Identification of problems in the functioning of individuals with schizophrenia from the expert perspective: An internet-based survey

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Abstract

Purpose: The purpose of the study was to identify aspects of functioning and related environmental factors that are relevant to schizophrenia from the perspective of health professionals experienced in treating individuals with this disorder using the International Classification of Functioning, Disability and Health (ICF).

Method: An international pool of experts from diverse health care disciplines was surveyed to identify problems in functioning experienced by individuals with schizophrenia and the environmental factors that impact their functioning. On the basis of established rules, all answers were translated to the ICF by two independent researchers.

Results: One-hundred and eighty-nine experts from all six World Health Organization regions identified 4776 meaningful concepts, of which 92% were linked to 347 different ICF categories. Of the 347 categories 194 were second-level categories, 151 were third-level categories, and 2 were fourth-level categories. Ninety-five second-level ICF categories, 43 third-level categories and one fourth-level category reached percentage frequency of at least 5%. The majority of the categories were attributed to body functions, activities and participation, and environmental factors.

Conclusions: Health professionals identified a wide range of problems in functioning that reflect the complexity and breadth of schizophrenia, specifically activity limitations and participation restrictions that are particularly relevant for individuals with schizophrenia. Knowing these functioning problems can guide the design of patient-oriented rehabilitation programs.

Implications for rehabilitation

1. Schizophrenia may result in impaired functioning in multiple daily life activities. The International Classification of Functioning, Disability and Health (ICF) can help in identifying the needs and problems of these individuals.

2. The reported list of ICF categories can facilitate a systematic application of the ICF in schizophrenia and can help to design and implement coordinated and patient oriented rehabilitation programs with a biopsychosocial approach.

3. According to health professionals surveyed, activity limitations and participation restrictions are broadly affected in this population and are highly influenced by neurocognitive and social cognitive deficits and environmental factors.

Introduction

Schizophrenia is a chronic mental illness that has a tremendous impact on the lives of individuals who have the disorder and their caregivers. Classical symptoms of schizophrenia, such as delusions and hallucinations, have been considered critical indicators of functional impairments [1]. In addition, disturbances in neurocognition and social cognition are frequently observed in individuals with schizophrenia, and contribute to poor functioning on different daily life activities, such as an engagement in meaningful work, self-care, independent living and maintaining satisfying interpersonal relationships [2,3]. Moreover, schizophrenia has a strong economic impact, encompassing direct health care and social system costs, as well as indirect cost, such as loss of productivity from unemployment, reduced work productivity among the employed, and exhaustive time devoted to caring for individuals with schizophrenia [4]. In recent decades, there has been increasing interest in the impact of schizophrenia on functioning. For example, several studies have related functional outcome to a number of factors, such as age, gender, education, illness duration, symptoms, cognitive dysfunctions, social cognition, and pharmacological and psychosocial treatments [1,5–8]; however, the studies' results remained inconclusive. This may be partly due to the different reference frameworks employed. Thus, in order to achieve consistent results, it would be of value to use a standard framework for exploring the factors that impact functional outcome of individuals living with schizophrenia.

The International Classification of Functioning, Disability and Health (ICF) [9], a conceptual framework and classification system developed by the World Health Organization, is an established standard for conceptualizing health and disability in a comprehensive and etiologically neutral manner. As a conceptual model, the ICF recognizes that functioning and disability is a result of the interaction between the

components body functions, body structures, activities and participation, environmental factors, and personal factors. At a practical level, the ICF provides a universal language that clinicians and researchers can use to determine what should be measured in a functional assessment. The ICF structures health and related domains into categories that are arranged in a hierarchical fashion. The categories are arranged in a stem/branch/leaf scheme so that a lower-level (more detailed third and fourth level) category shares the attributes of the higher-level categories of which it is a member. Figure 1 exemplifies the structure of ICF categories using the category "b167 Mental functions of language".

Insert Figure 1 about here

The letters b, s, d, and e refer to components of the classification – body functions (b), body structure (s), activities and participation (d), and environmental factors (e), respectively. The personal factors component is not yet classified in the ICF.

