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ICF-Based assessment and documentation of functioning and disability

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ICF-Based assessment and documentation of functioning and disability

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Table of contents

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EDITORIAL
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Editorial: ICF-Based Assessment and Documentation of Functioning and Disability

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Keywords: functioning, disability, International Classification of Functioning Disability and Health, patient reported outcome, assessment

Editorial on the Research Topic

ICF-Based Assessment and Documentation of Functioning and Disability

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People with any kind of health condition such as acute or chronic disease or injury might experience impairments in body functions and structures, limitations in activities and restrictions in participation. Problems in functioning, that is disability, can change over time due to the natural course of the health condition, the effect of an intervention and features of the social and physical environment.

The World Health Organization's International Classification of Functioning, Disability and Health (ICF) (1) offers a framework and a classification to classify functioning and disability using its components body functions, body structures, activities and participation, as well as contextual factors. The ICF has been promoted as a classification system to generate comparable and standardized data. To ensure standardization it is necessary to develop and test assessments and documentation tools that can be implemented in clinical practice and research. Sound methodological approaches are also required to ensure the appropriate conceptualization, application and implementation of the ICF.

The aim of the Research Topic "*ICF-based Assessment and Documentation of Functioning and Disability*" is to comment on innovative uses of the ICF in documentation and assessment and to explore the application of these tools, including new methodologies to serve the needs of various research areas. A total of nine papers were accepted for this edition using review methodology (e.g., scoping review), mapping exercises, psychometric study designs, quantitative and qualitative study designs as well as mixed methods study designs.

The Research Topic contains four articles with a strong focus on methodology using the ICF as a framework. Cuenot's article maps the GEVA [Guide d'évaluation multidimensionnelle (2)] items used for the multidimensional assessment of the needs of persons with disabilities in France to the ICF, and identifies GEVA items not included in the ICF and which might be available for updating the ICF. Karhula et al. perform a scoping review aiming to shed light on personal factors defined in studies carried out in rehabilitation settings. Macdermid reports on the application of the ICF linking rules (3) and how these rules can be used to support content validation of PROMs. Newman-Griffis et al. investigate natural language processing (NLP) technologies to analyse patient functioning information recorded with claims for federal disability benefits in the United States into ICF domains.

In total, three articles included in this Research Topic report on the development and application of ICF-based tools in patients with acute and chronic diseases. Backmann et al. present their mixed methods study focusing on functioning in a sample of persons with self-reported disability following COVID-19 in Denmark. Björklund et al. report on how to use the ICF classification to describe how professionals in healthcare, habilitation and school document problems with everyday life functioning of children who completed treatment for a brain tumor. Scheel-Sailer et al. contributed to this Research Topic with a research article reporting on the development and implementation of an institutional standard of assessments relying on the ICF as a framework—the Nottwil Standard—for patients with newly acquired spinal cord injury.

The remaining two articles focus on psychometric properties of existing and newly developed ICF-based tools. Nielsen et al. report on the validity and clinical utility of the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) (4) in older patients discharged from emergency departments. Stallinga et al. present their feasibility study on the usability of the preliminary ICF Core Set for patients after a hematopoietic stem cell transplantation from the perspective of nurses.

CONCLUSION

There is sufficient evidence to support the use of the ICF as a framework in assessment and the further development of validated tools for patient reporting of limitations in functioning in various contexts.

AUTHOR CONTRIBUTIONS

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

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ORIGINAL RESEARCH
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The Usability of the Preliminary ICF Core Set for Hospitalized Patients After a Hematopoietic Stem Cell Transplantation From the Perspective of Nurses: A Feasibility Study

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Background: A hematopoietic stem cell transplantation (HSCT) has a major impact on the functioning and perceived quality of life of patients. To describe the functioning of patients, a preliminary set of 53 categories of the International Classification of Functioning, Disability and Health (ICF) as relevant for HSCT patients has been selected earlier by a Delphi study. For the implementation of this preliminary ICF core set for patients after HSCT in clinical practice, a feasibility study was requested.

Methods: A feasibility study was conducted in an explanatory mixed-methods research design. Qualitative data were collected cross-sectionally by semi-structured interviews based on specific topics related to feasibility regarding the use of the preliminary ICF core set for HSCT patients from the perspective of nurses (five in ICF-trained nurses and five regular, untrained, nurses). Quantitative data, were collected longitudinally by using a mobile health application based on ICF in which the ICF trained nurses registered HSCT patients' functioning.

Results: Qualitative analysis indicated that using the preliminary ICF core set is practical and acceptable for providing information about the functioning of HSCT patients from the perspective of nurses. In addition, nurses indicated a demand for this information due to its impact on multidisciplinary meetings and clinical decision-making by involving relevant aspects of the functioning of patients. Management support, trained staff, and designated time to focus on functioning are mentioned as requirements for successful implementation. Quantitative analysis demonstrated that the most used 30% ($n = 17$) ICF categories are included in the preliminary ICF core set for HSCT patients ($n = 24$). Energy (b130) was the most used ICF category. Family relationships (d760) was the most frequently and highly positively associated ICF category.

Conclusions: From the perspective of nurses, the preliminary ICF core set for HSCT patients is feasible and relevant in gaining information regarding functioning. Applying this preliminary ICF core set for HSCT patients in the anamnesis and the nursing consultations contributes to this information. Further research is needed to look at the perspective of other professionals and HSCT patients themselves.

Keywords: ICF core set, hematology, stem cell transplantation, feasibility, functioning

INTRODUCTION

More than 50,000 hematopoietic stem cell transplantations (HSCTs) per year are reported worldwide, and ∼20,000 of these take place in Europe (1). Stem cells can be harvested from the patient (autologous) or from a matched donor (allogeneic) (2) and are dosed by an intravenous infusion (3). Stem cell transplantation is a treatment option for hematological malignancies as well as a number of other malignant and non-malignant diseases (1). The side effects of stem cell transplantation are medical symptoms like infections and organ dysfunction (4). Furthermore, there are side effects with an impact on the perceived quality of life, such as fatigue, anxiety, depressive symptoms, and sexual dysfunction (5, 6).

The primary purpose of HSCT from a medical perspective is to improve the health of an individual by curing the disease. However, the health of a patient after a HSCT also includes his or her experienced physical and psychosocial functioning (4). Therefore, healthcare provision of patients after a HSCT should be focused on functioning as well (7). The International Classification of Functioning, Disability and Health (ICF) is a classification that can be used as a tool to focus on functioning and supporting self-management of patients (8).

The World Health Organization (WHO) published the conceptual model of health as presented in **Figure 1**, in which the ICF and the International Statistical Classification of Diseases and Related Health problems (ICD) are included to describe the health of an individual (9). Functioning is conceptualized as a result of the dynamic interaction between a health condition (disease or disorder) and contextual factors (environmental and personal factors) (9). Functioning pertains to the functions of people, the performance of activities, and the areas of life in which they participate. The ICD classifies health conditions, whereas the ICF classifies functioning and environmental factors influencing functioning. Personal factors are lacking in the current ICF but, although different articles are published with preliminary lists (10), the WHO has decided to refrain from a classification of personal factors in the near future. The ICF is complementary to the ICD; both classifications are essential in completing the description of health (9).

The WHO's conceptual model of health is based on a biopsychosocial model. Using this model broadens the focus of healthcare from disease (biomedical) to functioning and contextual factors (biopsychosocial) (9, 11, 12). The biopsychosocial perspective fits the holistic orientation (8, 13), which is requested for person-centered care as a central theme in nursing and allied health professionals. Moreover, using the ICF will facilitate all professionals and disciplines to be effective partners in multidisciplinary teams due to the standard terminology of ICF (14). Implementing the ICF may be a first step in delivering healthcare with a biopsychosocial approach in which functioning is the focus of health care (8). Limitations related to implementing the ICF are demonstrated in relation to the utility of the ICF for routine practice (15). Tools that are simple to use are mentioned as an important step in this process (16, 17).

The ICF includes more than 1,500 categories. Each of these categories describes an aspect of functioning, for example, work and sleep. Every ICF category has a code, such as b134 (sleep) or d845 (work). These codes are referring to the categories of the ICF. To make the ICF feasible in daily practice, core sets are developed (18, 19). Core sets are sets of selected ICF categories related to a specific health condition (20, 21). For example, there are core sets for hearing loss (22), head and neck cancer (23), and stroke (24). Due to the lack of an ICF core set for HSCT patients, a development project has begun in 2015 in the Netherlands.

Following the guideline for the development of an ICF core set (20), a content analysis, a literature review, and a Delphi study were conducted (25). Currently, the first version, the preliminary ICF core set for HSCT patients (**Table 1**), needs to be explored and tested to examine the relevance in clinical practice. A feasibility study from the perspective of nurses was conducted, since nurses are the primary healthcare professionals involved in the functioning of patients (26).

The aim of this study was to evaluate the preliminary ICF core set for HSCT patients on its feasibility and to perform a quantitative exploration related to the use of ICF categories by nurses in the care of hematological patients hospitalized for autologous and allogeneic stem cell transplantation.

METHODS

Design

A feasibility study was performed to determine the usability of the preliminary ICF core set for HSCT patients (27). A qualitative-dominant, explanatory mixed-methods design was used to gain an insight into the usability with both quantitative and qualitative data (28). First, longitudinal quantitative data were collected by using the preliminary ICF core set for HSCT patients. Second, qualitative data were collected on specific topics related to the feasibility and the use of the preliminary ICF core set for HSCT patients. Qualitative data of the experience logs of nurses were collected to minimize the recall bias (28).

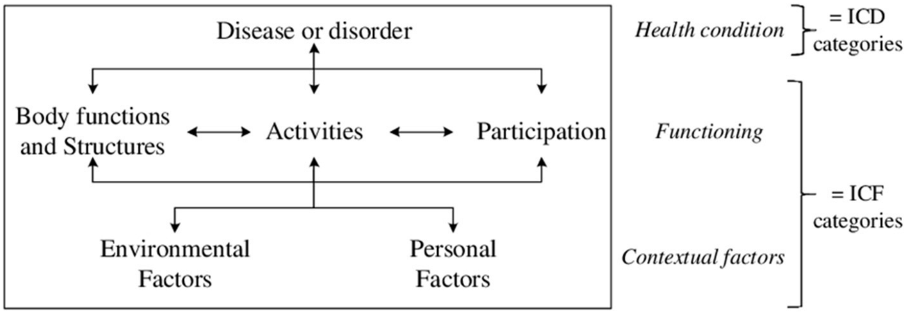

FIGURE 1 | WHO's conceptual model of health representing the interactions between the components (disease, body functions and structures, activities, participation, environmental and personal factors) of the health status. ICD, International Classification of Diseases; ICF, International Classification of Functioning, Disability and Health (8).

TABLE 1 | Preliminary ICF core set for HSCT patients.

Component	Chapter	Categories	Code
Body Functions	1. Mental functions	1. Energy/sleep/attention/memory/emotion/thought	1. b130/b134/b140/b144/b152/b160
	2. Sensory functions and pain	2. Taste/sensation of pain	2. b250/b280
	4. Functions of the cardiovascular, hematological, immunological, and respiratory systems	4. Heart functions/blood pressure/hematological system/immunological system/exercise tolerance	4. b410/b420/b430/b435/b455
	5. Functions of the digestive, metabolic, and endocrine systems	5. Ingestion/defecation/weight maintenance/ sensations associated with the digestive/ water, mineral, and electrolyte balance/ thermoregulatory/ endocrine gland functions	5. b510/b525/b530/b535/b545/b550/b555
	6. Genitourinary and reproductive functions	6. Sexual functions	6. b640
	7. Neuromusculoskeletal and movement-related functions	7. Muscle power/sensations related to muscles and movement	7. b730/b780
	8. Functions of the skin and related structures	8. Protective functions/repair functions/hair/nails	8. b810/b820/b850/b860
Activities and Participation	2. General tasks and demands	2. Undertaking a single task/ handling stress and other psychological demands	2. d210/d240
	5. Self-care	5. Washing/ caring for body parts/ dressing/ looking after health of an individual	5. d510/d520/d540/d570
	6. Domestic life	6. Preparing meals/doing housework/caring for household objects	6. d630/d640/d650
	7. Interpersonal interactions and relationships	7. Basic interpersonal interactions/complex interpersonal interactions/ informal social relationships/family/intimate relationships	7. d710/d720/d750/d760/d770
	8. Major life areas	8. Job employment/remunerative employment/economic self-sufficiency	8. d845/d855/d870
	9. Community, social, and civic life	9. Community life/recreation and leisure	9. d910/d920
Environmental Factors	3. Support and relationships	3. Immediate family/friends/ personal care providers and personal assistants/health professionals	3. e310/e320/e340/e355
	5. Services, systems, and policies	5. Legal services, systems, and policies/social security, services, systems, and policies/health services, systems, and policies	5. e555/e570/e580

