14 October 2016**. The theme for this year will be determined soon. All posters for the conference (both poster abstracts and the final versions of posters for print) must be submitted to the WHO Secretariat via the online submission platform (available at: <http://www.who.int/classifications/network/meeting2016/>). The title, abstract and profile must be submitted by **15 June 2016**. The final, complete poster must be submitted by **5 August 2016** using the appropriate poster template, at <http://www.who.int/classifications/network/meeting2016/>.

The **2016 Pacific Rim International Conference on Disability and Diversity** (25 & 26 April 2016, Honolulu, Hawai'i) will have a topic focus on the **ICF**, for the 3rd year in a row. More specifically, they have an Exploration Topic Area which focus on the ICF and Capabilities Approach (<http://www.pacrim.hawaii.edu/topics/exploration>). To that end they are inviting proposal submissions that demonstrate how the **capabilities approach** and/or the **ICF** can be used to positively impact the overall health and well being of individuals around the globe. More information on: <http://www.pacrim.hawaii.edu>.

Early September, **Ms Mea Renahan** announced her **retirement** per September 30th 2015 from the North American WHO-FIC Collaborating Centre (NACC) and from the Canadian Institute for Health Information (CIHI). The editorial board of the WHO-FIC Newsletter did not want to let this pass without showing our and the WHO-FIC network's appreciation for her work, and we invited Marjorie Greenberg – former co-head of the NACC – to write down some memories she has on her cooperation with Mea over the years.

“When Mea Renahan retired from the Canadian Institute for Health Information (CIHI) on September 30, 2015, she left

an impressive legacy, not only with CIHI but with the North American Collaborating Center (NACC) and the WHO Family of International Classifications (WHO-FIC) Network. Mea joined CIHI in 2001 and served as Manager of Classifications from 2003-2011, when she was promoted to Director, Data Standards, with responsibility for classifications and terminologies, as well as data quality. While leading the ongoing implementation and use of ICD-10-CA and the Canadian Classification of Health Interventions across all of Canada, Mea also played a critical role in NACC and the WHO-FIC Network. Most notably, Mea served as co-chair of the Network's Update and Revision Committee from 2004-2012 and assured strong Canadian support to all of the committees and reference groups in the Network. Mea was tireless in her support of health information, classifications and data standards at the national and global levels. She shared my passions and was my ally in the North American Collaborating Center and in the U.S. efforts to implement ICD-10 code sets, a goal that finally was achieved on October 1, 2015. Mea always spoke proudly of the positive impact of ICD-10-CA and CCI in Canada and helped those of us in the U.S. "keep the faith".

I have more memories of being with Mea in more places around the world than I can recount, but I'll mention a few. I recall walking together through the streets of Helsinki, while Mea considered assuming responsibility for the URC, and then watching her skilled and dedicated performance in this role over future years. I also remember being together in Tokyo for the launch of ICD-11, and then the subsequent trip to Odawara to work on the Network's strategic and business plans, when bad weather prevented us from even seeing Mt Fuji but still didn't dampen our spirits. And none of us can forget the spectacular 2010 WHO-FIC Network annual meeting Mea organized in Toronto, where we also met with our International Health Terminology Standards Development Organization (IHTSDO) Colleagues and took one of the Network's most memorable excursions to Niagara Falls and Niagara-on-the-Lake. Shortly before I retired in November 2013, the U.S. delegation was unable to attend the WHO-FIC Network Annual Meeting in Beijing, due to closure of the Federal Government; it was a great disappointment, but I was confident that the North American Collaborating Center was well represented by Mea and her able Canadian colleagues.

Mea will be missed, but we all wish her a well-deserved retirement!"

Marjorie S. Greenberg
Former head, WHO-FIC Collaborating Center for North America (1996-2013)

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International Organizations

Washington Group on Disability Statistics

Report of the Washington Group (WG) on Disability Statistics: the 15th Annual Meeting (Copenhagen, Denmark)

The Washington Group has held 15 annual meetings since its inception: (1) 2002, Washington, D.C., USA; (2) 2003, Ottawa, Canada; (3) 2004, Brussels, Belgium; (4) 2004, Bangkok, Thailand; (5) 2005, Rio de Janeiro, Brazil; (6) 2006, Kampala, Uganda; (7) 2007, Dublin, Ireland; (8) 2008, Manila, Philippines; (9) 2009, Dar es Salaam, United Republic of Tanzania; (10) 2010, Luxembourg; (11) 2011, Southampton Parish, Bermuda; (12) 2012, Bangkok, Thailand; (13) 2013, Amman, Jordan; (14) 2014, Buenos Aires, Argentina; and (15) 2015, Copenhagen, Denmark. Annual meetings are rotated through major geographic regions to facilitate participation, especially by low resource countries.

The Washington Group has sought to foster international collaboration and to ensure that the efforts of the group are broad-based and include voices from every region of the world. Therefore, representatives of national statistical authorities, disabled people's organizations and international organizations participate in the Washington Group. Currently, representatives of the national statistical offices of 133 countries and territories, 7 international organizations, 6 organizations that represent persons with disabilities, the Statistics Division of the Department of Economic and Social Affairs and other United Nations system entities are members of the Washington Group.

Overview of the Fifteenth meeting

The 15th meeting of the WG, hosted by Statistics Denmark, was held 27-29 October 2015 in Copenhagen, Denmark. Highlights from the meeting are presented below.