The ICF consists of more than 1400 categories. The large number of categories limits its utility in the clinical setting, as health professionals find it too extensive to incorporate into their daily practice. In addition to having a manageable set of categories, the ICF must be tailored to the needs of different users in order for it to be more practical for use in the clinical context. Improving the ICF's practicability is the primary motivation behind the development of the ICF Core Sets. ICF Core Sets, a selection of categories from the whole ICF that are considered the most relevant for describing the functioning of individuals with a given health condition, are developed using an evidence-based methodology established by WHO and the ICF Research Branch [10–12].

ICF Core Sets standardize what should be measured and reported for a given health condition, thereby facilitating the use of the classification. ICF Core Sets can be used to identify patients' needs, report and describe functioning in different settings (acute,

rehabilitation, etc.), assess response to interventions, and serve as a standard guide for developing assessment instruments (e.g., ASAS Health Index and WORQ) that capture functioning in specific health conditions or contexts comprehensively [12–16]. Currently, ICF Core Sets have been created for several acute, early post-acute and chronic conditions (e.g., stroke, multiple sclerosis, spinal cord injury and cerebral palsy) that are common in adult and child populations [12]. Until recently, no ICF Core Sets had been developed for schizophrenia. Since May 2015, the Brief and Comprehensive ICF Core Sets for individuals with schizophrenia are available [17]. They were developed in a project led by our research team at the University of Barcelona in collaboration with the ICF Research Branch, a cooperation partner within the WHO collaboration centre of the Family of International Classifications in Germany. Following the ICF Core Set development methodology [12], we conducted four independent studies that reflect the perspectives of health care professionals (expert survey), researchers (systematic literature review), schizophrenia patients and their caregivers (qualitative study), and clinical practice (multicenter empirical study), to gather evidence to support the final selection of categories for the ICF Core Sets for schizophrenia.

In the present study, we focused on capturing the experts' view on what factors are important to individuals with schizophrenia, using an internet-based survey of health professionals experienced in treating individuals with schizophrenia to identify problems in functioning in this health condition.

Materials and Methods

We conducted a cross-sectional, internet-based survey using a two-part questionnaire that were completed by a pool of expert participants from all over the world.

Recruitment of Experts

An ''expert'' was defined as someone who had at least 2 years of relevant experience (practice, research or both) in the field of schizophrenia, worked as a health professional (e.g. psychologist, psychiatrist, nurse, social worker, occupational therapist), and could communicate competently in English.

Experts were selected in two successive steps. Firstly, invitations to experts were sent out via e-mail. E-mail addresses of experts were obtained from the literature, including corresponding authors who had published articles on schizophrenia in the last five years professional organizations, journals' editorial boards, scientific committees, informal networks, and peers. In addition, experts who were contacted were asked to provide email addresses of other experts who may also be interested in participating in the study. A total of 1722 experts were identified and invited via e-mail to be included in the expert pool. Among them, 1318 did not reply to the invitation, 12 refused to participate (mainly due to lack of expertise or time), and the remaining 392 agreed to be included in the expert pool. Those who met the inclusion criteria (2 had less than three years of experience and were excluded) resulted in an expert pool of 390 (22.65%) professionals from 45 countries.

In a second step, a stratified random sample of experts, representing each profession and each of the six WHO world regions (Africa, the Americas, Eastern Mediterranean, Europe, South-East Asia, and Western Pacific), was drawn up to ensure equal representation across professions and WHO regions. An exception was made for the Eastern Mediterranean region, due to the extremely small number of experts identified. Consequently, all nominated experts from the Eastern Mediterranean region were included. In total, 307 experts were invited to participate in the survey.

Survey questionnaire

The selected experts received an email with an electronic link to the two-part questionnaire.

The first part of the questionnaire asked respondents for sociodemographic data and information on professional background. The sociodemographic data included country, age and sex, and the information on professional background covered profession, main field of practice, and years of professional experience. This minimum information was required to get a clearer picture of our study sample.

In the second part of the questionnaire, experts were asked six open-ended questions to examine which factors they considered relevant and important to individuals with schizophrenia. The open-ended questions are shown in Table 1 as were presented to the experts. Each question was related to a component of the ICF (body functions, body structures, activities and participation, environmental factors, and personal factors), without showing the experts the ICF component labels embedded in the questions. The environmental factors component was divided into supportive and hindering factors.

