Identification of common content between the questionnaire of the Health Survey (ISA-SP) and the International Classification of Functionality, Disability, and Health

Identificação de conteúdo comum entre o questionário do Inquérito de Saúde (ISA-SP) e a Classificação Internacional de Funcionalidade, Incapacidade e Saúde

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ABSTRACT: The purpose of this paper was to identify the common contents between São Paulo’s Health Survey Questionnaire (Physical Disability and Emotional Health Blocks) and the International Classification of Functionality, Disability, and Health. The first stage of the research consisted of the search for the modules of São Paulo’s Health Survey, which addressed the issue of disability, and the passages about this theme were highlighted and inserted into a new file. In the second stage, the significant contents were extracted. In the last one, these contents were codified to the codes of the International Classification of Functionality, Disability, and Health by two independent researchers. For the descriptive statistical analysis, crude numbers, percentages, and simple frequencies were used. The degree of agreement between the two professionals was calculated using Kappa’s coefficient and the confidence interval. The most common domains were those about functions and body structures and about activities and participation, in which the domain of environmental factors presented a lower frequency of approach.

Keywords: Health surveys. International Classification of Functionality, Disability and Health. Questionnaires.
INTRODUCTION

Over the last decades, due to the population’s epidemiologic and demographic changes, an interest on the development of indicators — focused not only on mortality, but also on morbidity — has been cultivated. Those would aim at the ability of people to develop their roles within society and at the evaluation of well-being and satisfaction concerning health conditions, encompassing not only the biological aspects of the diseases, but also their mental and social ones. The information about what happens after the diagnosis of a disease over time, especially concerning chronic diseases and accidents, are increasingly important in the healthcare area. Having the knowledge about the causes of death and diseases which occur more often is no longer enough for the planning of health action.

Although the secondary data sources of the information systems are essential, these cannot meet the needs of health information. Thus, the population-based surveys show increasing importance, as they provide the knowledge on the health profile of the population and on the distribution of risk factors for the development of diseases, as well as the ones which influence people’s health condition status.

Measures of functional capacity and mobility are often used in population surveys because of its social relevance and ease of interpretation, offering a convenient way to compare the impact of the different diseases, in different populations, at various time periods. The measures can also be used as predictors or prognosis indicators of the ability to live independently and of the need for personal care assistance. Although there is a growing inclusion of parameters about disabling processes in population surveys, there is
no consensus on what kinds of information should be included, making the comparison of data between the surveys rather difficult⁴, turning this disagreement into a theme of discussion for the scientific literature⁵.

In an attempt to reduce the gap between the available tools to measure the mortality and morbidity, and in order to develop a universal language for the area, in 2001, the World Health Organization (WHO) has approved the International Classification of Functionality, Disability and Health (ICF). According to this, the functionality (standard ICF term), used in a positive aspect, encompasses the functions and structures of the body, the activity and the participation. On the other hand, the disability would be the negative term of the process, resulting from the interaction between the individual’s disability, the limitations of their activities and the restrictions in their participation, along with environmental factors (barriers or facilitators of health conditions)⁷, as can be seen in Chart 1.

The ICF was proposed aiming to serve as the ideal tool to guide the understanding of results measuring, based on the patients’ answers⁸. The classification provides a wide and universally accepted perspective, in order to achieve and describe the phenomena which follow the diagnosis of different kinds of health conditions⁹. There is the possibility of using the ICF model in the multidimensional and in the population-based study’s evaluations, related to the disability’s processes, thus having a wider and more comprehensive view of what aspects can be affected by individuals and populations¹⁰. There also is a growing need for the use and exploration of classification in practical use in epidemiological researches⁴.

The identification of the common contents between the instruments for data collection from population-based surveys, and the ICF, can be a methodologically interesting activity to health research, as it highlights the way in which health surveys collect the information regarding disability. Studies with similar purposes have been conducted in several countries.

Chart 1. Definitions of International Classification of Functionality, Disability, and Health (adapted from PAHO/OMS⁷).

| Component                        | Definition                                                                 |
|----------------------------------|---------------------------------------------------------------------------|
| Bodily functions (b)             | Physiological functions                                                   |
| Body structures (s)              | Anatomical structures                                                     |
| Activity (d)                     | Executing a task or action                                                |
| Participation (d)                | Involvement of an individual in a real situation                           |
| Environmental factors (e)        | Physical, social and attitudinal environment in which people live         |
| Personal factors (not subject to classification) | Private history of life and lifestyle of an individual                      |
using a methodology similar to the one used in this article\textsuperscript{11-17}. In Brazil, the method has been used in various research areas related to health or functional recovery\textsuperscript{18-21}.