Population and Study Procedure

The study population consists of ICF-trained nurses and regular nurses working with patients hospitalized for HSCT at the Department of Hematology in a University Medical Centre in the northern parts of the Netherlands. Registered Dutch-speaking nurses with a minimum of 1 year of hematological experience were included. To be effective due to the limited number of ICF-trained nurses at the department who can serve as primary data sources, a purposeful sample was used. All the five ICF-trained nurses were included as a homogenous group supplemented with five regular nurses to ensure a collection of data with different perspectives regarding the usability of the preliminary ICF core set. Nurses were not eligible if they took care of fewer than

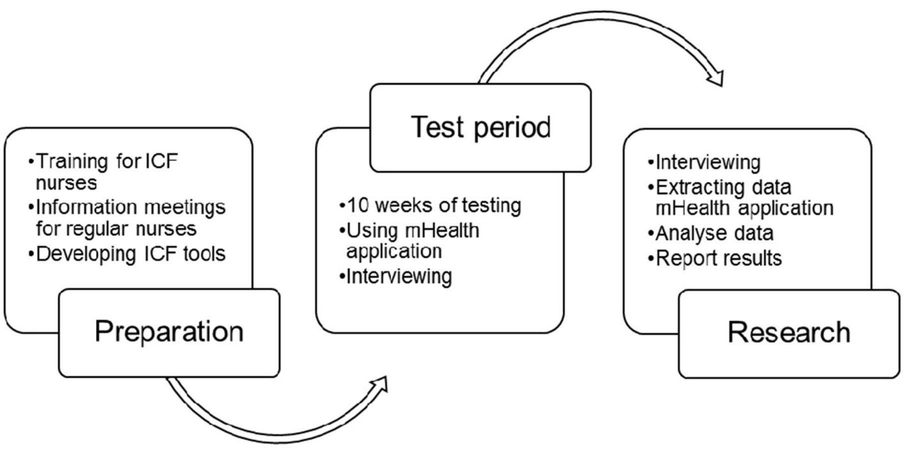

FIGURE 2 | Timeline research procedure. Both the preparation and research phase lasted 8 weeks.

two of the included patients during the test period. A convenient sample of all inpatients hospitalized for stem cell transplantation on January 16, and March 31, 2017, was included in the study (28).

In the study procedure (see **Figure 2** for the timeline research procedure), the five ICF nurses, selected by the head nurse of the hematology department as "ICF nurse," were trained by the ICF expert (HS) in using the preliminary ICF core set for HSCT patients, in doing the nursing consultations and in registration patients' functioning in the mobile health (mHealth) application. The training consisted of an every 3-week 4-h instructor-led discussion-based training in using the ICF. This training is part of an existing ICF training course developed and given over the past several years in the Netherlands (29). The format of the training is based on the concept of meaning and application-oriented learning, indicating that the training appeals to the experience of healthcare professionals and focuses on the practical application of the ICF in patient care. The regular nurses [not trained in ICF, but in daily practice confronted and as such familiar with ICF registrations in patient files and (multi)disciplinary consultations] of the department received information about the ICF project in departmental staff meetings. A new patient nursing anamnesis tool, based on the preliminary ICF core set for HSCT patients, was developed. By using the mHealth application, which includes the entire ICF including the preliminary ICF core set for HSCT patients, ICF nurses register the functioning of patients during the admission of patients and nursing consultations (twice a week on average) in the relevant ICF categories. In clinical practice, this means that the admission is started and registered from the preliminary core set and ends with the open-ended question of whether anything relevant to the functioning of patients should be added. The consultations are exactly the other way around: They start open and the patient can come up with anything that is relevant with regard to functioning. This is registered, and depending on previous consultations, both the nurse and the patient can return to and also use the categories of the preliminary core set. Regular nurses did not use the mHealth application, nor did they perform patient admissions or nursing consultations.

The test phase lasted for a period of 10 weeks in which the preliminary ICF core set for HSCT patients was used in clinical practice. Reports of the patient nursing anamnesis, the nursing consultations, and the experience of the ICF nurses with the use of the ICF core set were included in the logs of the mHealth application. A report of the patient nursing anamnesis and the results of the nursing consultations were added to the patient record to inform the regular nurses.

After 5 weeks of the test period, the first data and experiences regarding the use of the preliminary ICF core set were extracted from the mHealth application. The use of the ICF categories and the logged experiences were analyzed to complete the interview guide. A pilot interview was conducted to enhance the topics of the interview guide. The following topics were identified: practicality (structure, time investment, usability), implementation (design, facilitators, barriers), acceptance (positive, negative), demand (use of the ICF core set), and use of ICF categories (frequency, relevance, usability). The interviews were audiotaped and transcribed. The transcripts of the interviews were matched with the audiotapes. A written member check was performed after the qualitative analysis to determine the authenticity of the results (28). The qualitative analysis was matched with the experiences logs of the nurses to prevent recall bias. The remaining quantitative and qualitative data of the mHealth application were extracted at the end of the test period. For the interviews, the five ICF nurses were included, and also five regular nurses were recruited by email.

Data Collection

The quantitative data related to the use of the ICF categories were collected with the mHealth application (30). The data were extracted twice: at the mid and the end of the test period. Data were collected on the frequency of the use of ICF categories and the qualifier (negative, normal, and positive). These qualifiers in the mHealth application were assigned by the ICF nurses in consultation with the patient.

The qualitative data were collected by a mHealth application (30) and by interviews. ICF nurses reported their experiences with using the nursing anamnesis form and the nursing consultations in the log of the mHealth application (30). Semi-structured interviews with ICF nurses and regular nurses were conducted by researcher JB. The interviews were based on an interview guide and were performed in April 2017. The interview guide contained four focus areas preferred for this feasibility study: acceptability, practicality, implementation, and demand (31). The quantitative data regarding the use of ICF categories (frequency, relevance, usability) including the preliminary ICF core set for HSCT patients were added to the interview guide (fifth topic) to ensure the discussion of the use of the preliminary ICF core set for HSCT patients.

Data Analysis

The quantitative and qualitative data were analyzed separately. Quantitative data were analyzed using the software SPSS24 (IBM Corporate, New York, United States) and SAS (SAS Institute, North Carolina, United States). The ICF categories were analyzed with descriptive statistics by frequency and associations. The associations between the ICF categories used were analyzed with a chi-square test because the association is measured between binary variables (measured with negative–positive qualifiers) in a two-by-two table (32). Effect sizes [phi *(ϕ)*] were calculated and assessed against Cohen's criteria (ϕ 0.1 = small, ϕ 0.3 = medium, ϕ 0.5 = large), using Fisher's exact test to determine statistical significance by the p-value (32). Pearson's correlation coefficient was used to analyze the association between the 30% most used ICF categories and baseline characteristics such as age and hospital duration. An independent-sample t-test was utilized to analyze whether gender and kind of transplantation differ in terms of the top 30% most used ICF categories (32).

Qualitative data were analyzed using the software NVivo11 (QSR International, Melbourne, Australia). Deductive thematic analysis [initial coding (nodes) of the interviews, sorting different nodes into themes, and merging themes into the predefined topics] (33) was applied to the data and enabled the study to report in terms of feasibility by the experiences of the nurses participating in the test period. Intercoder agreement about items and topics was done by the researcher HS and the researcher JB to enhance the reliability of the qualitative analysis.

RESULTS

Ten nurses, five in ICF-trained nurses (ICF nurses) and five not in ICF-trained nurses (regular nurses), participated in the qualitative part of the study. **Table 2** presents the background characteristics of the nurses. No significant differences were found between the background characteristics of the ICF nurses and the regular nurses. A thematic analysis of the interviews resulted in 42 nodes, divided into 10 themes. The themes were linked to the existing topics: use of ICF categories, practicality, demand, acceptability, and implementation.

During the test period, 27 patients were hospitalized. Three patients refused to participate. The quantitative part of the study included 24 patients. **Table 3** presents the background characteristics of the patients.

Use of ICF Categories of the ICF Core Set

In the test period, 100 unique ICF categories are used by nurses for their patients for a total of 1,810 times. **Table 4** presents the most used (top 30% = 17 ICF categories) ICF categories. These most used ICF categories, except medication (e110), are included in the preliminary ICF core set for HSCT patients. Out of the most used ICF categories, 11 categories belong to the component of Body Functions and Structures, three to Activities and Participation, and three to Environmental factors. Energy (b130) was the most used ICF category ($n = 40$).

Associations between the most used ICF categories are shown in **Table 5**. Handling stress (d240) is significantly positively associated with family relationships (d760) ($\phi = 0.60$, $p < 0.05$), sleep (b134) ($\phi = 0.73$, $p < 0.05$), and pain (b280) ($\phi = 0.56$, $p < 0.05$). Family relationships (d760) is also significantly positively associated with sleep (b134) ($\phi = 0.63$, $p < 0.05$), support of immediate family (e310) ($\phi = 0.60$, $p < 0.05$), and immunological system functions (b435) ($\phi = 0.60$, $p < 0.05$). Handling stress (d240) and family relationships (d760) are the most frequent significantly associated categories. This means that more problems or strengths in one category are associated with more problems or strengths in another category. The other background characteristics, gender and kind of transplantation, did not differ in terms of the top 30% most used ICF categories.

In contrast to the quantitative analysis, demonstrating that some categories may be more relevant due to more frequent use than other categories, the qualitative analysis showed that all ICF core set categories for the HSCT patient are found to be relevant. Nurses explained that the reasons for different levels of relevancy included (i) the stage of disease, (ii) expectations of the patient, and (iii) impact of the disease. "*Yes, all of these ICF categories are relevant, but not in every moment of the disease" (V7 regular nurse).* Another nurse stated: "*Preparing meals (d630), is not relevant during the admission period, that's only applicable at home" (V1 ICF nurse).*

Practicality of the ICF Core Set

From the qualitative analysis, nursing anamnesis and nursing consultations are found to be feasible. The new ICF-related anamnesis was experienced as a good start of the admission. Although it is time-consuming, the effort is worthwhile. *"The time and energy you spent on the anamnesis, pays off during the admission [...] it causes less questions and uncertainties by patients later on" (V10 regular nurse).* The nursing consultations are experienced as thorough conversations and result in valuable information. Opinions of nurses regarding the frequency of nursing consultations depend on changes in condition or functioning of patients. Most nurses mentioned the optimal average frequency of nursing consultations being two or three times a week.

Some difficulties were found related to the use of the mHealth application, especially regarding loading speed (related to the Internet connection) and clarity of the information regarding admitted and discharged patients. "*The overview is not very clear, you can't easily see who and when information is reported*" *(V9 ICF nurse)*.

Demand for the ICF Core Set

In the qualitative section of the study, the demand for using the preliminary ICF core set is analyzed from the perspective of patients (articulated by nurses) and the perspective of nurses. From the perspective of patients, using the ICF core set allows (i) patients to receive more attention, (ii) have their needs discussed more frequently, and (iii) give nurses the ability to act on these needs. *"The ICF nurse is able to sit down and take some time for a patient. Patients experience this like: "They have time for me, they listen to me." "They can try to find a solution for the patients' needs" (V3 regular nurse)*. The nursing consultation creates more awareness about what is important to the patient. This supports self-management and "patient-centered care." "*The ICF can help the patient to structure their daily lives. What needs to be done and what is required? What can the patient do by himself and where does he need help?" (V5, ICF nurse)*.

From the perspective of nurses, demand for using the ICF core set can be found in improved communication between nurses, physicians, and other disciplines. "*You are able to support your professional input, patient needs are shown more clear" (V10, regular nurse)*. A nurse stated: *"With the ICF framework we can provide relevant information related to patients' daily life in professional terminology. This has an impact on the*

TABLE 2 | Background characteristics of nurses.

	ICF-trained nurses ($n = 5$)	Regular nurses ($n = 5$)	*P*-value
Gender (female) *n* (%)	5 (100)	4 (80)	1.000*
Age, years, median	38 (28-53)	39 (31-61)	0.421**
Work experience years, median	6 (5-35)	17 (6-40)	0.310**

*Fisher's exact test, **Mann–Whitney U-test.*

TABLE 3 | Background characteristics of patients.

	Autologous-tx (n = 12)	Allogeneic-tx (n = 12)	*p*-value
Gender (male) *n* (%)	9 (75)	10 (83)	1.000*
Age, years, median (SD)	60 (8)	56 (17)	0.422**
Hospital duration, days, mean (SD)	19 (5)	21 (10)	0.573**

*Tx, transplantation *Fisher's exact test, **Independent-samples t-test.*

TABLE 4 | Frequency of the most used (top 30%) ICF categories.