<center>Insert Table 1 about here</center>

Blank fields for the answers were provided after each question, and respondents were allowed to provide multiple answers. Answers were not limited in terms of word length, although respondents were instructed to be brief and concise, and to avoid abbreviations and vague technical terms. The survey platform was configured to allow experts to answer parts of the survey at different times. Consequently, a respondent could answer a few questions one day, and then complete the survey on a different day. The expected completion time for the survey was about 20-30 min.

Data collection lasted from April to September 2014. Electronic reminders (i.e., e-mails) were sent to the experts at regular intervals to encourage participation. Answers were kept anonymous by assigning an identification number to each participant.

Linking to the ICF

All responses gathered from experts were linked to the ICF by applying published linking rules [18]. The objective of the linking process was to translate the concepts found in the experts' responses into the most fitting ICF categories. One expert's response could therefore be linked to one or more ICF categories, depending on the number of meaningful concepts contained in the respective response (e.g., the expert's response "*delusions and hallucinations*" was linked to the ICF categories *b1602 Content of thought* and *b156 Perceptual functions*). Answers that were too general to be specified by an ICF category such as "negative symptoms" or "psychiatric symptoms" were coded as "not definable". The component "personal factors" is not yet classified in the current version of ICF. Thus, responses related to personal factors such as "gender" or "level of education" were coded as a "personal factor". Answers containing information related to health conditions (e.g., diabetes) were coded as "health condition". Finally, if the concept was not captured by the ICF classification (e.g., suicide) it was labeled ''not covered". Two individuals, who are trained and experienced in this process, independently linked all the responses. Disagreements between the two coders were reviewed and discussed and an agreement was made on the final linking.

Data analysis

Descriptive statistics were used to describe the sociodemographic characteristics of the participants and the number of times an ICF category was identified, based on the experts' responses. ICF categories were presented at the second, third and fourth levels. Only ICF categories that were mentioned by at least 5% at the second, third, or fourth level were shown. If one participant's answers were assigned repeatedly to the same ICF category, it was counted only once to avoid bias toward a specific category. When second-level categories were presented, third and fourth level ICF categories were reported at their corresponding second level. Accordingly, when third-level ICF categories were presented, fourth-level ICF categories were reported at their corresponding third level. This is appropriate since the lower-level categories share the attributes of the higher-level category. To evaluate the reliability of the linking results, the percentage of agreement was calculated based on the two independent linking versions. In addition, to examine the extent to which the achieved agreement exceeds chance, the Kappa coefficient and confidence interval were calculated.

Results

Participants

Out of 307 invited experts, 189 filled in the survey (response rate = 61.56%). However, 37 experts were excluded in the data analysis as they had completed only a part of the questionnaire.

Respondents' sociodemographic data and their self-rating of expertise are presented in Table 2. The participants were 28 to 80 years old ($M = 48.31$; $SD = 11.38$, $Mdn = 48.0$ years); and 81 (53.3%) were female. The sample included a diverse group of professionals, with psychiatrists and psychologists representing 65.14% of the sample. The remaining respondents were mainly comprised of nurses, social workers and

occupational therapists. Years of general professional experience ranged from 2 to 55 years, with a median of 21.5. Most of the participants had a mixed professional profile ($n = 83$, 55.33%) combining mainly clinical practice, research and/or educational activities, while 21.33% worked only in research, 10.66% worked mainly in education, and 10.00% in clinical practice.

Insert Table 2 around here

The respondents came from all six WHO regions: 38.82% ($n = 59$) were from the Americas, 28.29% ($n = 43$) from the European region, 16.45% ($n = 25$) from the Western Pacific region, 7.89% ($n = 12$) from the South East Asian region, 5.92% ($n = 9$) from the African region and 2.63% ($n = 4$) from the Eastern Mediterranean region.