WG Short Set and Extended Set on Functioning

The extended set of disability questions on functioning were added to the US National Health Interview Survey (NHIS) beginning in 2010. During the past year, analyses of individual domains were finalized using data from the 2010 and 2013 NHIS. A review of the algorithms developed for combining multiple domain questions into single domain indicators of disability and the standards for determination of cut-points were presented. Final analyses will be compiled and presented in a document describing the properties of individual domains of functioning – including programming syntax for replicating the analyses with other data files.

WG/UNICEF Child Functioning Module

The workgroup on the development of question modules designed to measure disability among children presented recent accomplishments. The Module on Child Functioning was included as part of a Demographic and Health Survey in Samoa. Preliminary findings on the Samoan data were presented. Further analysis of the Samoan data and data collected from additional field testing of the module will be used to inform the development of guidelines for producing statistics on children with disabilities. A user's manual and guidelines for analyses will also be finalized to accompany the Module on Child Functioning. The session also included a presentation by a representative from the London School of Hygiene and Tropical Medicine showing results using a pre-final version of the Module on Child Functioning in Cameroon, India and Fiji.

WG/UNICEF Module on Inclusive Education

The WG has also collaborated with UNICEF on the development of a module designed to measure facilitators and barriers to school participation. An update on the work accomplished in the past year, including the presentation of sample questions from the current version of the module were presented. Cognitive testing of the UNICEF/WG Module on Inclusive Education was carried out in the United States by the Question Design Research Laboratory (QDRL) at the National Center for Health Statistics (NCHS) in 2015. Results from the cognitive tests will be used to inform revisions to the module. Additional cognitive testing and field testing of the revised module are scheduled to take place in 2016. The final module is expected to be ready by the next WG meeting.

Disability Module for Labor Force Surveys

The WG has recently begun collaboration with the International Labor Organization (ILO) and University College of London on the development of a disability module intended for use in labor force surveys. A representative from ILO presented current practices used for collecting information on disability in labor force surveys and explained the need for the development of a module to collect information on the barriers people with disabilities face in the labor market. A second presentation included a review of the development of proposed module and provided examples of some of the questions that have been drafted. The module will include sections on barriers to participation in the labor force, workplace accommodations, social attitudes and social protection. The QDRL at NCHS is scheduled to conduct cognitive testing of the module in the United States in 2016. Revisions will be made based on the cognitive test results; followed by cognitive and field testing in additional countries.

Mental Health

The workgroup investigating the development of measures specific to mental health presented a review of their work plan. This includes a systematic review of existing questions on activity limitations, participation restrictions and

environmental barriers commonly associated with common and severe mental disorders is planned. The workgroup will also examine the existing WG questions to determine the extent to which they address the measurement of activity limitations and participation restrictions commonly associated with severe and common mental disorders.

Environmental Factors and Participation

Following the ninth WG meeting in Dar es Salaam, a workgroup was formed to look more closely at the development of a set of questions on environmental factors as they relate to the measurement of disability. An evaluation of the available approaches and questions were presented at subsequent meetings. Work on the development of questions on environmental factors and participation was revisited at the meeting in Copenhagen. The presentation included a review of the purpose for developing the question set as well as an overview of two approaches that can be used to capture information about the environment: 1) directly - measuring the environment independently of the person 2) indirectly - measuring the environment through the person's participation in selected activities. The major challenges associated with each approach and sample questions were also provided. It was agreed to proceed with measuring the environment indirectly through the person's participation in selected activities and the workgroup was asked to write up the proposal and to draft a set of questions for one domain to illustrate the proposed approach for discussion at the next meeting.

Frameworks for Indicators to Address Monitoring Disparities by Disability Status

The meeting in Copenhagen included a session focusing on the development of outcome indicators that can be used to measure the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) and attainment of the Post 2015 Sustainable Development Goals (SDGs).

The session included the following:

- a presentation by the Danish Institute for Human Rights on their work with the Danish Social Research Institute to develop a set of 10 statistical outcome indicators (Gold Indicators) that correspond with 10 key elements from the UN CRPD;
- a presentation describing the implementation of the Incheon Strategy in UN Economic and Social Commission for Asia and the Pacific (ESCAP) countries;
- a presentation by two representatives from Sightsavers on their work on a disability disaggregation two pilot projects – an Eye Health Project in Bhopal, India and a Neglected Tropical Disease (NTD) Project in Tanzania;
- a presentation on disability indicators for the SDGs was provided by a representative from UN DESA/UN Secretariat of the CRPD.

Country Activities

- The WG continues to monitor the collection of disability data internationally, and annually requests detailed information from member countries covering survey periodicity, sample size and frame, mode of data collection, language(s) used, and exact question wording along with response options. A review of Annual reports was presented.
- Individual country activities were presented by representatives from Brazil, Denmark and Morocco. These covered, respectively, a comparison of results from the 2000 and 2010 Populations Censuses in Brazil, practical experiences from the Danish disability registry and results from the 2004 and 2014 Censuses and 2014 National Survey on Disability in Morocco.