	ICF code	Description	Frequency (Total $n = 1,810$)	Percent (%)
1	b130	Energy	40	2.21
2	b525	Defecation	39	2.15
3	b152	Emotional functions	38	2.10
4	b535	Nausea	37	2.04
5	b280	Pain	35	1.93
6	b430	Hematological system functions	33	1.82
7	b510	Ingestion functions	32	1.77
8	d845	Work	32	1.77
9	e110	Medication	32	1.77
10	b134	Sleep	31	1.71
11	d760	Family relationships	31	1.71
12	e355	Health professionals	30	1.66
13	b455	Exercise tolerance functions	29	1.60
14	b250	Taste	28	1.55
15	d240	Handling stress	28	1.55
16	e310	Immediate family	28	1.55
17	b435	Immunological system functions	27	1.49

TABLE 5 | Associations [phi *(ϕ)* correlation coefficient] between the 30% most used ICF categories ordered by frequency (1 = most used).

17 immu.fun.	**b435**																	1.00
16 immi.fam	**e310**																1.00	0.24
15 hand.stres	**d240**															1.00	0.49*	0.24
14 taste	b250														1.00	0.50*	0.24	−0.01
13 exerc.toler.	b455													1.00	−0.06	0.18	0.18	0.18
12 health prof.	e355												1.00	−0.37	0.35	−0.10	−0.10	−0.10
11 fam.rel.	**d760**											1.00	−0.29	0.26	0.32	**0.60***	**0.60***	**0.60***
10 sleep	**b134**										1.00	**0.63***	−0.06	0.20	0.51*	**0.73***	0.29	0.29
9 medication	e110									1.00	0.19	−0.12	0.45	−0.45	0.24	0.03	−0.19	0.19
8 work	d845								1.00	−0.19	−0.12	−0.19	0.33	−0.34	0.15	−0.06	−0.06	−0.06
7 ingest.func.	b510							1.00	0.06	0.00	0.25	0.19	−0.06	0.20	0.07	0.07	0.07	0.29
6 hemat.func.	b430						1.00	0.49*	−0.10	−0.13	0.12	0.08	0.02	0.49*	−0.02	−0.02	0.40	0.19
5 pain	b280					1.00	0.07	0.06	−0.17	−0.19	0.41	0.26	−0.22	0.24	0.35	0.56*	0.15	0.15
4 nausea	b535				1.00	0.34	0.27	0.12	−0.16	−0.02	0.47*	0.19	−0.15	0.34	0.27	0.47*	0.27	−0.15
3 emotions	b152			1.00	−0.08	0.25	0.00	0.00	−0.25	0.09	0.35	0.43	0.09	0.00	0.10	0.31	0.10	0.31
2 defecation	b525		1.00	0.08	0.34	0.16	0.07	0.24	−0.17	−0.02	0.59*	0.49*	−0.22	0.05	0.36	0.36	0.36	0.15
1 energy	b130	1.00	0.54*	0.09	−0.02	−0.15	0.31	0.37	0.02	0.07	0.18	0.35	0.12	−.015	0.19	−0.03	0.40	0.19
		b130	b525	b152	b535	b280	b430	b510	d845	e110	b134	**d760**	e355	b455	b250	**d240**	**e310**	**b435**

[*] *Significantly associated: $p < 0.05$ Fisher's exact test; ϕ, 0.10 small effect, 0.30 medium effect, 0.50 large effect; boldface printed are significantly and highly associated with very large effect. The 30% most used ICF categories, including the full descriptions of the labels, are presented in* ***Table 4****.*

communication with physicians" (V1 ICF nurse). This is also reflected in multidisciplinary meetings. *"The nurse is presenting the patients' information in a clear structure, so that everything is discussed" (V6 ICF nurse).*

Acceptability of the ICF Core Set

The acceptability of the ICF core set was discussed in two aspects of healthcare: healthcare provision and the relationship between nurse and patient. Using the information from the nursing consultation, nurses can anticipate potential problems earlier on, consult other disciplines, and determine appropriate healthcare provision. *"With one patient, for example, the issue of continuing his treatment was clarified by the nursing consultations to both nurses and physicians. As a result, the patient was discharged to go home and die" (V4 regular nurse).* The regular nurses have experienced the ICF project as a valuable addition to regular care of patients. "*I see it as an addition [. . .] it creates a better picture of the patient" (V4 regular nurse).*

The ICF project adds value to the relationship between patients and nurses. The availability of the ICF nurse in nursing consultation results in continuity of the patient care process. "*Continuity [. . .] that you really know the patient from admission until discharge" (V8 ICF nurse).* As a result, a trust relationship between a nurse and the patient develops with more in-depth conversations related to functioning. "*You need to create a trust relationship. The more you talk to them, the more they tell you" (V9 ICF nurse).*

Implementation of the ICF Core Set

The implementation of the preliminary ICF core set was confronted with facilitators and barriers. There are two facilitators of the implementation indicated by ICF nurses and regular nurses. First, the ICF nurses stated that the close contact between them and the researcher HS was helpful in introducing the concept of functioning and reporting functioning correctly in the standard terminology of the ICF. Second, the regular nurses indicated that the availability of the ICF nurses was complementary to the regular care. The ICF nurses reduced the workload. "*I liked it, it eases the workload" (V3 regular nurse).*

The most significant barrier was the vulnerability of the organization. "*Illness of the ICF nurses or holidays were a disadvantage for the project because it disturbed the continuity. That's a pity" (V5 ICF nurse).* Regular care related to HSCT patients is highly biomedical-focused. The limited time of nurses gives biomedical care more priority at the expense of the ICF project and biopsychosocial care.

To enhance the performance of the ICF project, the nurses stated that expanding the amount of ICF nurses in the team is necessary. They explained that time and training is required by using the ICF core set. "*There need to be nurses capable to perform ICF consultations" (V3 regular nurse).* The most relevant requirement for the project, however, according to the ICF nurses and regular nurses, is a commitment from management. "*Both management support and staffing is required. With their support it will become a success" (V8 ICF nurse).*

DISCUSSION

The use of the preliminary ICF core set for HSCT patients provides information about functioning of patients during the hospitalization at the Department of Hematology. The ICF categories structure the communication among the disciplines and facilitate the nurses representing the needs of the patient. Additionally, using the ICF categories in nursing consultations makes patients aware of important aspects of their daily lives. This information is significant for multidisciplinary meetings and may impact the decision-making related to care and treatment plans.

This study provides meaningful insight into the application of the ICF core set in clinical practice. Following the recommendations of previous studies (34, 35), the current study focuses on how to use the ICF core set in clinical practice. Important facilitators, such as efficiency, managerial support, and coaching, were obtained. These facilitators are found in previous studies as well (35, 36). Another benefit of using the ICF core set is regarding multidisciplinary communication. Mainly because the structure of the ICF ensures the evaluation of all aspects of the functioning of patients without a primary focus on disease and disability, as found in other studies (37, 38). The finding that the relevance of ICF categories is related to the stage of the disease is comparable with the study of Scheuringer et al. (39). They found unique aspects of functioning in the post-acute or long-term context. The ICF components Activities and Participation, regarding the relationship, employment, and recreation categories, are used more frequently in the long-term context (39). However, the current study demonstrates that, near to the expected dominance of the most frequently used ICF categories classified in the Body Functions characterizing the acute stage of the disease, also the relationship and employment categories are present in the top 30% most used categories (**Table 4**). Furthermore, the results of this study show that the frequency of these categories increases with longer hospitalization. This can be explained by the differences in research methods. Scheuringer et al. (39) used a survey to determine the ICF categories by opinions of experts. The current study tested the use of the ICF categories in actual clinical practice. Testing the ICF core set revealed that the top 30% most used ICF categories, except for medication (e110), were all included in the preliminary ICF core set for HSCT patients. The study conducted previously to develop the preliminary ICF core set for HSCT patients did not determine the category medication (e110) (25). This can be explained by the content analysis that was performed at the time based on the daily patient reports, whereas medication (e110) was reported on a different form. Studies in medication management related to HSCT patients demonstrated that adherence is an issue due to the complex medical regimes (40, 41). Family relationships (d760) were the most frequently and highly positively associated ICF category. Due to the qualitative-dominant study design, apart from the associations, no further quantitative analyses are performed on the qualifiers. Related to the literature demonstrating the limited psychometric properties of ICF categories (42), a well-designed quantitative study is required to perform extensive analyses on the qualifiers.

Certain aspects must be considered to interpret the results of the current study. First, due to limited time and practical reasons, such as training and coaching, the study sample included only nurses from the Department of Hematology from one University. Given these specific circumstances, the results are not yet generalizable. Nevertheless, to gain a better understanding of using the ICF core set in clinical practice, a scope for one team was recommended (43). Moreover, it is argued that a "bottom-up" approach will be helpful for the nurses to own the process and results in a successful implementation (44).

Second, the results of this study were collected with semi-structured interviews in an attempt to collect expert opinions of nurses. Consequently, some of the results, especially those involving the patient, were indirect. However, the use of expert opinions is often useful in the early phase of applying a model in clinical practice (28). Another limitation was the mHealth application (30). Disturbances related to Internet connection as well as getting a clear overview of patients hampered an easy registration of functioning of patients. Nevertheless, the application provided a reliable way to report the data related to the used ICF categories and to extract the data for scientific research. Intercoder agreement about items and topics by the researcher HS and the researcher JB enhanced the reliability of the qualitative analysis. Finally, the involvement of an ICF expert (the researcher HS) ensured the content validity and helped the nurses learn the fundamentals and report the ICF categories correctly (35).

The results of the study may bring implications for the practice of nursing. In the current study, a structured terminology usable for communication among disciplines was in demand in the nursing field. The ICF provides the structure and the terminology. This structured terminology allows nurses to provide relevant information regarding the functioning of patients. In addition, the terminology will be recognized by physicians and other disciplines and will probably result in better communication between nurses, physicians, and other relevant health professionals.

CONCLUSION

From the perspective of nurses, all ICF categories in the preliminary ICF core set for HSCT patients are determined to be relevant and useful in gaining information regarding functioning. Medication (e110) was the only missing category in the core set and should be considered for inclusion. Family relationships (d760) was the most frequently and highly positively associated ICF category with a very large effect. Information related to the functioning of patients provides the nurses with better insight into the situation of patients. The ICF core set can also help patients recognize what is important in their daily lives. Applying the ICF core set with the anamnesis and the nursing consultations contributed to these results. However, as mentioned in literature and demonstrated in this study, training and a well-working tool are requested to perform the consultations and register information of patients in the right way. Further research is needed to look at the perspective of other professionals and HSCT patients themselves.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

This study was conducted according to the principles of the World Medical Association (WMA) Declaration of Helsinki. The Medical Ethics Review Board of the University Medical Center Groningen confirmed that the Dutch Medical Research Involving Human Subjects Act does not apply to the current study. The nurses who participated in the study signed an informed consent before the interview. The patients signed a general informed consent before hospitalisation. All participants were informed that their participation in this study was voluntary and that they could withdraw from the study at any time. All data was anonymised and stored on a secure USB stick and the secured hard drive of the hospital. Only researchers HS and JB had access to the data.

AUTHOR CONTRIBUTIONS

HS, JB, SH, and PR designed the study with input from HO-M and MK. HS, JB, and SH developed and planned the preparation and testing phase. JB recruited participants and collected and analyzed data with supervision of HS. RS supervised the statistics. HS and JB led the writing of the manuscript. HO-M, MK, LO, and PR supervised the execution of the study. All authors contributed to the review, editing, and final approval of the manuscript.

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REVIEW
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ICF Personal Factors Strengthen Commitment to Person-Centered Rehabilitation – A Scoping Review

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Background: The International Classification of Functioning, Disability and Health (ICF) classification is a biopsychosocial frame of reference that contributes to a holistic understanding of the functioning of a client and the factors involved. Personal factors (PFs) are not currently classified in the ICF due to large societal and cultural diversity and lack of clarity in the scope of such factors.

Aims: To ascertain which factors in the ICF classification have been defined as PFs in different studies and what conclusions have been drawn on their role in the ICF classification.

Methods: The study was a scoping review. A systematic search for articles published in 2010–2020 was performed on the Cinahl, Pubmed, ScienceDirect, and Sport Discus databases. The PFs specified in the articles were classified according to the seven categories proposed by Geyh et al. socio-demographic factors; position in the immediate social and physical context; personal history and biography; feelings; thoughts and beliefs; motives; and general patterns of experience and behavior.

Results: The search yielded 1,988 studies, of which 226 met the inclusion criteria. The studies had addressed a wide variety of PFs that were linked to all seven categories defined by Geyh et al. Some studies had also defined PFs that were linkable to other components of the ICF or that did not describe functioning. Approximately 22% (51) of the studies discussed the role of PFs in rehabilitation.

Conclusions: The range of PFs in the ICF classification addressed in the reviewed studies is wide. PFs play an important role in rehabilitation. However, according to the reviewed studies, a more precise coding of PFs is not yet warranted.