Description of responses and ICF categories

Experts mentioned 4776 meaningful concepts, which 92% were linked to 347 different ICF categories. One-hundred ninety-four (55.91%) were second-level ICF categories, 151 (43.52%) were third-level ICF categories, and 2 (0.58%) were fourth-level ICF categories. The rest of the concepts (n = 382, 8%) were coded as "hc, health condition" ($n = 60$, 1.26%), "nc, not covered" ($n = 103$, 2.16%), "nd, not definable" ($n = 193$, 4.04%), and "pf, personal factors" ($n = 26$, 0.54%). The calculation of reliability between the coders revealed an agreement of 72.42%, with a Kappa coefficient of 0.448 (95% CI 0.425–0.472).

Ninety-five second-level ICF categories reached a percentage equal to or higher than 5% (Figure 2). Out of these 95 ICF categories, 19 (20.00%) were related to body functions, 7 (7.37%) to body structures, 33 (34.74%) to activities and participation, and 36 (37.89%) to environmental factors. Forty-three third-level ICF categories reached a percentage equal to or higher than 5% (Figure 3): 17 (39.53%) were related to body

functions, 1 (2.33%) to body structures, 15 (34.88%) to activities and participation, and

10 (23.26%) to environmental factors. A unique fourth-level ICF category, *s1100*

Frontal lobe, exceeded the cutoff of 5%, with a percentage of 5.92% ($n = 9$).

Insert Figure 2 about here

Insert Figure 3 about here

Discussion

This is the first expert survey that explores the problems of functioning of individuals

with schizophrenia from an international perspective, involving different health

professions and using the ICF as a frame of reference. ICF provides a neutral language

framework and has been used previously to describe the perspective of experts in

different health conditions [19–23].

The experts who participated in the survey came from all six WHO world regions, and

dealt with individuals with schizophrenia in clinical, research, educational and

administrative settings. The multicultural and multinational standpoint and different

professional backgrounds contributed to broadening the spectrum of ICF categories that

were identified, and to highlighting the complexity and breadth of the lived experience

of individuals with schizophrenia. Moreover, the participants' high level of experience

was remarkable, further adding weight to their expert input to the study.

A number of relevant ICF categories were identified in body functions and body

structures, representing mainly mental functions and brain structures that are affected by

schizophrenia. Several of the most frequently mentioned mental functions (e.g., *b130*

Energy and drive functions, *b152 Emotional functions*, *b156 Perceptual functions and*

b160 Thought functions) are closely related to the most common symptoms of

schizophrenia (American Psychiatric Association, 2013) such as negative symptoms,

delusions and hallucinations. The relevance of other frequently identified categories related to neurocognitive functions (e.g., *b140 Attention functions*, *b144 Memory functions*, and *164 Higher-level cognitive functions*) and psychosocial functions (e.g., *b122 Global psychosocial functions*) is supported by several studies showing that both neurocognitive and social cognitive deficits are core features of schizophrenia [2,3,24,25].

Based on these results, it is not surprising that the most frequently identified body structure was *s110 Structure of brain*. Numerous studies have found that patients with schizophrenia present subtle, but consistent structural differences in several brain structures [26–28] and a different pattern of brain activity [29,30] compared to healthy controls. Moreover, these differences seem to occur most commonly in the gray matter of the frontal, temporal, cingulate and insular cortex, the thalamus and basal ganglia [28], and they have also been linked to the neurocognitive and social cognitive deficits associated with schizophrenia [25,31]. Here, it is worth pointing out that the unique fourth-level ICF category exceeding the cutoff is *s1100 Frontal lobe,* which shows that participants consider them to be important.

The experts acknowledged the importance of several aspects in the components of activities and participation and environmental factors, as evidenced by the large number of categories identified in these components and the high percentage of agreement among participants for specific categories in these components. These findings are consistent with the fact that schizophrenia has major implications for everyday functioning in areas such as independent living, forming and maintaining interpersonal relationships, employment, and leisure [3,5,7,32,33]. Social cognition and neurocognitive deficits, as well as affective disturbances have been shown to be highly related to activity limitations and participation restrictions [3,34–37]. Participants have

also emphasized the importance of problems in *d570 Looking after one's health*, *d2401 Handling stress* and in some categories in the chapter *d7 Interpersonal interactions and relationships*. Additionally, one of the most frequent categories highlighted by the participants in the chapter *d8 Major life areas* is *d845 Acquiring, keeping and terminating a job*. This last finding is in agreement with a considerable number of studies which underscore the worryingly low employment rates among schizophrenic patients [8,38,39], despite the significance of work on illness outcome [33,40–42]. Specifically, previous studies have found that having paid employment is associated with fewer psychiatric hospital admissions, decreased positive and negative symptoms, and improvements in self-confidence, stress management and self-sufficiency [8,40–42].