Besides that, such identification process may determine the way of approaching the components of the functionality-disability process by health survey. This way, it can be used as a tool in order to verify the approach to disability, according to the model proposed by the WHO. In other cases, the identification of the inquiries’ concepts with the ICF can provide with a universal language for comparison between studies from different countries or locations, even with disparate instruments, since the process generates, as a product, codes of the ICF that may be similar. These information may be used for adjustment and orientation of the data collection, when necessary. In this sense, the objective of this study was to describe the common contents between the Health Survey of São Paulo (ISA) (Block E – Physical Disability and Block M – Emotional Health) and the ICF, presenting the ICF’s chapters, to which the contents of the ISA questionnaire were related to.

**METHODS**

This study was conducted by identifying the common content between the ISA questionnaire and the ICF. The ISA in the state of São Paulo was conducted, in 2003, at some areas with a complex sampling, by clusters in two stages, the first one consisting of census sectors (70), and the second one consisting of households (2,249). The residents were randomly assigned to a sample of eight demographic areas (less than 1 year of age; 1 to 11 years of age; 12 to 19 years of age, male and female; 20 to 59 years of age, male and female; and 60 years of age or more, male and female). The size of the smaller group sample (less than one year of age) was of 300 children, defined based on the estimated proportion of 50% (\(p = 0.50\)), a 95% confidence interval (95%CI) (\(z = 1.96\)), a sampling error of seven percentage points (\(d = 0.07\)) and an outlining effect of 1.5 (\(deff = 1.5\))\textsuperscript{22}.

Two municipalities from the country side of the state, Campinas and Botucatu, were studied. Besides that, other areas of analysis are located in the metropolitan region of the city of São Paulo, i.e. the cities of Taboão da Serra, Embu and Itapecerica da Serra, in addition to the health district of Butantã, located in the city of São Paulo.

The data collection instrument consisted of a questionnaire composed by the following blocks: Block A (general information about the family composition required to establish the first elements of living conditions); Block B (visiting control); Block C (morbidity for the period of 15 days and demand for health services and satisfaction, in Block C); Block D (diagnosis of chronic diseases, with two other subdivisions – D1 (hypertension) and D2 (diabetes)); Block E (physical disability and demand for health care of this problem in Block E); Block F (accidents or violence within the 12 months previous to the interview); Block G (use of dental care services in the last 12 months and health care services in the last 15 days previous to the interview, still describes the health services used); Block H (use of health care services for preventive screenings for diseases such as hypertension, breast, uterus and prostate cancer); Block I (data on the use of vaccines and also
some questions about the knowledge of dengue transmission and control); Block J (consumption of medical drugs); Block K (hospitalizations in the 12 months previous to the interview and description of the services used); Block L (life style – physical activity, diet, smoking and alcohol consumption); Block M (Emotional Health); Block N (health self-assessment); Blocks O and Q (socioeconomic characterization of the interviewee (O) and the head of the family (Q)); Block P (family and household characteristics); Block R (monthly household expenses on health) and Block S (prenatal, childbirth and the first year of life for all children under one year of age)23.

The research team coordinating the project consisted of professors and researchers from the Schools of Public Health (Faculdades de Saúde Pública – FSP) and Medicine, both part of the University of São Paulo (Universidade de São Paulo – USP); University of Campinas (Universidade Estadual de Campinas – Unicamp); Health Institute of the State of São Paulo (Instituto de Saúde do Estado de São Paulo) and the São Paulo State University (Universidade Estadual Paulista – UNESP). The initial survey was funded by the State Department of Health of São Paulo (Secretaria de Estado da Saúde de São Paulo) and by the São Paulo Research Foundation (Fundação de Amparo à Pesquisa do Estado de São Paulo – FAPESP)23, providing the conduction of subsequent investigations in the cities of São Paulo and Campinas24. As a result of such studies, scientific articles were published25-33. Furthermore, it is noteworthy that the ISA is a result of a collective effort between academies — represented by the Universities involved — and public health management, as evidenced by the financial support of the Secretaria de Estado da Saúde de São Paulo.

The present research was conducted in three stages, often used in similar studies11-17. The first of them consisted in the search of the ISA modules that addressed the issue of disability, which were then selected, and the questions relating to disability were highlighted from the total instrument and inserted into a new file. Then, in a second stage, the significant content were extracted from the sections and placed into evidence for the next stage of the research. In the last stage, there was the codification of the highlighted contents for the ICF codes. This process was executed by two independent researchers, with knowledge of the ICF, of its taxonomy and experience, and of the training in the process of codification, according to the proposed and published rules14. At the end of the work of the coders, a comparison between the results and the discordances were settled by a consensus between the two parts. The rules for codification are shown in Charts 2 and 3.

Measures such as pure numbers, percentages and simple frequencies were used for descriptive statistical analysis. The degree of agreement between the produced codifications by both professionals who performed the binding process was calculated by the Kappa coefficient and the confidence interval. The software used was the SPSS, version 7.0.