Keywords: international classification of functioning disability and health, client-centeredness, person-centeredness, personal factors, rehabilitation, scoping review

INTRODUCTION

Over the past 20 years, the International Classification of Functioning, Disability, and Health (ICF) has become a generally accepted biopsychosocial framework for rehabilitation (1). Through the provision of uniform concepts and a commonly shared frame of reference, the ICF classification has changed the practices and the statistics used to assess functioning and disability (2). However, the utilization of the ICF still needs to be further developed in the Nordic countries (3). In the ongoing rehabilitation reform led by the Finnish Ministry of Social Affairs and Health, the ICF classification is seen as a framework for establishing uniform practices in the assessment and documentation of functioning (4).

Enabling sufficient functioning is a complex process, as it comprises multiple interacting components that must be tailored to individual needs and situations (5). The Nordic countries appear to have a common conceptual understanding of client-centered practice (6), which is supported by applying the bio-psycho-social framework of the ICF in the complex processes of rehabilitation (7).

The ICF contains a broad range of categories for describing body functions and structures and activities and participation. In addition, environmental factors, which is one component of the contextual factors, can be defined as a barrier or a facilitator for functioning. However, the other component of contextual factors, personal factors (PFs), which are defined as the background information about the life and lifestyle of an individual, have not been classified (1). PFs include the resources, means of coping, education, and behavioral patterns of an individual. Identifying these functioning-related factors helps to understand how one's clients are, how they think, how they evaluate and understand their own situation, what they hope for, and how they cope in their daily lives. PFs and their interpretation influence the choice of rehabilitation services and measures, as well as other forms of support (8). Hence, the key question is how to identify and take into account the diverse PFs that affect the functioning of an individual in the same way as other factors included in the ICF classification.

It has been suggested that full utilization of the ICF classification is hindered by the fact that PFs are not categorized in the same way as their other components (9). Given the absence of a formal categorization of PFs in the ICF, studies have used various other categorizations. For example, in their review, Muller & Geyh (10) compared the background and content of eight different classifications. These classifications included, in varying degrees, the following 12 areas: socio-demographic factors, behavioral and lifestyle factors, cognitive psychological factors, social relationships, experiences and biography, coping, emotional factors, satisfaction, other health conditions, biological/physiological factors, personality, and motives/motivation. On the other hand, the use of a more precise classification of PFs has also been criticized. Leonardi et al. (11) suggested that PFs such as gender, age, or education may have implications for the disability of a person and are therefore important in understanding functioning. However, they did not favor a more precise classification of PFs, as this could lead to "blaming" clients for their functional limitations. Simeonsson et al. (12) proposed that before constructing a taxonomy of codes for PFs, one should critically assess the need for PFs as a separate component in the ICF classification. These conflicting views suggest that there is a need to systematically examine how PFs are defined and manifested in rehabilitation studies.

The role of PFs in the ICF classification is also linked to the ongoing discussion on the need for a full reconsideration of the ICF classification framework. An alternative ICF model in which medical health status is incorporated in PFs has been proposed (13). Moreover, Mitra and Shakespeare (14) proposed a visual scheme of the model in which environmental and personal factors are located at the top of the model, thereby emphasizing their importance. They also highlighted the importance of well-being, quality of life, and individual experience of agency when re-designing the ICF model. The need to review the ICF model is also shared by Sykes et al. (15), who suggested that any such process should be based on research evidence and, importantly, include people with disabilities. This ongoing discussion on if, and if so how, PFs should be included in the ICF indicates a need to systematically identify, analyze, and summarize how PFs have, to date, been studied in the field of rehabilitation.

In 2011, Geyh et al. (16) presented an overview of conceptualizations of the PFs component of the ICF. The review comprises 79 articles in which more than 200 concepts in total were labeled as PFs. Examples of the most significant of these include self-efficacy, attitudes, expectations, motivation, personality traits, and life goals. PFs were described in the articles as affecting disability and health and as having a significant role in the assessment of functioning and rehabilitation and in research and social security settings. The authors concluded that the PFs need to be standardized (16). In 2019, Geyh et al. (8) presented a classification of PFs. In this scoping review, we systematically collected research articles published after Geyh et al.'s work in (2011) (16) and applied the classification by Geyh et al. (8) in our analysis.

In 2017, the Finnish Rehabilitation Reform Committee submitted proposals for reforming Finland's rehabilitation services. Based on those proposals, the rehabilitation services reform was planned to take place between 2020 and 2022 as part of both a wider national reform program and as separate legislative projects. One important development area concerns the use of the ICF framework in organizing and producing rehabilitation services that meet the individual needs of the clients (4). The present review contributes to this reform work and aims, in particular, to provide a basis for determining the role of PFs in harmonizing monitoring systems and indicators of functioning. This review assembles research data and views on the need for the assessment of PFs and the possible need for a more precise classification as part of a comprehensive assessment of functioning. Our purpose was twofold: first, to summarize the PFs that have been investigated in research articles, irrespective of the study design, and second, to describe the reflections of the authors on the issue of PFs.

MATERIALS AND METHODS

Study Design and Data Search

This study followed the scoping review methodological framework (17, 18). This method was appropriate, given the present objective of mapping the evidence on PFs. Literature searches were conducted by an expert information specialist in consultation with the research team. The search was undertaken in the following electronic databases: Cinahl, PubMed, ScienceDirect, and Sport Discus, and all potentially relevant studies published from 2010 to 2020 were extracted. The search terms were as follows: (ICF[Title/Abstract] OR "International Classification of Functioning"[Title/Abstract]) AND (personal[Title/Abstract] OR context*[Title/Abstract]). All study designs were eligible, whether qualitative, quantitative, or mixed methods. Methodology or guideline reports were also searched.

Study Selection and Relevancy Rating

Throughout the selection process, the eligibility of studies was determined by applying established criteria: an article was included for the assessment of relevancy if it addressed one or more PFs in the context of ICF and excluded if it made no mention of PFs. Data selection was performed independently by two researchers. In addition, all members of the research team participated in the consensus discussions, in which the data selection protocol and choices were refined based on the inclusion and exclusion criteria. In the first step, the titles and abstracts were screened by two researchers.

The relevance of the full-text articles in relation to the research questions was then determined using the classification by Goodman et al. (19) (**Table 1**). Two researchers screened whether the article addressed one or more of the factors defined in the article as an ICF PF. Thereafter, articles were rated for relevance on a scale of one to six (1 = low relevance; 6 = high relevance). After the relevance ratings, only articles rated 5 and 6 were included in the further analysis.

Data Analysis and Synthesis

Data extraction and analysis were conducted in two separate phases. The first phase of the data analysis included studies that reached level 5. Data on PFs were extracted, categorized according to the classification by Geyh et al. (8), and entered into a chart. The relevant descriptive characteristics of the studies (e.g., frequencies of methods used and study populations) were gathered and analyzed (see **Tables 2**, **3**).

In the second phase, all the studies at level 5 that reached level 6 were extracted (see **Table 1**), and subjected to qualitative thematic analysis. All these studies included reflections on the role of PFs in rehabilitation. These reflections were subjected to a qualitative thematic analysis. The thematic analysis was implemented using a mind-mapping process in which the researchers analyzed qualitative themes identified in the reflections. Team members met frequently to compare mind maps and further consider their interpretations of the thematic categories and produce a thematic map of the findings. Thematic analysis was used to broaden knowledge on the role of PFs in rehabilitation research.

RESULTS

Characteristics of the Articles

A total of 226 definitely relevant (level 5) research articles were included in the analysis. Of these, 51 articles were classified as direct and highly relevant (level 6), as the authors had reflected in the discussion section on the role of PFs in rehabilitation (**Figure 1**).

The research designs of the included articles ranged from quantitative, qualitative, and mixed methods to conceptual/theoretical (**Table 2**). The target groups of the articles were also heterogeneous, comprising different client groups and professionals (**Table 3**).

Personal Factors in the Research Articles

The 226 articles addressed a wide variety of PFs. The PFs mentioned in articles, along with references to the articles in question, and factors included in the ICF as part of a component other than PFs or that do not describe functioning, are presented in **Supplementary Table** 1. The factors were linked to all seven of the categories defined by Geyh et al. (8). Of these articles, 154 articles (68%) addressed PFs that were linked to General patterns of experience and behavior (category 7). PFs related to Socio-demographic factors, most commonly gender and education (category 1) were addressed in 145 articles (64%), and factors related to Thoughts and beliefs (category 5), such as self-expectations and interest in various issues, in 106 articles (47%). PFs were also linked to the other four categories. PFs linked to Motives (category 6) were addressed the least, in only 25 articles (11%). Moreover, almost half of the studies (46%) dealt with PFs other than those listed in the classification of Geyh et al. (8). These included other diseases, quality of life, severity of injury, and compliance with treatment (**Supplementary Table 1**).

Factors included in the ICF as part of a component other than PFs or that do not describe functioning were mentioned as PFs in 71 articles (31%). For example, personality or personality traits related to ICF body functions (b126 temperament and personality functions) were defined as a PF in 17 articles, pain (b280–289) in 10 articles, and body mass index (b150 weight management functions) in 10 articles. Similarly, support from family, friends, or others was defined as a PF in 9 articles, although they are listed under environmental factors in the ICF (e3 support and interpersonal relationships). Factors that do not describe functioning but which were defined as PFs included lack of time, the ability of the therapist to communicate, and preparation for therapy.

Roles of Personal Factors in Rehabilitation

The thematic analysis (of 51 articles) highlighted three themes on the role of PFs in rehabilitation: a person- and client-centered rehabilitation process, commitment to rehabilitation, and the

TABLE 1 | Relevance scale of the publication, adapted from Goodman et al. (19).

Relevance	Definition
Included studies	
6 = Directly and highly relevant (these studies are also included in class 5)	The abstract explicitly addresses PF. In the results section of the articles, PF are described in relation to the ICF classification (for example, as an outcome measure or factors affecting functioning). In addition, the role of PF in rehabilitation is reflected on in the discussion section.
5 = Definitely relevant	PF are mentioned in the abstract. In the results section of the articles PF are described in relation to the ICF classification (for example as an outcome measure or as a factor affecting functioning).
Excluded studies	
4 = Probably relevant	PF are mentioned in the abstract. The article does not distinguish which PF are defined as falling within the ICF classification.
3 = Possibly not relevant	The article mentions PF, but the focus on PF is not well articulated or consistently a focus throughout the paper.
2 = Probably not relevant	PF are mentioned in the abstract. Only a minor focus on PF.
1 = Definitely not relevant	The article makes no mention of PF.

TABLE 2 | Research designs of the included studies.

Design	Number of studies Data $n = 226$ Relevance level 5	Number of studies Data $n = 51$ Relevance level 6
Systematic or scoping review	39	9
Association of factors (for example regression analysis, latent class analysis)	72	14
Qualitative study (for example content analysis, phenomenological study, qualitative descriptive or case study)	48	10
ICF core set development and/or validation	20	11
Theoretical papers or recommendations	20	5
Quantitative descriptive/ cross-sectional study	14	3
Development and/or validation of measures	7	
Delphi study	4	
Other (Development of treatment, study protocol)	2	

need for classifying PFs (**Figure 2**). Each theme comprised different sub-themes.

Person- and Client-Centered Rehabilitation Process

In sum, the PFs reflected on in this group of articles largely concerned person- and client-centered care (20–39). PFs support a bio-psycho-social point of view of rehabilitation (40) and allow a comprehensive observation of functioning (8). In general, PFs were argued to be meaningful in person- and client-centered care (29). Professionals should permit the individual to drive the process (35). The role of PFs was reflected on in the different phases of rehabilitation. For example, the age and gender of a person seem to be especially important factors in rehabilitation planning (21, 23, 41–43). In addition, the classification of PFs helps in identifying the individually perceived needs of the clients and the planning of individual care (i.e., medication) (44). It also helps professionals to plan and select rehabilitation interventions for clients (45) and enables them to see the effects of these interventions (31). PFs seem to be more relevant to physical activity and training than environmental factors (38). A PF may act as a significant enabler or deterrent in determining the social, medical, or rehabilitative benefits sought (46). Consideration of PFs can have an impact on multiple outcomes, including quality of life (24, 32, 47), functioning and participation in society (32), and social integration (48).

Commitment to Rehabilitation

Several articles discussed PFs around the theme "commitment to rehabilitation." In particular, the role of PFs in motivating rehabilitation was addressed in many articles. Hawkins et al. (25) argued that PFs should be taken into account when planning rehabilitation as they are relevant to motivation. It was also argued that PFs can promote or hinder the motivation of a person (30), device uptake (49), return to work (50) and realistic goal setting in rehabilitation (27). Giving consideration to personal interests generates resources and prevents frustration with rehabilitation, and thus promotes the commitment of a client (51). Positive coping strategies, self-efficacy, and an optimistic attitude toward rehabilitation are important factors in its success (33, 52, 53). They also allow us to understand and take note of the experience of illness and satisfaction by the clients with their activities (54). Willingness and an optimistic attitude toward rehabilitation are thus meaningful factors (30). The confidence of a person in his/her own abilities and capacities is also important in promoting commitment to the rehabilitation process (51). PFs can also help in identifying the challenges that rehabilitation presents to individuals (31).