Regarding environmental factors, the experts stated that the support of *e310 Immediate family* and *e315 Extended family*, *e320 Friends* and other close people, and their attitudes (e*410, e415, e420)* towards individuals with schizophrenia, have a considerable influence on the individual's functioning. Societal attitudes (*e460*) were also frequently mentioned as either a supportive or hindering factor in the immediate environment and living conditions of individuals with schizophrenia. Aspects related to accessibility to health (*e580*), employment (*e590*), housing (*e525*) and social security (*e570*) services, systems and policies were also frequently mentioned.

These data are consistent with the literature that emphasizes that the physical, social and attitudinal environments in which individuals with schizophrenia live and conduct their lives play an important role in functioning [1,43]. Thus, aspects such as the need for continued medical supervision, the difficulty in finding and keeping a job, and the fact that the income of a high proportion of patients depends on community aid mean that health, labor and social services and systems also play a vital role in the recovery and

functioning of these patients [42,44,45]. A high number of experts also highlighted the prominent role of *e110 Products or substances for personal consumption* (whereby inferring drug use). This reflects the literature that point to an association between drug abuse, specifically cannabis abuse, and poor outcomes, or even a precipitant of psychosis in individuals with predisposition [43,46].

The list of "candidate" ICF categories resulting from the present study, that included the corresponding frequencies, was one of four lists resulting from each of the four studies – expert survey, systematic literature review, qualitative study, multicenter empirical study – that were given to the participants of the May 2015 international consensus conference to consider when deciding on the categories to include in the Brief and Comprehensive ICF Core Sets for individuals with schizophrenia [17]. The results of this expert survey helped to ensure that the ICF Core Sets for schizophrenia, among other things, reflect the know-how of those who provide valuable health care and social services to individuals living with schizophrenia.

The response rate of the final sample was quite high, and the final sample represented the basic characteristics of the initial expert pool; however, only experts from countries that have access to e-mail technology, and those who were fluent in the English language (self-reported) may have led to some selection bias. Moreover, there was a limited number of participants from Africa and South East Asia, thus reducing the representativeness of the sample in these regions.

Despite these limitations, the present study shows that the resulting list of ICF categories has the potential to facilitate a systematic application of the ICF in the individuals with schizophrenia from an international and multidisciplinary perspective. The participating experts identified a wide range of problems in functioning, specifically activity limitations and participation restrictions that are particularly

relevant for individuals with schizophrenia. Knowing these functioning problems can guide the design and implementation of patient -oriented rehabilitation programs with a biopsychosocial approach.

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Table 1. Open-ended questions used in the expert survey

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1. If you think about the **body and mind** of individuals with schizophrenia what **does not work** the way it is supposed to?

2. If you think about the **body** of individuals with schizophrenia, **in which parts** are their problems?

3. If you think about the **daily life** of individuals with schizophrenia, **what** are their problems?

4. If you think about the **environment** and the **living conditions** of individuals with schizophrenia, what is **supportive** for them?

5. If you think about the **environment** and the **living conditions** of individuals with schizophrenia, what is **hindering** for them?

6. If you think about the individuals with schizophrenia, what is **important** about them and **the way they handle** their condition?