Collaborative Activities

- A representative from the Australian Department of Foreign Affairs and Trade (DFAT) provided an overview of DFAT's collaborations with the WG, University College London, UNICEF, UN Statistics Division and the Australian Bureau of Statistics. DFAT has provided funding to the WG to improve collection and analysis of disability statistics globally by strengthening the WG's capacity to broadly disseminate and provide technical assistance to support the consistent implementation of the WG's existing data collection tools; and to develop measures of participation and activity limitations related to mental health.
- An overview of the United Kingdom's 'Leave No One Behind' promise was presented by a representative from the UK Department for International Development.
- An overview of the WG's collaboration with Handicap International (HI) was provided by two representatives from HI. The presentation included a few examples of projects conducted by HI that incorporate the use of disability data and the timeline of events leading to the eventual collaboration between HI and the WG.
- A post-meeting session on the Global Network on Monitoring and Evaluation for Disability-inclusive Development (MEDD) was led by a representative from the UN DESA/UN Secretariat of the CRPD.

Plans for the Sixteenth meeting

The 16th meeting is scheduled to take place in Pretoria, South Africa in late 2016.

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World Health Organization

ICD-11 News

In April 2015, the external review report for the ICD-11 revision process was completed; and in May 2015, WHO

produced its response to the report. The ICD-11 revision review recommended that strong focus be placed on the Joint Linearization for Mortality and Morbidity Statistics (JLMMS) as a priority. WHO's response to the report confirmed this priority, and stated that the 2016 strategy for the JLMMS will focus on developing:

- i. A classification that meets the needs of the Member States;
- ii. A sustainable model beyond 2018; and
- iii. Improved health information implementation beyond 2018 in both high and low resource settings

Major milestones for the ICD-11, and especially for the JLMMS, include providing updates to the WHO Executive Board and World Health Assembly (WHA) in 2016 and 2017 leading to endorsement by the WHO Executive Board and WHA in May 2018.

The broad range commitments to ICD-11 revision are supported by a set of revision-specific committee structures. The recent addition of new technical staff to WHO and a Project Manager supplements the existing WHO CTS team. Also, WHO intends to publish quarterly newsletters on ICD-11 revision progress; this contribution being an excerpt of the first newsletter (November 2015) (http://www.who.int/entity/classifications/icd/revision/2015_11_ICD11_Newsletter.pdf?ua=1).

ICD-11 Progress in 2015

Since WHO's response to the review report, changes have occurred to support the directions recommended in the report. In particular – and elaborated upon hereafter:

1. The formation of the Joint Linearization for Mortality and Morbidity (JLMMS) Task Force.
2. The release of a frozen version in May 2015.
3. Significant technical work underway.
4. Traditional Medicine, a new component of the ICD, is well progressed, ready for testing.
5. The shape of ICD-11 and the JLMMS now evident.

1. JLMMS Development

Besides formation of the JLMMS task force, progress regarding the JLMMS has involved – among other things – a) restructuring the infectious diseases chapter, 'diabetes' and 'postoperative complications', as well as editing 'dementia'; b) designing the linearization for primary care; c) editing the Reference Guide (volume 2); d) developing a testing strategy and multilingual version of the data entry program (ICD-FiT); and e) coordination of on-going translations.

2. Frozen version release

Besides the release in May 2015 of a frozen version of ICD-11 content on the ICD-11 browser (<http://apps.who.int/classifications/icd11/browse/l-m/en>), the browser can also be used to see the ICD foundation

component (all ICD entities; not mutually exclusive; multiple parenting allowed) and linearization(s) (a subset of the foundation component; with mutually exclusive entities; primary parents identified). Through the browser one can also download single chapters or all chapters of the ICD-11 beta draft for review purposes and see differences between consecutive versions of the beta draft.

3. Tool development

Through the ICD-11 browser one can also access the proposal platform, which is in active use. Also, in 2015 a coding tool was developed (<http://icd11ct.cloudapp.net/ct-2015-05-31>), as was a tool to translate ICD-11 into other languages, a mapping tool (ICD-11 ↔ ICD-10) and a review tool.

4. Traditional Medicine chapter

In 2015, draft Coding Guidelines and Index documents were developed for this chapter. Also, further harmonization of the Traditional Medicine Chapter terminology was achieved. Currently, there are Traditional Medicine Chapter draft translations in Chinese, Japanese, Korean (all completed), French and Spanish (ongoing). Pilot field tests for clinical utility will commence – Europe-wide; as will the first round of international peer review for this specific chapter.

5. How ICD-11 differs from ICD-10

Figure 1 gives an overview of the ICD-11 chapters. ICD-11 has many new elements, most strikingly perhaps are several new chapters:

- Chapter 3 Diseases of the Blood and Blood forming organs
- Chapter 4 Disorders of the Immune System.
- Chapter 5 Conditions related to Sexual Health.
- Chapter 8 Sleep-Wake Disorders
- Chapter 26 Extension codes
- Chapter 27 Traditional Medicine

New Concepts:

- Foundation component: Everything (ever) in ICD
- Entity: Each element in the foundation
- Linearization: also known as a Classification (e.g. JLMMS)
- Stem code: Category (includes former ‘dagger’ codes)
- Extension code: Additional information
- Linearization parents: Classification hierarchy, Chapter, Group, Category

Content Model:

- ICD-11 categories have a short and a long definition
- All ICD-11 categories include separate information on anatomy, etiology, and other aspects; accessible through searches, or when browsing in the tabular list

New Coding Scheme:

- The chapter numbering: now Arabic numbers, not roman numerals

ICD-11 / JLMMS Chapters

At a Glance

- Chapter 01** – Infectious diseases
- Chapter 02** – Neoplasms
- Chapter 03** – Diseases of the blood and blood-forming organs
- Chapter 04** – Disorders of the immune system
- Chapter 05** – Conditions related to sexual health
- Chapter 06** – Endocrine, nutritional and metabolic diseases
- Chapter 07** – Mental and behavioural disorders
- Chapter 08** – Sleep – Wake disorders
- Chapter 09** – Diseases of the nervous system
- Chapter 10** – Diseases of the eye and adnexa
- Chapter 11** – Diseases of the ear and mastoid process
- Chapter 12** – Diseases of the circulatory system
- Chapter 13** – Diseases of the respiratory system
- Chapter 14** – Diseases of the digestive system
- Chapter 15** – Diseases of the skin
- Chapter 16** – Diseases of the musculoskeletal system and connective tissue
- Chapter 17** – Diseases of the genitourinary system
- Chapter 18** – Pregnancy, childbirth and the puerperium
- Chapter 19** – Certain conditions originating in the perinatal period
- Chapter 20** – Developmental anomalies
- Chapter 21** – Symptoms, signs, clinical forms, and abnormal clinical and laboratory findings, not elsewhere classified
- Chapter 22** – Injury, poisoning and certain other consequences of external causes
- Chapter 23** – External causes of morbidity and mortality
- Chapter 24** – Factors influencing health status and contact with health services
- Chapter 25** – Codes for special purposes
- Chapter 26** – Extension Codes
- Chapter 27** – Traditional Medicine

Figure 1: ICD-11 chapter list

- The coding scheme for categories: now minimum 4 characters, 2 levels of subcategories
- Asterisk codes become Clinical forms or Extension codes. Additional sub-classifications become extension codes

Terminology:

- ICD-10 had a range of expressions to describe a causal relationship between conditions in a code title. In ICD-11, the preferred term is “due to”
- ICD-10 had a range of expressions indicating the coincidence of two conditions in a code title (e.g. “in” or “with”). In ICD-11, the preferred term is “associated with”

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This WHO-FIC newsletter contribution is an excerpt of the first ICD-11 newsletter (November 2015); available at http://www.who.int/entity/classifications/icd/revision/2015_11_ICD11_Newsletter.pdf?ua=1.

FIC around the World

Australia

The need for an integrative measure of functioning (IMF)

Functioning and disability are measured in the context of complex relationships and interactions among people, communities, services and systems. A result has been the development of a growing array of specialized measurement instruments, specific to purpose, health condition, setting or service provider. An alternative approach, particularly relevant for large national programs, is an integrative, generic measure, relevant to diverse purposes and populations (1).

Two Australian searches for measurement tools

Two major national programs in Australia have searched unsuccessfully for a suitable, generic measure of functioning.

Australia’s National Disability Insurance Scheme (NDIS) aims to “support the independence and social and economic participation of people with disability”. The NDIS provides funding to people to enable them to purchase “reasonable and necessary supports” and thus to exercise choice and control in the pursuit of their goals (NDIS Act ss.3, 34, 35).

Recording and measurement instrument(s) were required: for understanding the support and environmental changes needed, the methods and costs of meeting these needs, and to monitor progress.

The second, and equally unsuccessful, search for measures related to activity-based funding for sub-acute hospital patients, particularly rehabilitation patients. The report on the search and analysis acknowledged the difficulty of balancing the competing demands of instrument sensitivity, avoiding ceiling and floor effects, clinical utility, ease of completion, and the need for the instrument to be usable across settings.

Results

Analysis of these two searches in Australia revealed common challenges and pointed to apparently similar solutions (1). In both cases it was concluded that the desired tool should be ICF based, cover the full range of Activities and Participation chapters, take account of environmental factors, and measure need for “support” or “assistance with functioning”. Given the breadth of the programs and the diverse populations served, instruments specific to health conditions or settings could not be used in either national program. The findings demonstrate the need for a generic, integrative measure of functioning (IMF), applicable in rehabilitation, disability support, and related fields.

Discussion and Conclusion

These findings are relevant in policy development and information management internationally. An IMF based on the ICF Activities and Participation chapters, incorporating environmental factors and including measures of “need for support or assistance” would provide a complementary or partner instrument to the WHODAS which uses “difficulty” as its measure. Such an IMF could deliver a range of benefits, including supporting person-centred care, by providing comprehensive information on functioning across all life domains, facilitating data-sharing and communication across service interfaces to promote continuity of care, and reducing the burden and cost associated with repeated assessment.

An IMF could also provide a basis for harmonizing the conceptual approach to and measurement of functioning in fields such as chronic disease, aged care, mental health and public health, where people’s successful functioning is a core aim of the service system. The lack of an IMF has limited cooperation across programs – for example, cooperation for the benefit of people who need services bridging the disability and mental health services sectors (2). Equity is a fundamental principle of public health, with reduction of health disparities a primary goal. People with disability are typically disadvantaged in their health outcomes due to various structural factors. Specifically, information on environmental facilitators or barriers to functioning is needed to inform public health policy that is relevant for people with disabilities. An ICF-based IMF, incorporating environmental factors, would have utility in a

variety of public health applications, and support progress towards a unified epidemiology of health and disability.