RESULTS

Of the 56 questions contained in the selected ISA (Blocks E and M), significant contents was extracted from 71 of them. From these, 64.8% would refer to the first and 35.2%, to the second block. The results are shown in Figure 1.
Chart 2. Content codification rules of the International Classification of Functionality, Disability, and Health codes.

| Number | Rule |
|--------|------|
| 1.     | After a person makes the connection of the concepts with the ICF categories, another must have good knowledge of the concepts and fundamental taxonomic properties of ICF, as well as the chapters, domains, categories and details of the classification, including their definitions. |
| 2.     | Each significant concept shall be linked to the most precise ICF category. |
| 3.     | The term “other specified”, represented only by the code of number eight, shall not be used. In case the content of a meaningful concept is not clearly stated to the corresponding ICF category, the additional information which cannot be linked shall be documented. |
| 4.     | The term “unspecified”, represented by the code of number nine, shall not be used. In this case, the category of lower hierarchical level is to be applied. |
| 5.     | If the information provided by the significant concept is not enough to make a decision about the most precise category of the ICF, the concept shall be connected to the nd (not defined) denomination. Special cases for this rule: Significant concepts relating to physical or mental (emotional) health, the acronyms nd-gh, nd-ph or nd-mh (not defined – general health, not defined – physical health or not defined – mental health) shall be assigned, respectively. Significant concepts relating to quality of life shall be assigned to nd-qol (not defined – quality of life). |
| 6.     | If the significant concept is not contained in the ICFs, but it is clearly a personal factor, the acronym pf (personal factor) shall be assigned. |
| 7.     | If the significant concept is not included in the ICF, and it is clearly not a personal factor, the acronym nc (not covered) shall be assigned. 8. If the significant concept refers to a diagnosis or a health condition, the acronym hc (health condition) shall be assigned. |

ICF: International Classification of Functionality, Disability and Health.

Source: Adapted from Cieza et al.

Chart 3. Specific rules for the linkage process of the health state measures.

| Classification | Specific rules for the health state measures |
|----------------|---------------------------------------------|
| a.             | After starting the process of connecting the measures of health status with the ICF categories, identify all significant content within each considered item. |
| b.             | The response options of an item shall be linked to ICF categories, in case they may contain significant concepts. |
| c.             | The time interval to which the items refer to as “during the past week” shall not be linked to the ICF. |
| d.             | In case one of the significant concepts of a item is explained by examples, both the concept and the example must be linked. However, the ICF category to which the examples get linked to shall be placed between parentheses. |

ICF: International Classification of Functionality, Disability and Health.

Source: Adapted from Cieza et al.
The overall percentage concordance was 53.5%, being 60.1% for Block E and 40% for Block M. The Kappa coefficient found for the overall concordance was 0.48 (95% CI 0.34 – 0.60); 0.58 (95% CI 0.41 – 0.71) for Block E and 0.44 (95% CI 0.32 – 0.58) for Block M.

For Block E, from the 46 contents, extracted and transformed into ICF categories, most of them would refer to activities and participation (32.6%), followed by bodily functions (19.5%). Only 8.7% of the contents would relate to environmental factors and 2.2% to body structures. In addition to that, 19.5% of the contents could not be precisely defined with the ICF categories (8.7% referring to environmental factors, 6.5% to personal and 4.3% to activities and participation) and 17.4% of the significant contents were not covered by the classification domains. Regarding Block M, 60% of the 25 contents refer to bodily functions, 12% to activities and participation. For the contents which were not determined into any specific ICF category, the frequency was 24% (16% for environmental factors and 8% for activities and participation). Only one of the contents (4%) was not covered by the classification.

After analyzing both blocks, the results were as follows: 33.8% of the content refers to bodily functions, 25.3% to activities and participation, 5.6% to environmental factors, and only 1.4% to body structures. It was also observed that 21% of the contents were not properly connected to the ICF categories (9.8% of them are personal factors and 11.2% are environmental factors, activities and participation). These contents had their domains identified. However, a more accurate correspondence to the codes of second or third levels was not possible, due to their nonspecific nature. The frequency of contents which were not covered by the classification — such as time, birth, useful role in life and disease, among others — was 12.7%.

**Figure 1.** Number of significant contents identified in the ISA and its distributions among the International Classification of Functionality, Disability, and Health components.
DISCUSSION

Cross-sectional population-based studies have been widely used to determine prevalence and for diagnosis in health for both national\textsuperscript{35-36} and international levels\textsuperscript{40-42}. In the case of the surveys that address the issue of disability, the incorporation of the concepts advocated by the WHO, through the ICF, is crucial for the estimation of the prevalence of disabilities not to be impaired, and that the results are not biased.