Table 2. Demographics and professional experience of the surveyed experts ($n = 152$ respondents)

Age	
mean (SD); median [range]	48.31 (11.38); 48 [28-80]
Sex	
female n (%)	81 (53.3%)
WHO region	
n (%)	
	The Americas: 59 (38.81%)
	Europe: 43 (28.29%)
	Western Pacific: 25 (16.44%)
	South East Asia: 12 (7.89%)
	Africa: 9 (5.92%)
	Eastern Mediterranean: 4 (2.63%)
Profession	
n (%)	Psychiatrists: 59 (38.82%)
	Psychologists: 40 (26.32%)
	Nursing: 26 (17.11%)
	Social workers: 10 (6.58%)
	Occupational therapist: 15 (9.87%)
	Others: 2 (1.32%)
Years of experience	
mean (SD) median [range]	22.51 (11.03); 21.50 [2-55]
Working area*	
n (%)	

Clinic	81 (53.29%)
Research	106 (69.74 %)
Management	15 (9.87%)
Education	73 (48.03%)
Other	5 (3.29%)

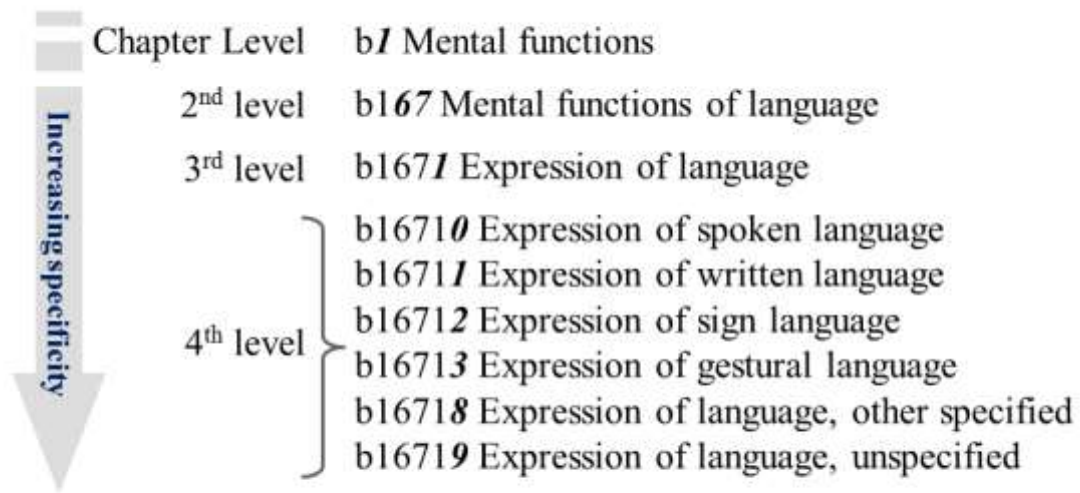*Some professionals may work in different professional areas

Figure 1. Structure of ICF categories exemplified by the b167 Mental functions of language

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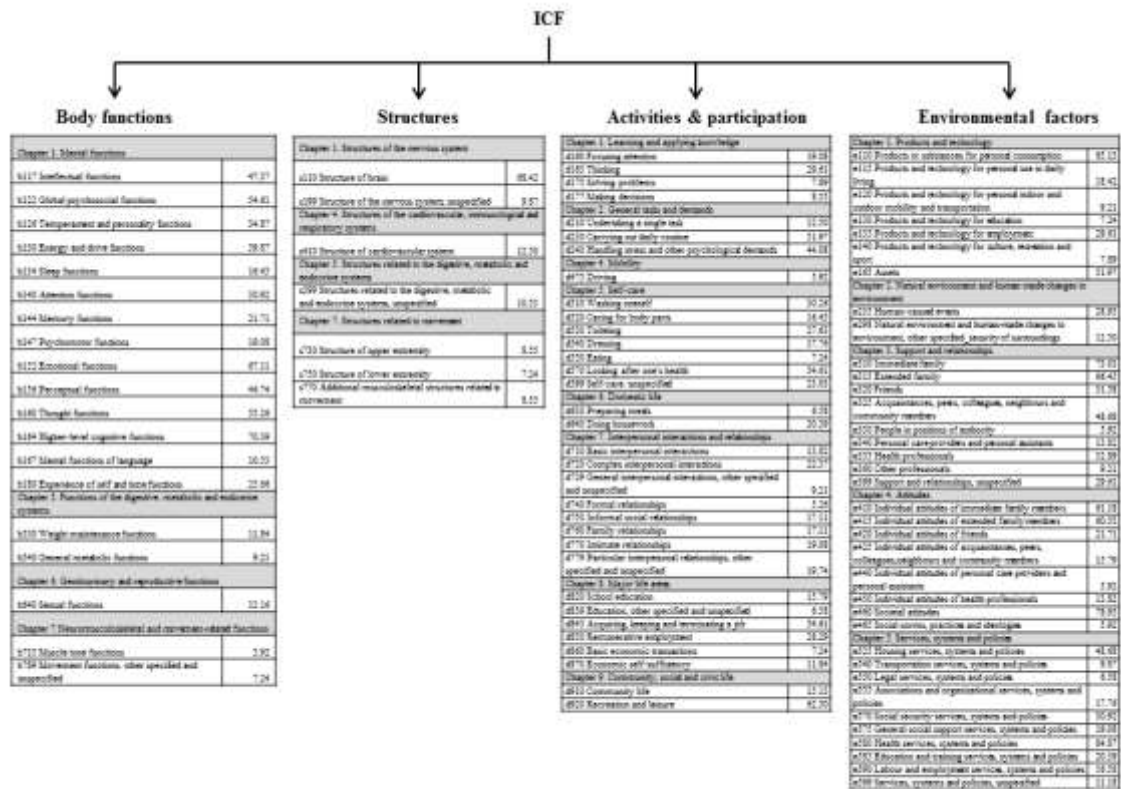
language