Need for Classifying Personal Factors

The need for a classification of PFs was considered in the articles from different perspectives. Generally, it was stated

TABLE 3 | Target groups of the included studies.

Target group	Number of studies Data $n = 226$ (Relevance level 5)	Number of studies Data $n = 51$ (Relevance level 6)
Certain infectious and parasitic diseases (HIV)	1	
Endocrine, nutritional and metabolic diseases (diabetes mellitus, obesity, cystic fibrosis)	4	1
Neoplasms (cancer, pelvic chondrosarcoma)	10	3
Mental and behavioral disorders (mental disorder or illness, autism spectrum, attention deficit hyperactivity disorder, disorders of psychological development, cognitive impairment, transsexualism)	17	4
Diseases of the nervous system (multiple sclerosis, epilepsy, cerebral palsy, motor neurone disease, Parkinson's disease, complex regional pain syndrome)	23	
Diseases of the eye and adnexa (age-related vision loss)	1	
Diseases of the ear and mastoid process (benign paroxysmal positional vertigo, Meniere's disease, hearing loss or disability, tinnitus)	9	1
Diseases of the circulatory system (stroke)	21	5
Diseases of the respiratory system (chronic obstructive pulmonary disease)	1	1
Diseases of the musculoskeletal system and connective tissue (for example arthritis, rheumatoid arthritis, osteoporosis, neuropathic pain)	33	6
Diseases of the genitourinary system (pelvic organ prolapse)	1	
Congenital malformations, deformations and chromosomal abnormalities (Marfan syndrome, spina bifida)	2	
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (apraxia of speech, aphasia, falls)	4	
Injury, poisoning and certain other consequences of external causes (for example brain injury, spinal cord injury, burn injury)	32	10
External causes of morbidity and mortality (lower limb amputation)	3	1
Factors influencing health status and contact with health services (occupational health, homeless people, wheelchair users)	8	
Disabilities, diseases and health conditions, unspecified (physical disabilities or impairments, chronic diseases or conditions)	33	11
Other (for example multilingual speakers, childhood development, special educational needs, older adults)	18	5
Theoretical (for example ICF children and youth version, PF classification development)	5	3

that professionals should recognize the benefits of having a classification of PFs (47, 55), notably in the context of rehabilitation (56). For example, a classification would help interprofessional teams to achieve a consensus on care and rehabilitation (33). Furthermore, a classification would facilitate a comprehensive and systematic examination, description, and documentation of problems and resources of a client and how these impact on functioning (55, 57) and would also save time (46). Making assessments and decisions based on the use of non-standardized individual factors involves high risks (46). The systematic gathering of data can assist in planning and implementing more precisely targeted interventions and in monitoring rehabilitation outcomes (31). A standardized classification could also help professionals to develop common concepts and documentation (12, 58). It was also argued that non-standardized use presents a risk in rehabilitation (8). Without the inclusion of PFs, the model of functioning remains narrow and reduces the status of an individual to one of illness and disability bereft of autonomy, subjectivity, and humanity, and thus ignores the whole life context of the individual. Without PFs, the ICF is an unhumanized model (8, 12, 40).

DISCUSSION

This scoping review summarized the literature on research that included discussion of ICF PFs to better understand what PFs are and to analyze their role in rehabilitation. As in the previous review by Geyh et al. (16), the studies included in this review were heterogeneous in their research settings, target groups, and targeted stage of the rehabilitation process. Mentions of PFs were extracted from all the eligible studies and, excepting those that were clearly not PFs, grouped into seven categories according to Geyh et al. (8). PFs were most often linked to personal experiences or habits, sociodemographic factors, and personal thoughts and beliefs. The qualitative analysis of the importance and meaningfulness of PF in rehabilitation yielded three themes: a person- and client-centered rehabilitation process, commitment to rehabilitation, and the need for classifying PFs. Armed with these findings from recent research studies, we entered the debate on the role of PFs in rehabilitation, their importance in understanding functioning and disability, and their ethical use (11, 15).

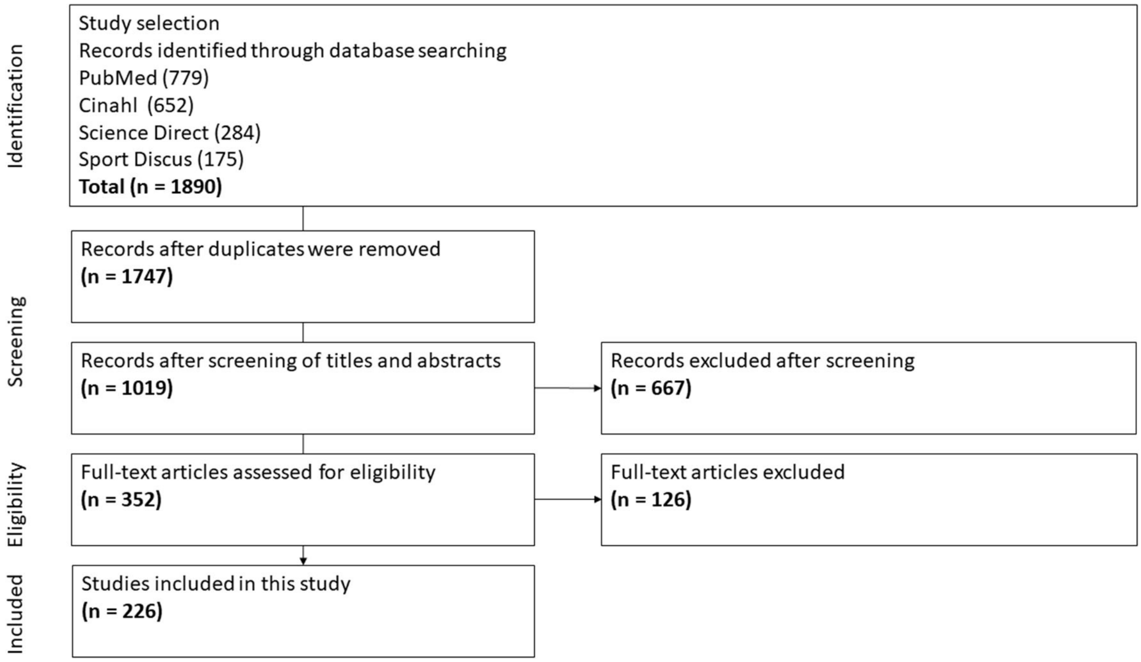

FIGURE 1 | Flow chart of the study.

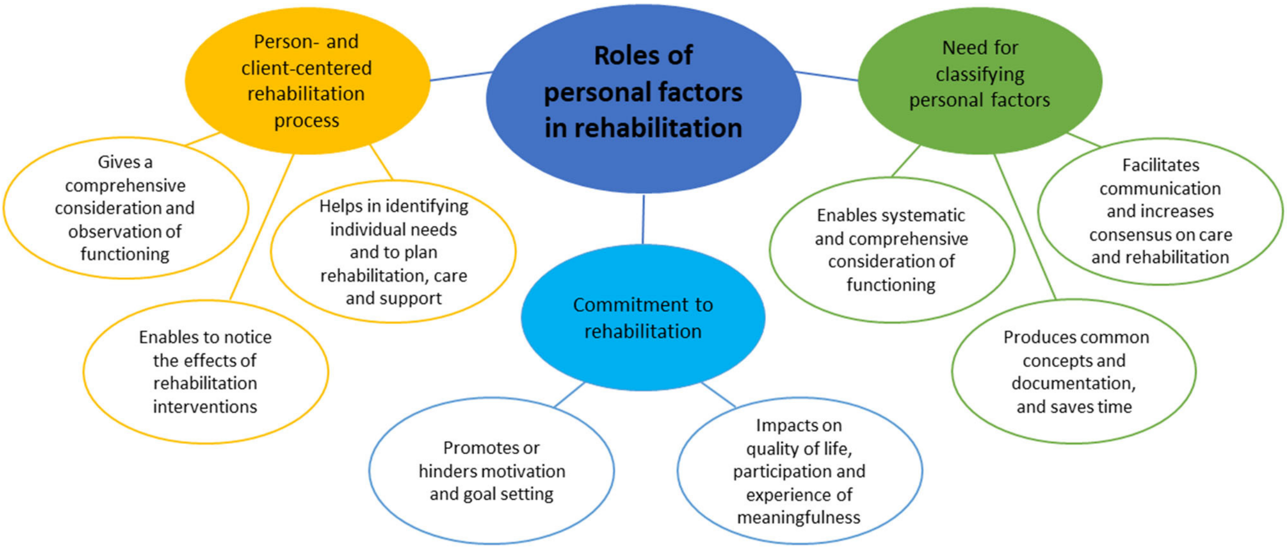

FIGURE 2 | Roles of personal factors in rehabilitation.

Personal Factors in Rehabilitation Studies

Overall, the studies revealed a wide range of different types of PFs. While the included studies used heterogeneous methods and focused on different target groups, they all considered PFs to be important factors in assessing functioning and in planning and implementing rehabilitation. While all the included studies ($n = 226$) included an analysis of PFs, they were not always the central aim. In fact, only a quarter of the included studies ($n = 51$) focused on PFs to the extent of explicitly drawing conclusions about them, and only 14 studies called for the classification of PFs.

Martinuzzi et al. (59) argued for the importance of adding PFs described by clients to those that are already described in classifications. The same PFs were mentioned in different types of research studies, thereby indicating how essential they are for understanding situations from the perspective of a client. Surprisingly, however, the PFs named in many studies were clearly not PFs and could be linked to some of the existing ICF components. A possible explanation for this is that the ICF is still not thoroughly understood with respect to which factors belong to which components. Alternatively, the short descriptions given about the PFs in the ICF may not be clear enough for users. These results are in line with those of Martinuzzi et al. (59), who emphasized the need to understand the whole ICF model, including the relations between its components, when assessing PFs. However, it can be also argued that the ICF itself is ambiguous. In particular, factors such as personality or motivation, that can be linked to the ICF b1 mental functions category and linked to the ICF as PFs in the studies included in this review, showed that these constructs merit consideration when further developing the ICF.

Roles of Personal Factors in Rehabilitation

Our thematic analysis showed that PFs play an essential role in rehabilitation. Three different themes on their role emerged. The first theme concerned their role in supporting a person- and client-centered rehabilitation process. Assessment of PFs is essential when planning rehabilitation and when documenting information on functioning. Asking and understanding about PFs can foster core components of person- and client centered rehabilitation such as respect for values, beliefs, experience, and contexts, and inclusion of family as defined by the client (60). It has also been argued that person-centered care could have a positive effect on rehabilitation outcomes, although it has not yet been fully implemented in rehabilitation settings (61). The rehabilitation process combines two theoretical frameworks: treatment theory, which provides tools on how a change in a particular factor can be brought about, and enablement theory, which acknowledges that functioning is complex and determined by multiple factors, and which seeks to model these complex interrelationships (62). To apply enablement theory in the rehabilitation process, it is essential to understand individual variation in PFs. Our results show that PFs contribute essential information that should be linked with information on functioning in the rehabilitation process of a person. However, in clinical practice professionals mostly document them in the history of a client in a narrative form. Using unified terminology could enhance documentation quality, but this does not necessarily mean that all PFs should be contained in a single classification.

The second theme highlighted the importance of PFs for the commitment of a person in various rehabilitation programs and in different phases of rehabilitation. Motivation is clearly a personal matter, and it has been noticed to be an important predictor of adherence to, for example, exercise interventions (63) In addition, it is important to take into account that different clients consider different things important, as this affects commitment. Similarly, the need, highlighted by Lee et al. (64), to recognize the experience of purposefulness by a client influences rehabilitation outcomes. Professionals can learn how to support empowerment and strengths of a person by considering how various PFs might facilitate or hinder the commitment of a person. These findings support previous studies that have suggested reorganizing the ICF model to emphasize PFs (13, 14). Notably, we found no mention of the concern that a classification of PF within the ICF could lead to "blaming" the person for their functional limitations (11) in any of the studies. Instead, PFs were invariably used to support clients in their rehabilitation process.