A feasible 'application pathway' is often required to translate basic research into practice (3). The desire for 'quick' translation is common but often unrealistic. Sometimes research is needed to demonstrate the methods and benefits of the next steps in translation; that is, further research and development may be needed to translate 'basic research' into a form which can then be applied. This is important work and can take time. An IMF would provide a flexible measurement tool enabling large national programs to move forward to apply the ICF. It is needed, and should be developed.

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Belgium

The design of the ICF-Lab in Flanders

In Belgium, the ICF is a recently emerging framework. More and more sectors and disciplines want to work in a biopsychosocial way, and want to use the ICF to do so. Various organizations recommend the use of the ICF, which includes the Riziv, the federal agency responsible for the financing of outpatient rehabilitation centers. In the field practitioners are actively looking how to implement the ICF.

To prepare students for these changes in the field, it is important to explore how the ICF can get a place in the curriculum. The ICF is a comprehensive framework and classification system that only guides little to how it should be used. This offers great possibilities, but on the other hand it also creates a lot of questions and uncertainty for the users. In facing these challenges, there is a great need for mentoring and coaching to implement the ICF. In light of this need, the ICF-Lab was developed by the Social work Department of Howest.

Methods

The expertise regarding the use of the ICF was built up during the development of the ICF-Lab. This was done on the basis of a literature study, by an exploratory study of the implementation and use of ICF in outpatient rehabilitation centers and by the use of an ICF Train-the-Trainer course.

In the ICF Train-the-trainer course the vision of the center of expertise, ICF-Lab, was created. The vision was created by using mindmapping. Some keywords were written on a poster which were considered as essential elements in developing the vision of the ICF-Lab. By grouping, and connecting these elements, a structure was formed. From this structure, the vision statement of the ICF-Lab was formulated and presented to both insiders and outsiders of the Social work Department for feedback.

Results

The exploratory research revealed that employees develop resistance if there are too many expectations and if they are overwhelmed with too much information. Therefore the ICF-Lab stresses a bottom-up approach. By taking into account the strengths of an organization, we plan to design a possible implementation approach together with the organization and their staff, so that the organization and their employees co-own the approach. The employees of the ICF-Lab do not assume an expert role. The ICF-Lab will be focusing strongly on visioning. The ICF is a tool for the translation of the biopsychosocial thinking and should not be a goal in itself.

The ICF-Lab aims to support organizations and staff in their paradigm shift to a more holistic and circular view of functioning. Empowering and encouraging a participatory attitude are essential elements. From this vision, the ICF-Lab provides customized training and coaching processes. In this way, organizations are supported in an accessible way during the implementation process.

Conclusions

The ICF-Lab aims to support practitioners in the field and future professionals by learning-related activities about the ICF. Practitioners and students foremost need to master the vision of the biopsychosocial model. Only then the ICF can be used as a means to translate thoughts into actions. The added value, the purpose of the ICF must be clear. Expectations and knowledge should be made in an accessible and gradual way to avoid resistance from employees. Therefore the challenges that the staff of an organization meet in the use and implementation of the ICF and the strengths of the staff are the building blocks of a participatory, bottom-up approach.

The ICF-Lab wants to apply the principles of the conceptual framework, ICF's vision, into the vision of the ICF-Lab. The attitude of posing as a coach instead of an expert, which includes an empowering attitude that supports staff members' strengths, is central in this vision. By doing so,

the ICF-Lab aims to develop an expertise in coaching organizations and their employees in the implementation of the ICF.

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Poland

Conference on Children with functioning problems related to Cerebral Palsy and ICF

A large conference, was held in Zamosc, Poland, on the 11-12 December 2015 to facilitate an interdisciplinary and international discussion about the problems of children with cerebral palsy (CP) based on the biopsychosocial model and ICF.

CP and other developmental disabilities/health problems are a worldwide interdisciplinary challenge and require a comprehensive and integrated approach. The aim of this effort is actually to increase the level of participation of people with CP in social life equally to other people. Around 350 physicians, therapists, pedagogues and other specialists participated in the conference.

Several international speakers presented a specific view on children with CP and possibilities of integrating the ICF-framework and language in every day practice:

- P. Rosenbaum (Canada) focused on the Concepts in Childhood Developmental Disabilities: New Ideas for the 21st Century,
- J. Dutkowsky (USA) presented an overview of the history of CP in his presentation: "Cerebral Palsy Comes of Age",
- M. Jozwiak (Poland) presented the way in which mobility and movements can be improved by surgical interventions in "Goals and strategy of lever arm deformities correction in cerebral palsy children",
- V. Schiariiti (Canada) presented the development of "ICF Core Sets for children and youth with CP: Celebrating Abilities and Cultural Differences", specifically drawing attention to a positive approach towards thinking about the child's 'strengths', instead of 'problems',
- B. Batorowicz (Canada) approached CP from a participation perspective in her talk: "Fostering meaningful participation in childhood activity settings: Occupational

therapy and transdisciplinary approach.”,

- H. Ten Napel (Netherlands) presented the state of art of what is known presently on “Examples of effective implementation of ICF in European experiences”,
- D. Fraser (Scotland) zoomed in on the possibilities of communication with children with CP in: “AAC to facilitate functional communication skills and participation of people with Cerebral Palsy in society“,
- E.Feketene Szabo and P. Csuka (Hungary) presented the ‘conductive teaching’ method developed 20 years ago by their centre, and now being applied in Poland as well in “Holistic model of support for people with CP in Peto Institute”,
- A. Coates & L. Watson (UK) explained passionately the success of their Institute in the UK in “The Percy Hedley Foundation, Newcastle as a model of integrated support for people with CP and their families”,
- M. Król (Poland) presented the progress that has been made in the 25-years of existence of the Association in “Holistic model of support for people with CP in Zamosc-25 years of experience”

Also two panel discussions were held with ‘former’ children with CP and their parents from the “Step by step” Association and the lecturers, focusing on the conditions necessary for inclusion of these, now, adults with CP, into social life.