Figure 2. Percentage of ICF second-level categories linked to the concepts named by the participants.

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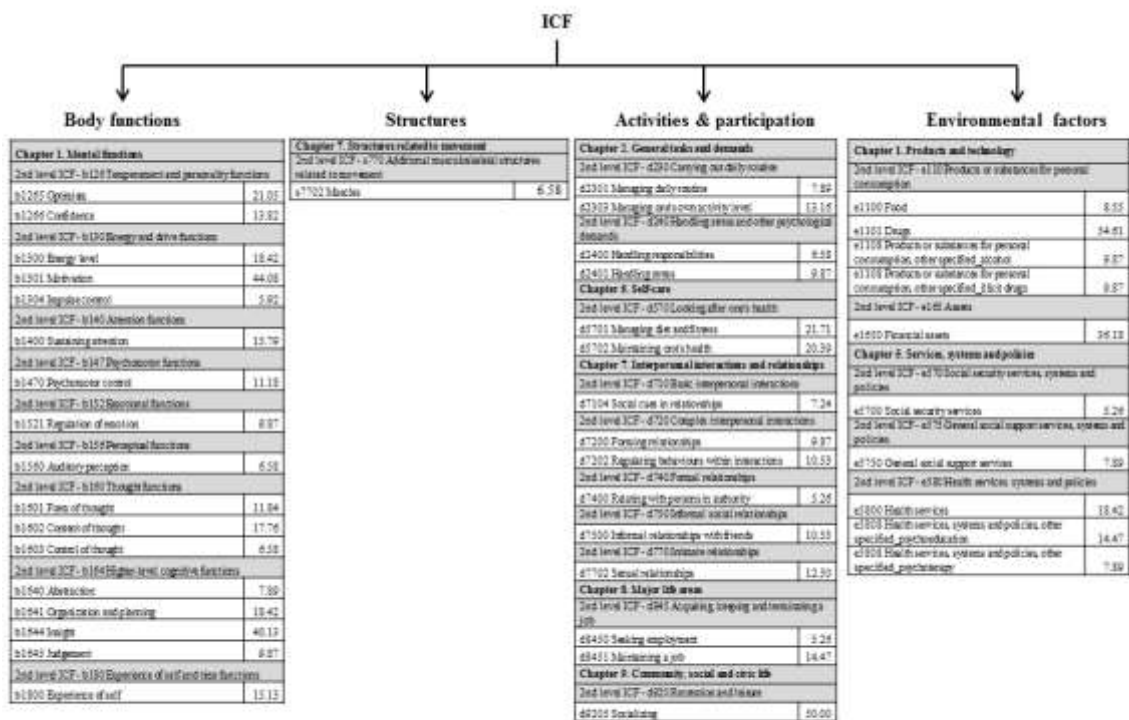
Figure 3. Percentage of ICF third-level categories linked to the concepts named by the participants.

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participants