The third theme concerned the importance of classifying PFs for the benefit of professionals. Studies supporting this idea identified the need to develop the ICF classification and its core lists to include PFs. This would create a comprehensive and systematic tool to facilitate communication, increase consensus, and save time. Another question concerned whether a minimum generic list of essential PFs could be developed for use in clinical practice with all clients. Clinically, the ICF can be used to organize and code the assessment data on functioning and environmental factors. As the PFs of the client can have a strong influence not only on health and functioning but also on the rehabilitation process, professionals would benefit from reliable tools to help in the assessment and guide the discussion. Such a tool could be, for example, a minimum list of potentially important PFs. In client-centered practice, the professional should, together with the client, consider which factors are important and relevant for that client and use this knowledge to discuss how best to help the client go forward in the rehabilitation process (65). Future research should evaluate whether this would enhance core elements of client-centered rehabilitation, such as communication and partnership (66). It seems that in the absence of a generally accepted classification, several differing classifications have arisen (10, 67). Based on this scoping review, the classification proposed by Geyh et al. (8) covers a lot of important PFs of relevance for client-centered rehabilitation. However, a large number of PFs were not included in the Geyh et al.'s (8) classification. This must be borne in mind when applying the classification in clinical practice. Since the completion of the present analysis, Grotkamp et al. (68) published a classification that includes PFs more broadly related to, for example, life situation and physical functioning compared with Geyh's classification. It would therefore be useful to apply them as complementary classifications when assessing functioning in relation to PFs in clinical practice.

Research: Clinical and Ethical Implications

This review did not seek an answer to the question of whether to classify PFs or not. All the included studies stated that they are important, while a few proposed classifying them. However, a complete taxonomy or classification of all possible PFs may not be necessary as some of them are already included in other classifications or instruments. Many information structures in health and social care include PFs, particularly factors in categories 1 and 2 of the classification by Geyh et al. (8), such as gender, age, occupation, or education. In Finland, the National Code Server has defined some common information components to unify documentation of the same type of data using the same structures. These components include PFs related to life habits (category 7), such as motion, nutrition, sleep/rest, as well as smoking and alcohol use habits (69). Rehabilitation professionals also use instruments that focus on PFs and structurally assess PFs based on the subjective experience of clients. For example, the Occupational Performance History Interview (OPHI-II), a method that collects unique data on a person's functional history during working age (70) can be subsumed under personal history (category 3). PFs regarding health, feelings, and mood of the self (category 4) and attitudes, expectations, and motives (categories 5 and 6) of the self can either be discussed freely with the client or incorporated in a structured interview, using, for example, the Readiness for Return to Work Questionnaire (71) or the relevant part of the Model of Human Occupation Screening Tool (MOHOST), which assesses the own will and motivation of the client (72). Future research should explore precisely what instruments or other methods of PF are available and whether they are comprehensive enough to describe and document the wide variety of PFs.

All the public health care institutions of the Nordic countries subscribe to a democratic value system, in which all citizens have equal rights to individualized and person-centered health care services (73). In many countries, the professional use of PFs is guided by legislation and other principles. For example, the UN Convention on the Rights of Persons with Disabilities (74) stipulates that all disabled people should be treated equally. The new EU legislation takes this one step further and considers a client's personal data, such as functioning or PFs, as sensitive data (75). In the EU, at least, this gives clients better protection and control over their personal information and how this information is used in rehabilitation processes. Moreover, health care professionals are under a duty to base their decisions and actions on ethical principles. These include empathy, honesty, and confidentiality. Finnish physical therapists, for example, should adhere to the basic ethical principles of doing good, avoiding bad actions, and respecting client autonomy and justice (76).

Strength and Limitations

A key strength of this study was the implementation of a rigorous and systematic methodological approach. Furthermore, by addressing the importance of PFs in rehabilitation research and practice, this study may be of value in the future development and use of the ICF classification.

This scoping review synthesized the key characteristics attributed to PFs in the rehabilitation literature. Due to the broad focus of the study, we may have failed to identify all the relevant studies. However, consultation with an information specialist throughout the search process reduced the likelihood of this limitation. To enhance the trustworthiness of the data, the team members cross-checked and verified the search results in pairs. Owing to the scoping review method (77), the methodological quality or risk for bias of the included articles was not evaluated. Moreover, this study does not produce a critically appraised answer to the question of whether PFs should be classified. The broad aim of the review generated a large number of references. More specific inclusion and exclusion criteria might have enabled a more precise focus on the role of PFs in rehabilitation.

Conclusions

A substantial number of studies concluded that PFs have an important role and a specific meaning in rehabilitation processes. PFs foreground the principle of person- and client-centeredness in such processes. Furthermore, when PFs are well understood and taken into account in assessing the functioning of a client, the professional will have a better understanding of how to strengthen the commitment of a client. Professionals would also benefit from a classification of PFs to facilitate systematic documentation and save time. Future research should define what tools to use and what factors to include in a list of the minimum PFs needed to guide rehabilitation processes. In the meantime, it is recommended to use the ICF framework as an instrument for the structuring of information and concepts related to functioning, even if PFs have not been further defined at the level of categories. The classification developed by Geyh et al. (8) and/or that by Grotkamp et al. (68) can serve as checklists when mapping, together with the client, which PFs promote or hinder activity and participation, and how important different factors are to the client.

AUTHOR CONTRIBUTIONS

MK, AK, SS, HA, EX, and TH: Conceptualization. MK, HA, and AK: Theoretical framework and literature review. MK: Project administration. MK, AK, SS, EX, TH, and HA: Analysis and writing and editing. All authors have read and agreed to the published version of the manuscript.

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SUPPLEMENTARY MATERIAL

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Construct Validity and Clinical Utility of World Health Organization Disability Assessment Schedule 2.0 in Older Patients Discharged From Emergency Departments

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Introduction: The World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) is designed to measure functioning and disability in six domains. It is included in the International Classification of Diseases 11th revision (ICD-11). The objective of the study was to examine the construct validity of WHODAS 2.0 and describe its clinical utility for the assessment of functioning and disability among older patients discharged from emergency departments (EDs).

Material and Methods: This cross-sectional study is based on data from 129 older patients. Patients completed the 36-item version of WHODAS 2.0 together with the Barthel-20, the Assessment of Motor and Process Skills (AMPS), Timed Up and Go (TUG), and the 30-Second Chair Stand Test (30 s-CST). Construct validity was examined through hypothesis testing by correlating the WHODAS with the other instruments and specifically the mobility domain in WHODAS 2.0 with the TUG and 30 s-CST tests. The clinical utility of WHODAS 2.0 was explored through floor/ceiling effect and missing item responses.

Results: WHODAS 2.0 correlated fair with Barthel-20 ($r = -0.49$), AMPS process skills ($r = -0.26$) and TUG (r=0.30) and correlated moderate with AMPS motor skills ($r = -0.58$) and 30s-CST ($r = -0.52$). The WHODAS 2.0 mobility domain correlated fair with TUG ($r = 0.33$) and moderate with 30s-CST ($r = -0.60$). Four domains demonstrated floor effect: D1 "Cognition," D3 "Self-care," D4 "Getting along," and D5 "Household." Ceiling effect was not identified. The highest proportion of missing item responses were present for Item 3.4 (Staying by yourself for a few days), Item 4.4 (Making new friends), and Item 4.5 (Sexual activities).

Conclusion: WHODAS 2.0 had fair-to-moderate correlations with Barthel-20, AMPS, TUG, and 30s-CST and provides additional aspects of disability compared with commonly used instruments. However, the clinical utility of WHODAS 2.0 applied to older patients discharged from EDs poses some challenges due to floor effect and missing item responses. Accordingly, patient and health professional perspectives need further investigation.

Keywords: WHODAS 2.0, older patients, functioning, ICF, rehabilitation

INTRODUCTION

Identifying the level of disability among older patients hospitalized with a medical diagnosis is an essential component of their treatment, as it is used to drive the discharge planning process and possible referral to rehabilitation (1). Discharge planning often requires a multidisciplinary approach and involves a tailored plan for the patient to facilitate prompt and efficient discharge. Accordingly, instruments measuring different aspects of disability are used in a clinical context (2–4), including the Barthel Index, the Functional Independence Measure (FIM), the KATZ ADL Index, the 30-Second Chair Stand Test (30s-CST), and the Timed Up and Go (TUG) (2–4).

The World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) (5) is based on the International Classification of Functioning (ICF) framework (6). WHODAS 2.0 is a generic patient-reported instrument that measures functioning and disability. The use of WHODAS 2.0 is recommended as suitable for describing and quantifying the level of disability associated with a health condition and is included in the new International Classification of Disease 11th revision (ICD-11) (7, 8). WHODAS 2.0 is a generic, multi-dimensional questionnaire that rates functioning from the respondent's subjective perspective. It enables comparison across different groups and settings for six different functional domains that reflect a hierarchy of disability, which is especially useful for clinical purposes and in research (5). There are different modes and versions of WHODAS 2.0, including 12- and 36-item versions, with the instrument having been translated into more than 40 languages (5, 8–11).

A number of studies have been conducted that examine the reliability and validity of the WHODAS 2.0 among different populations (5, 9, 12–14). In a sample of 1,190 patients with chronic diseases, the 36-item interviewer-based version demonstrated high reliability and a good ability to discriminate and detect change over time (12). Additionally, the 36-item version were found to have high reliability and validity in a sample of 1,000 elderly people (60–70 year) in Poland (10). In a systematic review of 810 studies, the authors concluded that WHODAS 2.0 offers a valid, reliable, self-report measure of disability for a variety of populations and settings (8).

Although the psychometric properties of WHODAS 2.0 seem solid, the validity and clinical utility of WHODAS 2.0 among older patients with a medical diagnosis in an emergency department (ED) setting has not yet been explored. Accordingly, the objective of this study was to examine the construct validity of WHODAS 2.0 and to describe its clinical utility for assessing disability and functioning among older patients discharged from EDs.

MATERIALS AND METHODS

The present study adhered to the STROBE guidelines for standard of reporting (15).

Study Design

This cross-sectional study is based on baseline data from a previous non-randomized controlled trial including older patients (16). The objective of the trial was to examine the effectiveness of an intervention aimed at reducing the risk of readmission among older patients discharged from the ED. The intervention consisted of an assessment of patients' limitations in performing daily activities, referral to further rehabilitation in primary care, and a follow-up visit at home the day after discharge (16).

Setting

The study took place at an emergency department at a 1.150-bed University hospital in Denmark. Patients were included from March to December 2014.

Participants

Inclusion criteria for participants were as follows: people aged $\geq$65 years admitted with an acute medical diagnosis to the ED on weekdays only. Those who were admitted from a nursing home, transferred to other hospital departments, unable to communicate, and declared terminally ill were excluded. In this study, we use baseline data from patients in the intervention group. All participants included in the study gave written consent for their enrolment. The study was approved by the Danish Data Protection Agency (J.nr. 2012-41-0763) and by the Danish Health Authority (3-3013-608/1/).

Data Sources and Measurement

The World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) The 36-item interviewer-based version was used except for the four items regarding employment, as most of the patients were retired. WHODAS 2.0 is designed to evaluate functioning in six domains: D1 "Cognition," D2 "Mobility," D3 "Self-care," D4 "Getting along," D5 "Life activities" (items related to work are not included), and D6 "Participation."

Participants were asked to indicate their experienced level of difficulty over the preceding 30 days using a 5-point rating scale by taking into account the way in which they normally perform a given activity and including the use of whatever support and/or help from either a person or the use of aids. A standardized algorithm that weights the items and the level of severity (17) was used to determine the score, ranging from 0 to 100 (with high scores indicating greater disability). Missing data were handled in accordance with the WHODAS 2.0 manual: the mean scores across all items within the domain were assigned to the missing item response (17).

Barthel-20 is one of the most commonly used measures of functioning in older patients (18). The instrument measures a person's level of independence in performing daily activities. The scale is ordinal and comprises ten basic activities (grooming, bathing, feeding, getting on and off the toilet, ascending and descending stairs, getting dressed, bladder incontinence, bowel incontinence, walking, and transferring). Barthel has been evaluated in different settings with older patients with acceptable psychometric properties (18, 19). A widely adopted modification, the Barthel-20 uses a score range from 0 (high dependence on assistance) to 20 (independent of assistance). In this study, the Barthel-20 was used as a self-report instrument conducted through interviews (20, 21). Participants with missing data were excluded from the analyses.

Assessment of Motor and Process Skills is a standardized, observation-based, occupational therapy instrument that measures the quality of a person's performance of daily activities in a natural and task-relevant environment. Quality is determined by the person's effort, efficiency, safety, and independence in performing two different tasks. The AMPS consists of two scales, one measuring motor skills and one measuring process skills. The quality of each skill is scored on a 4-point ordinal scale and then converted into an overall mean score for motor and process abilities, using the AMPS software (22, 23). AMPS has been evaluated in different settings with older patients with acceptable psychometric properties (23, 24). As AMPS are observation based there are no missing data.