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The Netherlands

Evidence-based interventions for geriatric patients

A geriatric patient is an elderly patient with complex problems on physical, psychological and social aspects (1). The complexity and intertwining of medical-biological, psychological and social factors, multiple pathologies, polypharmacy, atypical presentation of diseases and reduced reserve functions distinguishes these patients from a young adult and the more vital elderly. This means that not the age, but the "profile" determines whether someone is a geriatric patient. In this profile, an average of four medical conditions exists. As age increases, more and more elderly people fit this profile, but not every elderly patient is a geriatric patient.

Sharp rise in heart failure due to ageing population

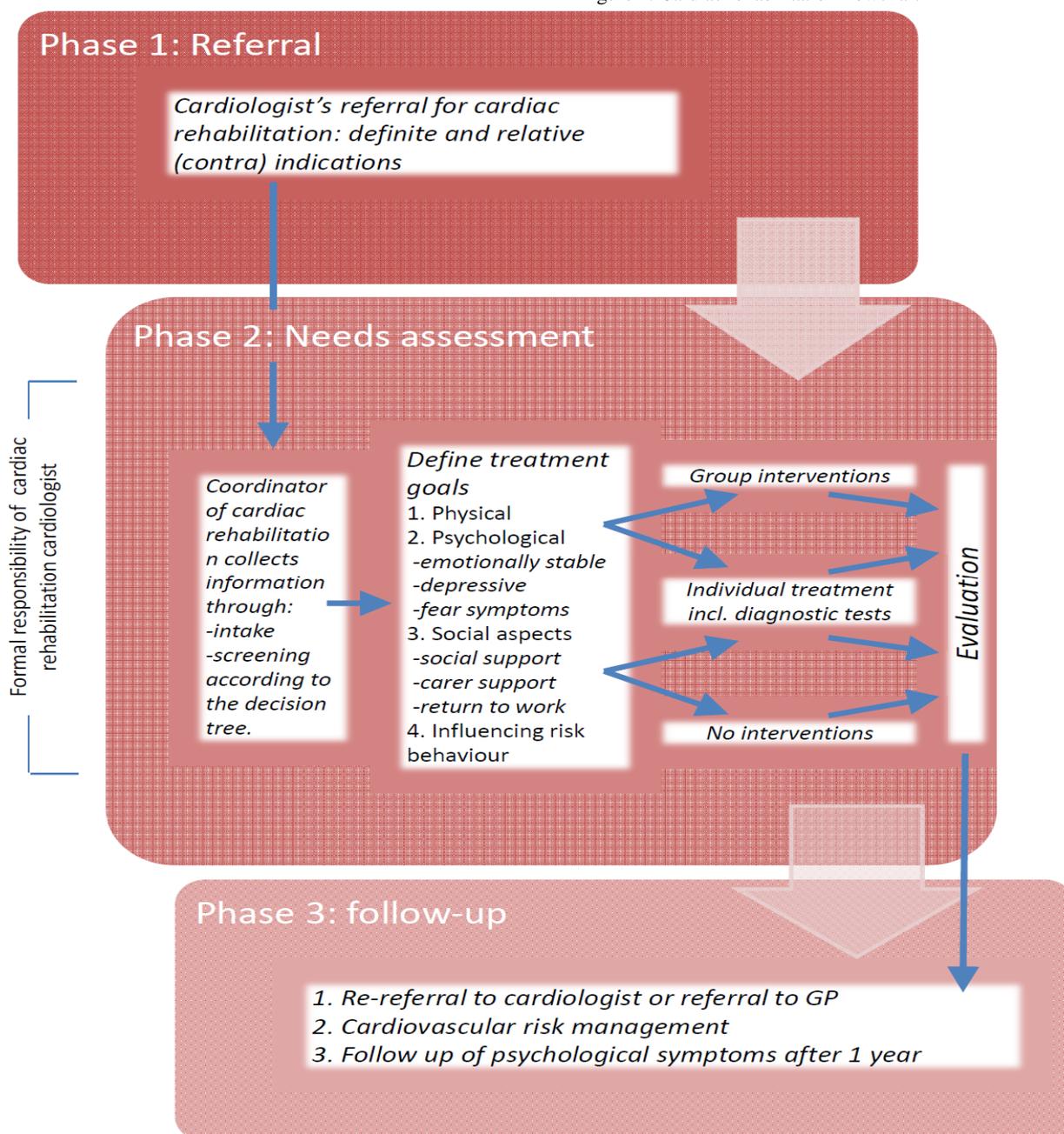
According to the National Institute for Public Health and the Environment (RIVM; 2), the number of elderly people with heart failure will sharply rise until 2025. Currently, 130.000 people suffer from heart failure in The Netherlands. The expectations are that this number will have risen to 195.000 by 2025 due to the ageing population. For geriatric patients with cardiovascular disease and/or heart failure, it is

important that the medical specialist (consultant) or general practitioner refers them to Geriatric Rehabilitation Care (GRZ). This improves the quality of life and reduces complications.