The discussion about the correct survey of the prevalence of people with disabilities in population studies has been targeted by the scientific community\textsuperscript{43-45}. In this sense, the World Report on Disability also presents varying prevalence according to location, level of development and other variables\textsuperscript{46}. The improvement of instruments for data collection proves to be essential in the process of determining the prevalence of disabilities among the studied population groups, once that, in some cases, errors and inconsistencies can be generated, due to the inadequacy of the data collection instrument\textsuperscript{47}.

Considering these statements, the discussion of the domains or facets of functionality/disability, covered by health surveys, will contribute towards the improving the data collection instruments, and as a result, improving the quality of the data collected by these studies. In this sense, the detection of the domains used in the preparation of the questionnaires will help incorporating into these instruments the domains which were not included, making the proposal for disability’s multiple causes to be satisfactorily addressed. The ICF, in turn, provides the theoretical background for better comprehension of the concepts involved in the subjects’ functionality/disability, which are already being incorporated into health surveys\textsuperscript{48,49}.

In addition to bringing new concepts about the functionality/disability, the ICF has also been proposed with the intention of being an instrument for usage in areas such as national and international reports\textsuperscript{50} on disabilities; scientific health researches\textsuperscript{51,52}; clinical\textsuperscript{53,54} and epidemiological usage\textsuperscript{55,56}, and in the area of social politics, among others such as the educational field\textsuperscript{57}.

In a recent systematic review of the literature using the methodology of connecting instruments to the ICF, the authors have pointed out that this kind of work is a useful way to apply the classification of scientific researches. They have stressed that 100 articles have been published in 58 scientific journals, having been distributed over 50 different acting fields. It was also observed that the tool has demonstrated a great ability of usage in the description and comparison of the information on the quantitative and qualitative data related to the processes of disabilities\textsuperscript{58}.

The results of this study indicate a higher frequency of categories relating to bodily functions. This fact shows a higher affinity of the deficiency of the ISA-SP approach to the biomedical model, present in most quantitative health studies. This is a reductionist approach\textsuperscript{59}, reflecting the higher education and health research systems, deeply influenced by Cartesianism, which cares for the attention to the individual, to the disease and to the affected organs and bodily functions\textsuperscript{60,61}. The biopsychosocial model, as opposed to the biomedical one, even having been proposed in the decade of 1970, continues with little participation in
the health research area\textsuperscript{39}. The approach proposed by the ICF seeks to break this paradigm, by providing a theoretical framework with components other than the physical or biological ones. The WHO suggests that other factors, such as psychological and social ones, have as much influence on the functionality/disability as the biological ones do\textsuperscript{62}, enriching their approach as the ways of visualizing the matter broadens.

It was also observed, by the results presented, that the environmental factors are barely addressed in the instrument. The environment is a component of the explanatory model of the disabling process proposed by the WHO and it has direct relation to the process and to the other components involved\textsuperscript{14,63-65}. It is important to highlight that, at the time environment is not considered in the creation of the collection instrument, an important limiting or facilitating factor is excluded, increasing the chances of bias in the study. Future versions of the ISA and other population health surveys should incorporate the environment, in a more consistent way, as a builder and a component of the debilitating process, so as to approach such process in a more satisfactory manner, as recommended by the WHO.

Literature reports show the concordance between coders, measured by the Kappa coefficient, ranging from 0.67 (95\% CI 0.56 – 0.78) to 1.00\textsuperscript{15}. It is noteworthy that the overall concordance of the raters of this study was 0.48 (95\% CI 0.34 – 0.60), values that cannot be considered different from 0.67, due to the analysis of the presented confidence intervals. The low concordance for the emotional health block observed in this research could be explained by the difficulty of encoding the contents related to the Chapter of Mental Functions (b1) of the ICF, resulting from the degree of subjectiveness of these concepts. Furthermore, the reproducibility between raters in the content encoding process shows variations\textsuperscript{66,67} or values below or above the ones found both here and in various other studies\textsuperscript{68-70}, mentioned even in differentiated variations, according to the chapter of each of the ICF’s domains\textsuperscript{71}. The non-coverage of the content was reported in another research, which has analyzed eight scales and found non-coverage percentages raging from 0 to 30\%\textsuperscript{11}, among them all. The rate of the present survey was 12.7\%, which is among the variation shown.

**FINAL CONSIDERATIONS**

The domains of body functions and structures and of activities and participation were the ones presenting the most codes in the study’s questionnaire, as oppose to the environmental factors being the least addressed ones within the research. This research may contribute to the growth of health research in Brazil as it documents the ICF’s — present or absent — in the health survey questionnaire, through transparent and reviewed methodologies. Thus, it is possible to create an empirical basis for future discussions on concepts which could, or should, fit into future health surveys. These discussions should not be limited only to the ISA questionnaire, but rather expanded to other studies with the same methodology, which seek for information regarding the occurrence of disability among the population.

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