Timed Up and Go was originally described as a mobility test for frail older persons. TUG is widely used, it is simply to apply in a clinical context and it is recommended to use in Geriatric Emergency Medicine Guidelines (25, 26). It reflects a person's ability to get up from an armchair, walk three meters, return, and sit down. Participants were asked to walk as fast and safely as possible while wearing regular footwear. If needed, the participants were allowed to use their customary walking aid. The faster a person can move, the better. A score of <20 s reflects independence in basic transfer (27). TUG has been evaluated in different settings with older patients with acceptable psychometric properties (28). No missing data exist in the TUG.

Thirty-Second Chair Stand Test is a physical performance instrument that assesses lower body strength as an important proxy for mobility. The simplicity of the test makes it easy to use, requiring <5 min. The test was administered using a chair with no arm rest. When given the signal to "go," the participant rose to a full standing position and was then instructed to complete as many full stands as possible within 30 s. A low score (<8), indicates disability (4). 30 s-CST has been evaluated in different settings with older patients with acceptable psychometric properties (4, 29) and the Danish Health Authorities recommend the instrument to be used in clinical contexts (30). No missing data exist in 30-CST.

Patient Characteristics

Demographic and clinical variables such as age, gender, marital status, days of admission, and comorbidity measured with the Charlson Comorbidity Index (CCI) (31) were extracted from the Danish National Patient Registry.

Procedures for Measurement

Interviews were conducted using the WHODAS 2.0 and Barthel-20 by occupational therapists with experience in the acute care area and who had been trained to administer these specific instruments. After interviewing the participant, the occupational therapist performed the AMPS (16). Next, a physiotherapist performed the 30 s-CST and TUG (16).

The occupational therapists and physiotherapists participated in a 2-week training period to ensure correct implementation of both the interview-based and performance-based tests prior to the inclusion of participants. The training included review of written instructions, repeated practice in using the tests, and supervision (16).

Analytical Strategy

The terminology and concepts proposed by the Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN) were applied (32). Construct validity based on hypothesis testing is defined as "*the degree to which the scores of a measurement instrument are consistent with hypotheses, regard relationships with scores of other instruments*" (32). A priori hypotheses were tested based on the assumption that instruments that represent the same construct would be moderate correlated, while instruments that measure different aspects of the construct would be fair correlated.

To identify similarities and differences between the constructs of the instruments, we provided an overview of how the instruments were linked to the ICF (See **Table 1**) (17, 33–36).

Based on the linking to ICF, we expect WHODAS 2.0 to describe the construct of functioning in broader terms than the other instruments, and hypothesize a fair correlation ($r = 0.25$–0.49) between WHODAS 2.0 and the following five instruments: Barthel-20, AMPS motor scale, AMPS process scale, TUG, and 30 s-CST. We expect the WHODAS 2.0 domain D2 "mobility" to be more closely correlated to TUG and 30 s-CST as their constructs are related to mobility and thus, hypothesize a moderate correlation ($r = 0.50$–0.74).

The clinical utility of WHODAS 2.0 was explored by analyzing floor and ceiling effects and subgroup analysis of missing item responses. Missing responses in WHODAS 2.0 were analyzed before replacing the missing value with mean score across the other items in the domain.

TABLE 1 | Links between first-level ICF categories and measurement instruments.

ICF: Activities and participation	WHODAS 2.0 (17)	Barthel-20 (36)	AMPS (35)	TUG (34)	30 s-CST (34)
d1 Learning and applying knowledge			X		
d2 General tasks and demands	X		X		
d3 Communication	X				
d4 Mobility	X	X	X	X	X
d5 Self-care	X	X	X		
d6 Domestic life	X		X		
d7 Interpersonal interaction and relationships	X				
d8 major life areas	(X)				
d9 Community, social and civic life	X				

Statistical Methods

Descriptive statistics were used to present the characteristics of the study population. Frequencies and proportions were reported for categorical variables. For the continuous variables, the median and interquartile range (IQR) were used for skewed data, while the mean and standard deviation (SD) were used for normally distributed data.

Construct validity was estimated using either Pearson's or Spearman's correlation coefficient (as appropriate) with 95% confidence intervals (CI). Interpretation of the correlation coefficients was based on the following: fair ($r = 0.25–0.49$), moderate ($r = 0.50–0.74$), and excellent ($r \geq 0.75$) (37).

Floor and ceiling effects were examined through descriptive statistics and subgroup analyses. Such effects occur if more than 15% of patients achieve either the lowest or highest possible score (32). Subgroup analyses were conducted to explore whether participants with more than 15% missing item responses were different from the rest of the group. All tests were two-tailed, assuming a 5% significance level. Analyses were performed using STATA 15.

RESULTS

Participants

In total, 179 patients aged 65 years or more were invited to participate, of whom 144 (80%) agreed to take part [see flowchart in (16)]. Due to more than two missing item responses in some of the WHODAS domains, 15 participants were excluded, resulting in a study sample of 129 participants for this study. There were no significant differences between participants and excluded patients in relation to age, gender, comorbidity score, AMPS, or TUG. Significant differences were found for Barthel-20 and 30 s-CST (see **Supplementary Material**). Descriptive statistics for the study sample are presented in **Table 2**.

Main Results

Table 3 presents the correlations between the sum scores for the WHODAS 2.0 and the other instruments. Fair correlations were found with the Barthel-20, AMPS process skills and TUG, while moderate correlations were found with the AMPS motor skills and 30 s-CST. For the WHODAS 2.0 mobility domain, a fair correlation was found with TUG, while the correlation with 30 s-CST was moderate.

TABLE 2 | Characteristics of the participants ($n = 129$).

Characteristics	
Mean age, years (SD)	80.4 (7.8)
Female, *n* (%)	68 (53%)
Marital status, *n* (%)	
Widowed	43 (33%)
Divorced	28 (22%)
Married	52 (40%)
Single	6 (5%)
Comorbidity, *n* (%)	
Low: score 0–1	66 (51%)
Moderate: score 2–3	42 (33%)
High: score >4	21 (16%)
Days of admission, mean (SD)	1.123 (0.69)
WHODAS 2.0 sum score, mean (SD)*	25.3 (17.0)
Barthel-20, median (IQR)#a	19 (17–20)
AMPS motor, mean (SD)#b	1.08 (0.80)
AMPS process, mean (SD)#b	0.90 (0.85)
TUG score, mean (SD)*c	15.2 (10.7)
30 s-CST, mean (SD)#d	6.6 (4.8)

*High score indicates severe disability.

#Low score indicates severe disability.

[a] *Barthel-20 n = 125.*

[b] *Assessment of motor and process skills n = 83.*

[c] *Timed up and go n = 110.*

[d] *30 s-Chair Stand Test n = 116.*

As more than 15% of participants exhibited either floor or ceiling effect in the Barthel-20 and 30 s-CST (**Table 4**), secondary analysis was performed excluding participants with a score of 20 for the Barthel-20 and a score of zero in the 30 s-CST. This did not change the overall result, as the correlation between the WHODAS 2.0 and the Barthel-20 remained fair [$r = -0.26$ (95%CI −0.51; 0.001)] and the 30 s-CST moderate [$r = -0.52$ (95%CI −0.66; −0.38)].

Mean score of WHODAS 2.0 domains are presented in **Table 4**. Due to high SD, median and IQR are also presented. Missing item responses were present in all WHODAS 2.0 domains except for D2 "Mobility." The highest proportion of missing responses were present in Item 3.4 (Staying by yourself for a few days) (18.6%), Item 4.4 (Making new friends) (17.9%), and Item 4.5 (Sexual activities) (31.8%) (see **Supplementary Material**).

Participants with missing responses had a significantly lower score in Barthel-20 than participants who provided a response (18 vs. 19, $p < 0.05$). For Item 3.4, participants with missing responses had significantly higher scores in AMPS motor (1.38 vs. 0.97, $p < 0.05$) and process skills (1.35 vs. 0.75, $p < 0.05$) than participants who responded. For Item 4.5, participants with missing responses were significantly older (83.2 vs. 79.2, $p < 0.05$) than participants who responded (see **Supplementary Material**).

Floor effect, indicating no disability, was identified in four WHODAS 2.0 domains: D1 "Cognition" (21%), D3 "Self-care" (36%), D4 "Getting along" (36%) and D5 "Life-activities" (21%), as shown in **Table 3**. A significant difference between participants with the lowest possible score (floor effect) and other participants was found in relation to the AMPS motor skills and 30 s-CST scores, where participants with a score of zero in the domains had higher scores in both AMPS motor skills and 30 s-CST.

TABLE 3 | Correlation with 95% confidence intervals between WHODAS 2.0 and other measures of functioning.

	WHODAS 2.0	D2. Mobility
Barthel-20[#,a]	−0.49* (−0.63; −0.34)	
AMPS motor[¤,b]	−0.58* (−0.72; −0.43)	
AMPS process[¤,b]	−0.26* (−0.48; −0.04)	
Timed Up and Go[¤,c]	0.30* (0.11;0.50)	0.33* (0.16;0.49)
30 s. Chair Stand Test[¤,d]	−0.52* (−0.65; −0.40)	−0.60* (−0.71; −0.49)

[#] *Spearman correlation.*

[¤] *Pearson's correlation.*

[a] *Barthel-20 n = 125.*

[b] *Assessment of motor and process skills n = 83.*

[c] *Timed up and go n = 110.*

[d] *30 s-Chair Stand Test n = 116.*

[*] $p < 0.05$.

In domain D3 "Self-care," participants with a score of zero were significantly younger, had a higher Barthel-20 score, and a lower score in TUG than other participants. A significantly higher Barthel-20 score was also identified for participants with a score of zero in domain D4 "Getting along," compared to other participants. In domain D5 "Life-activities," differences were found between participants with a score of zero and other participants in relation to age, gender, Barthel-20, AMPS process skills and TUG (**Supplementary Material**). Ceiling effect was not found in any of the WHODAS 2.0 domains, meaning that none of the participants reported severe disability.

DISCUSSION

The current study is the first to examine the construct validity and clinical utility of the WHODAS 2.0 36-item version in a sample of older patients discharged from EDs. The results demonstrate fair-to-moderate correlations between WHODAS 2.0 sum scores and WHODAS 2.0 mobility domains and the Barthel-20, AMPS, TUG, and 30 s-CST instruments. Floor effect and missing item responses were present in four domains: D1 "Cognition," D3 "Self-care," D4 "Getting along," and D5 "Life-activities" while missing item responses were identified in Items 3.4, 4.4, and 4.5.

We expected a priori that the correlation between WHODAS 2.0 sum score and the Barthel-20, AMPS, TUG, and 30 s-CST would be fair, while the correlation between the WHODAS 2.0

TABLE 4 | Distribution of the instruments score.

Domain	Mean (SD)	Median (IQR)	Range	Missing, *n* (%)	Floor[*], *n* (%)	Ceiling[#], *n* (%)
WHODAS 2.0[a]	25.3 (17.0)	22.8 (10.9–36.9)	0–69	–	1 (0.8%)	0
D1. Cognition	16.0 (16.6)	10.0 (5.0–25.0)	0–70	5 (4%)	27 (21%)	0
D2. Mobility	36.7 (28.5)	31.3 (12.5–62.5)	0–94	0 (0%)	15 (12%)	0
D3. Self-care	20.0 (23.2)	10.0 (0.0–30.0)	0–90	25 (19%)	47 (36%)	0
D4. Getting along	19.1 (21.5)	16.7 (0.0–33.3)	0–83	51 (40%)	47 (36%)	0
D5. Life-activities	33.8 (30.5)	30.0 (10.0–50.0)	0–100	3 (2%)	27 (21%)	7 (5%)
D6. Participation	27.2 (19.3)	25.0 (12.5–37.5)	0–83	15 (12%)	9 (7%)	0
Barthel-20[b]	18.3 (2.3)	19 (17–20)	8–20	–	0	55 (44%)
AMPS motor[c]	1.08 (0.80)	1.09 (0.6–1.6)	−1.7 to 2.6	–	–	–
AMPS process[c]	0.90 (0.85)	1.08 (0.6–1.4)	−3.8 to 2.6	–	–	–
Timed Up and Go[d]	15.2 (10.7)	11.1 (8.7–17.4)	5.2–60.2	–	–	–
30s. Chair Stand Test[e]	6.6 (4.8)	7 (2–10)	0–19	–	28 (24%)	–

[a] *WHODAS 2.0, n = 129.*

[b] *Barthel-20 n = 125.*

[c] *Assessment of motor and process skills n = 83.*

[d] *Timed up and go n = 110.*

[e] *30 s-Chair Stand Test n = 116.*

[*] *Percentages that scores lowest possible score.*

[#] *Percentages that scores highest possible score.*

mobility domain and the other instruments measuring mobility would be moderate. However, the results revealed that due to varied CIs, all the correlations (except the correlation between WHODAS 2.0 and AMPS process skills) were either fair or moderate. Our hypotheses cannot therefore be verified. The highest correlations (moderate) with WHODAS 2.0 were found with the AMPS motor skills and 30 s-CST, while the highest correlation for the mobility domain was found with 30 s-CST. The fair-to-moderate correlations between the WHODAS 2.0 sum scores and the other well-established instruments may indicate similarity of constructs but also that the WHODAS 2.0 is measuring other aspects of functioning and disability. The linking of the instruments to ICF shows that the WHODAS 2.0 are covering a broader aspect of functioning than any of the other instruments (17). WHODAS 2.0 are covering elements from seven activity and participation domains (domain 2–7 + 9) and sparse elements from one domain (domain 8), while the other instruments covers fewer domains. The 30 s-CST and TUG only cover the domain mobility, and are thus seen as unidimensional instruments. In other studies that examine the construct validity of WHODAS 2.0, correlations have also been reported mainly as fair-to-moderate compared with other multidimensional instruments such as the Short Form 36 (14, 38). In those studies, with fair to moderate correlation, the authors conclude that their results provide evidence for the validity of WHODAS 2.0 (14, 38). However, it can be questioned whether a fair-to-moderate correlation should be considered an expression of validity or rather an expression of different instruments measuring related but different constructs (39). The trade off between using a multidimensional or unidimensional instrument of disability must be careful considered in a clinical context with high patient flow, but our results indicate that the use of a multidimensional instrument such as WHODAS 2.0 provides additional aspects of disability compared with commonly used instruments in this population.