Every year 25.000 to 30.000 patients in the Netherlands are admitted to a Geriatric Rehabilitation ward/clinic for further recovery or rehabilitation (3,4). Their average age is 79 years with a diversity of disease etiology and age related symptoms. Of these patients, 60% will be discharged home (or back to their nursing home) after an average admittance of 2 months. Approximately 10% die during the admittance and for the remaining 30% a (internal) transfer to a nursing home is necessary. More than half of geriatric patients will not reach the level of functioning they had before admittance due to complications. The reason for this, according to Hoogerduijn (5), is both due to personal (ageing) and institution-related factors (infections,

medication problems and the effects of bed rest). Hoogerduijn also identifies underlying factors with the health care professional, such as a negative attitude, lack of knowledge and lack of medical focus. For example, Hoogerduijn points out that 10 days of bed rest results in 15 years of ageing for the patient. Health care professionals should ensure that patients have as much active movement as possible, preferably 15 minutes of walking every day. Frequently occurring chronic diseases such as cardiovascular disease and/or heart failure often accompany the complexity of the geriatric patient. This leads to a decreased self-reliance, an increase in need for care and a reduced quality of life. In addition, elderly people often have lost their partners, their peers are deceased and their children often work and live far from home and have their own families to take care of. This may make them more vulnerable (6).

Figure 1: Cardiac rehabilitation flowchart



Geriatric Rehabilitation Care

Geriatric Rehabilitation Care (GRZ; 7) is a relatively new sub-specialty in geriatric medicine. It is short-term, integrated, multidisciplinary and recovery-orientated rehabilitation care for vulnerable patients. The main goal being that the geriatric patient, having followed the rehabilitation program, may again return home. The GRZ focuses on geriatric patients who are not medically stable, with a moderate to low physical and/or mental capacity but who are motivated and trainable. These patients follow their rehabilitation in a nursing home or a GRZ center. After dismissal, it is possible to temporarily continue the GRZ program as an outpatient. The consultant in geriatric medicine is in charge of the program as a specialist in geriatric medicine with a specialization in geriatric rehabilitation. Geriatric patients, who are medically stable, qualify for Medical Specialist Rehabilitation (MSR), which takes place in a rehabilitation center. These patients can cope with a high intensity of therapy, for which more specific rehabilitation facilities are required.

Indication for cardiac rehabilitation

The flowchart "Beslisboom Hartrevalidatie" (8) (Figure 1; page 10) has been developed for the referral to cardiac rehabilitation. The flowchart, in combination with a patient consultation, determines which interventions, with the best scientific evidence, are most suitable. By answering five questions the physical, psychological and social functioning of the patient and their cardiovascular risk profile with risk behavior are made clear. The flowchart leads to clear goals and the interventions to reach these goals.

According to the Multidisciplinary Guideline of Cardiac Rehabilitation (9) coronary patients of advanced age benefit from a multidisciplinary cardiac rehabilitation program if they are motivated for the program. The guideline states that similar/comparable outcomes as rendered with younger patients can be expected for elderly coronary patients, yet older people are often excluded from cardiac rehabilitation. Health care professionals state several reasons for this, ranging from "patient is too old and doesn't see the need", "patient is not motivated" to "patient has a lot of co-morbidities" and "patient needs to travel too far to the rehabilitation center".

Coronary patients who fall under the specific diagnosis group "elderly with heart disease" and the heart failure patient NYHA class II-III, by whom medication has been optimally dosed/can get a referral for cardiac rehabilitation. Existing co-morbidities such as cancer, lung disease and neurological disorders are taken into consideration as relevant background information in the referral process. This could lead to programs being adjusted or not followed.

Restrictions and ambition

Not only the medical diagnosis but the limitations and participation ambition of the patient are key factors within the GRZ. Based on of the ICF framework (10) (Figure 2)

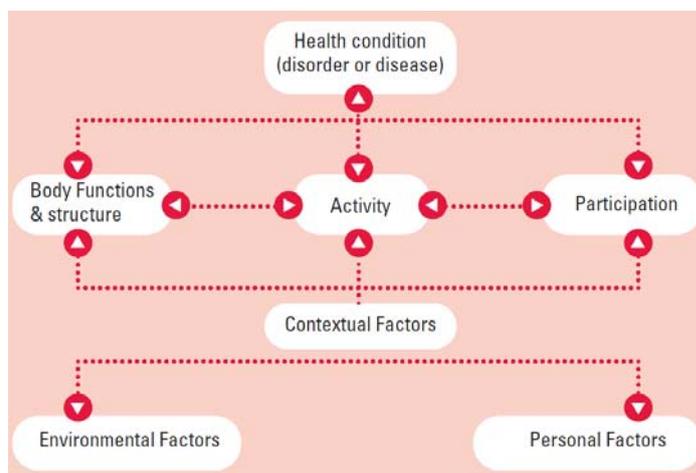


Figure 2: ICF framework (10)

health care professionals can translate the patient's needs and treatment into appropriate rehabilitation treatment (intensity of care; 11). In addition to the patient's needs, there may be other complicating factors that may influence the duration and intensity of the rehabilitation treatment. The ICF model distinguishes between personal factors (the individual background of the patient) and external factors (physical and social environment of the patient).

Patients capacity/capability

With referral to personal factors, the capacity and capability of the patient, both physically and psychologically, determine the degree of intensity of the rehabilitation treatment. Learnability and trainability are considered to be part of the mental capacity. That is also the case for motivation; which is important in reducing risk behaviors, lifestyle change and patient empowerment (12,13). In the study "Empowerment with Cardiovascular Patients" (14) the focus on the influencing of risk behavior appeared to lag behind with GRZ patients. When examining the 12 risk factors, it seemed that all cardiovascular patients had between 2 and 9 risk factors. In particular, low exercise rate (n= 30) and stress (n= 22) were common.

Comorbidity

The degree of vulnerability and multimorbidity is not recognized as a determining factor in the treatment because, by definition, GRZ patients are always assumed to have a low degree of capability/capacity. Secondary diagnoses are irrelevant for the GRZ treatment. It can however be the case that complications and limitations arising from co-morbidities are determinative for the physical and/or psychological capacities and rehabilitation. The presence of comorbidities has no definite consequences for the referral system in The Cardiac Rehabilitation Flowchart or rehabilitation within the GRZ. External factors, such as specific housing facilities and individual health aids, the so-called environmental factors – partly determine the duration of the clinical treatment for GRZ clients. These factors are in the background with coronary rehabilitation.

Measuring vulnerability

Vulnerability – defined as a "dynamic state of an individual with deficiencies in one or more domains of human functioning (physical, psychological, social) which is caused under the influence of a diversity of variables and by which there is an increased chance of the occurrence of adverse outcomes" (6) - can be made measurable with the aid of the Tilburg Frailty Indicator (TFI; 15). The TFI is a user-friendly list of fifteen questions that can be filled in by the elderly patient individually or with the help of a health professional. The outcome of "yes" or "no" answers indicates the degree of vulnerability in physical, psychological and social functioning. The maximum score (fifteen) indicates the highest degree of vulnerability. A score of 5 and up regards people as vulnerable. Problems may include: decline in ADL, loss of weight, strength, balance, vision, hearing, memory, coping and social support. The TFI can depict the functioning of the elderly, a month prior, during or post hospital admission. The TFI can also be used by health professions for "Early Detection of the Vulnerable Elderly (VKE)" this would mean it is also possible for the GP to intervene.

The TFI tool helps health care professionals to identify the vulnerable elderly in a straightforward manner. Therefore interventions can be started timeously and unnecessary loss of quality of life is avoided as a consequence. The fact that TFI measures vulnerability on physical, psychological and social aspects encourages for multidisciplinary interventions. This could include the collaboration of health workers from different professions, who have a uniform goal, that being, a correct diagnosis and treatment.

Multidisciplinary approach

GRZ and cardiac rehabilitation are geared towards the same interventions: stimulating the patient towards life activities, coaching exertion levels and improving physical fitness/lifestyle advice, providing relevant information, promoting self-management, relaxation exercises and coping with limitations. According to Van Balen (16) there is insufficient evidence to verify effects of GRZ for cardiac failure as opposed to cardiac rehabilitation after a heart attack or surgical intervention. This is the reason that Van Balen underlines the importance of a multidisciplinary approach and further development of "Care Pathways for heart failure" (17) so that knowledge and expertise within health care professionals are facilitated.

Interdisciplinary care goes a step further because the health care professionals offer the best care to patient and caregiver. One example is creating a chain of care through integrated care pathways with health care professionals from both hospital settings and external or domiciliary settings. The Dutch Patients Consumers Federation (NPCF) and Verenso recommend this type of work collaboration as a Performance Indicator (18).

Integration of care

The Chronic Care Model (CCM; 19, 20) is a model that makes the integration of care transparent. The consultant is not in charge of the co-ordination of care in this model, the tasks and responsibilities are delegated to the health care professionals. Collaboration between the patient and a proactive team of health care professionals is of crucial importance, as is a well-informed patient who actively participates with his/her treatment plan. This leads to a better quality of life and fewer complications. Recommended interventions are; informing patients, encouraging patients to engage in activities, support and improvement of self-management.

"Bridge" function

The Nurse Practitioner (NP; 22) has a "bridge" role ensuring the quality of care for patients from their health care professions. He/she is the expert who maintains an individual treatment relationship with the geriatric cardiovascular patient and offers integrated care and cure from the perspective of the patient. Also, the NP is able to facilitate self-management capacities of patients, which improves their quality of life. Based on clinical reasoning (anamnesis, physical and/or psychiatric examination) the NP can make additional diagnoses, and appropriate medical, nursing, therapist and evidence based interventions can be started. The NP is also independently qualified to make referrals and arrange certain interventions. The NP promotes continuity and quality of nursing and medical treatment. He/she plays a crucial role in care coordination, allocation of tasks, and improving quality of care and life. This role is also crucial in counselling and coaching nurses and health care professionals. Above all, he/she is a source of information for professionals and for patient or target group- related research. Finally, the NP plays a leading role in the innovation of the nursing profession and health care and contributes to the professional development of the nursing profession and the quality of care.

Conclusion

In order to develop evidence-based interventions as health care professionals for geriatric patients with cardiovascular illnesses or heart failure, interdisciplinary integration of Cardiac Rehab with GRZ is a must. Let's strive for this together!

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