We identified a mean sum score of 25.3 with wide SDs (SD 17.0) for the WHODAS 2.0. In other studies, similar mean scores were identified for patient samples with different diagnoses and disabilities. In one validity study, a mean sum score of 22.9 (SD 16.1) was found in a younger (but disabled) population (40). In another study from 2017, a mean sum score of 30.9 (SD 16.2) was reported in a sample of patients at a specialized somatic rehabilitation clinic (38), while another study (12) identified a mean score of 24.8 (SD 19.3) in a sample of 1,119 patients with chronic conditions. Whether a mean score of 25.3 is low or high depends on the population. To our knowledge, no normative score for an older population with the 36-item version of the instrument is available. However, in (40), the sample of disabled people was compared with a sample of people with no reported disabilities. The mean WHODAS 2.0 sum scores were found to be significantly different in the two groups (22.9 for the disabled group compared with 12.9 in the group not reporting disability).

We found floor effect in the following domains: D1 "Cognition," D3 "Self-care," D4 "Getting along," and D5 "Life-activities." Participants with a domain score of zero—indicating no disability—had a significantly higher score in the AMPS motor skills, 30 s-CST, and Barthel-20 (D3, D4, and D5) and a lower score in TUG (D3 and D5). In relation to age, participants with a score of zero in D3 and D5 were significantly younger than other participants. Floor effect has also been reported in other studies. In a study from 2014 (9), the authors reported floor effect in the D4 and D5 domains, while another study reported floor effect in the D3 and D2 domains (40). When floor effect occurs, it reduces the variability of the instrument and may therefore affect the validity. However, we found consistency between domains with floor effect and the scores of the other instruments indicating no disability. We found no ceiling effect, which is in contrast with other studies that have reported ceiling effect for the WHODAS 2.0 (12, 41). This means that none of the participants reported severe disability. Both floor and ceiling effects are important when it comes to the clinical utility of an instrument. An instrument with ceiling or floor effect hampers the possibility to detect change in disability over time

In Items 3.4, 4.4, and 4.5, more than 15% of the participants had missing responses.

For all three items, these participants had a significantly lower score for the Barthel-20 than participants who responded. This indicates that participants with lower functioning found in Barthel-20 were more likely to have missing responses. The highest proportion of missing responses was found for Item 4.5 (Sexual activities), with 32% of the sample having missing responses. This is in accordance with other studies (9, 12) that also report a high proportion of missing values for this item. A possible reason may be that for some, the issue of sexual activity is considered either a private matter or not relevant. In this sample, 40% were married, while 60% were either widowed, divorced, or single. Although this may have influenced participants' responses, our subgroup analysis revealed that there were no significant differences between responses and missing responses in relation to marital status (**Supplementary Material**). More than 15% missing responses in item 3.4 and 4.4 may be related to the relevance of the questions. Staying by yourself for a few days (Item 3.4) and Making new friends (Item 4.4) may not have been relevant for a part of this population in the last 30 days. The reasons for not responding to certain items for this population need further examination.

The relatively high proportion of missing responses in the three items indicates that completion of the WHODAS 2.0 36-item version may pose some challenges for this population, which may hamper the clinical utility. Instead, the 12-item version (not including these three items) may be easier to apply. A study from 2020 (13) reported no missing responses in the validation of the 12-item version with an older population. However, that study was an epidemiological survey and not conducted in a clinical context with patients discharged from hospital. The 36-item version is more comprehensive; accordingly, using the 12-item version may result in less information across the different domains, information that may otherwise be useful in a clinical context where patients' further rehabilitation needs to be planned prior to discharge. Whether the 12-item version might be more suitable than the 36-item version among the older population in a clinical context needs to be explored in future studies.

Another aspect that needs further examination among this population is the use of a timeframe of 30 days when answering the questions, which may be problematic. Older patients with an acute admission to an ED may have experienced a sudden, but unrecognized disability that could influence the accuracy of their self-reported functioning, leading to an underestimation of their disabilities (16). Whether the WHODAS 2.0 is able to detect sudden disabilities, an issue of importance in a clinical context, should be further explored. This is highly relevant, especially as the instrument is included in the ICD-11.

Although examining the clinical utility of WHODAS 2.0 in a population of older patients at the ED is new, its utility in other populations has been examined extensively in the recent years (42–44). The WHODAS 2.0 was found a useful measure of disability in a population with chronic pain (42) and for stroke survivors (43) were WHODAS 2.0 showed good reliability and validity. In addition, the WHODAS 2.0 has also been found useful for valid interpretations of disability in people with psychiatric health conditions (44).

STRENGTHS AND LIMITATIONS OF THE STUDY

The construct validity of WHODAS 2.0 was measured in this study with hypotheses testing. Construct validation is often considered less powerful than criterion validation; however, when no gold standard is present, hypothesis testing can be used to examine whether the instrument measures what it is supposed to measure (32). The sample included in this study was above the number ($n = 50$) recommended as a minimum (45) for validity studies, although lower than some comparable studies (14, 38). The relatively small sample size affects the CIs and thereby the uncertainty of the results.

Clinical utility of the WHODAS 2.0 were examined through floor and ceiling effect and subgroup analysis exploring participants with more than 15% missing item response. For clinical use, it would however, have been relevant to examine the responsiveness of WHODAS 2.0. This was not possible due to the cross-sectional study design.

Another limitation of the study is the generalization of the results. The sample included only older patients discharged from EDs, which may hamper generalization. The limitation of generalization emphasizes the importance of continuing to study the value and psychometric properties of the WHODAS 2.0 in samples of patients treated in different settings and with different health conditions.

CONCLUSION

In conclusion, WHODAS 2.0 demonstrated fair-to-moderate correlations with the Barthel-20, AMPS, TUG, and 30 s-CST instruments. The results indicate that WHODAS 2.0 provides a different aspect of functioning and disability than instruments commonly used with older patients. WHODAS 2.0 provides value in a clinical context, as it is distinguished from other instruments as being a measure that applies the ICF biopsychosocial approach. However, the clinical utility of the WHODAS 2.0, used with a population of older patients discharged from EDs, also poses some challenges due to floor effect in four of the domains and due to missing responses for three items. Together with its compatibility with the ICD-11, the WHODAS 2.0 is expected to become widely used in clinical contexts; however, its utility from patient and health professional perspectives need further investigation.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The study was approved by the Danish Data Protection Agency (J.nr. 2012-41-0763) and by the Danish Health Authority (3-3013-608/1/). All participants included in the study gave written consent for their enrolment.

AUTHOR CONTRIBUTIONS

LN, LO, HK, and TM: study conception and design and critical revision. LN and TM: analysis and interpretation of data. LN: drafting of manuscript. All authors contributed to the article and approved the submitted version.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fresc.2021.710137/full#supplementary-material

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A Mixed Methods Study of Functioning and Rehabilitation Needs Following COVID-19

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COVID-19 can lead to a long-term loss of functioning, which may affect activities and participation in daily living in various ways. The extent and characteristics of post-COVID-19 persistent symptoms are currently being studied extensively worldwide. The purpose of this exploratory study is to explore functioning and rehabilitation needs among persons with self-reported disability following COVID-19. This mixed methods study is based on data from patient-reported outcome measures (PRO), tests of body functions, visual drawings and focus groups among persons with self-reported disability after having suffered from COVID-19. PRO covered quality of life, activity and participation. Tests of body functions targeted strength and endurance. Focus groups and visual drawings elaborated on how post COVID-19 persistent symptoms affected functioning, activities and daily living. Data was collected in August and September 2020. The study sample consisted of 11 women, nine men, aged 35–79 years. Self-reported PRO data showed low quality of life and disability among the participants primarily related to fatigue, energy and drive, breathing and concentration. Tests of body functions showed low strength in lower extremities but otherwise no striking limitations on a group level. Analysis of the focus groups generated the following four themes: (1) *Persistent symptoms,* particularly in regards to concentration, memory, lack of energy, fatigue and headaches. (2) *Balancing activities* in daily living with fluctuating symptoms. (3) *Uncertainty and Powerlessness*, which included a need for directional guidance in order to regain functioning and unmet needs regarding further clinical assessment of persistent symptoms, referral to rehabilitation and returning to work. (4) *Hope* associated with the experiences of recovery - and for the future. This study highlights that persons with persistent symptoms after COVID-19 may experience a range of limitations in their daily living. This points toward a need for individual assessment and guidance to tailor relevant rehabilitation.

Keywords: COVID-19, rehabilitation, persistent symptoms, functioning, disability, quality of life, mixed methods, ICF

INTRODUCTION

The corona virus disease 2019 (COVID-19) outbreak and pandemic has affected a large number of persons worldwide, and a significant number of persons have experienced different degrees of illness. In 2021 the number of confirmed infections with the virus, SARS-CoV-2, is still steadily rising counting nearly 150 million cases and over 3 million deaths at the end of April 2021 (1).

During the pandemic it has become clear that some persons experience long term sequelae or "post COVID-19 persistent symptoms," as termed by The World Health Organization (2). International systematic literature reviews based on the present and previous pandemics (SARS and MERS) show that persons who have been ill with viral disease can experience different challenges in relation to functioning and activities of daily living (3, 4). In addition, preliminary knowledge shows that persistent symptoms including fatigue, headache, dyspnoea and myalgia are highly prevalent among persons who have suffered from COVID-19 and that 80% experience one or more persistent symptoms (4, 5). However, we do not know the full extent of consequences of COVID-19, their impact on daily living and the overall need for rehabilitation, yet. The list of potential post-COVID-19 symptoms is long and studies worldwide are steadily uncovering the long-term consequences in further detail. Although persons with longer and more severe courses of illness may have an increased need for rehabilitation, recent research shows that persons with short courses also present with persistent disability (4, 6, 7). A large group of persons are therefore likely to need evidence based post-COVID-19 rehabilitation on both general and specialized level to also accommodate those with severe disability (8–10).

Healthcare systems worldwide have been struggling to adapt and manage both safety precautions and the treatment of many patients with an unknown life-threatening illness. In the same way, rehabilitation of persons with post COVID-19 persistent symptoms has represented unexplored territory. It is thus necessary both to describe the type and frequency of typical disability and rehabilitation needs following COVID-19, and to understand persons' experience of COVID-19-related persistent symptoms in their daily living. This knowledge is required to tailor disease specific rehabilitation. Such knowledge can also create a basis to evaluate to which extent existing knowledge from other illnesses can be part of the foundation for post COVID-19 rehabilitation interventions. To illuminate these areas, knowledge from different research methods must be used and combined: Quantitative methods can be used to describe the type and frequency of present disabilities and rehabilitation needs. Qualitative research methods can help us gain an in-depth understanding of the experience of COVID-19-related persistent symptoms in daily living.

The purpose of the present exploratory study is to uncover functioning and rehabilitation needs among persons with self-reported disability following COVID-19.

MATERIALS AND METHODS

The study was conducted as an explorative mixed methods study of persons who were ill with COVID-19 during spring and summer of 2020. The study is based on a convergent parallel design, in which the quantitative and the qualitative data are collected and analyzed concurrently. The results are then related to each other and interpreted (11).

The quantitative data include both patient-reported outcome measures (PRO) and tests of body functions and the qualitative data consist of focus groups including visual drawings.

Throughout this article, the ICF terminology is used according to the WHO standards (12).

Setting and Organization

The study was conducted at REHPA, The Danish Knowledge Center for Rehabilitation and Palliative Care. The center is organized and imbedded in both a University and hospital setting. Some of the research at REHPA is conducted in a research clinic, where study participants can stay during group-based courses with different research purposes.

The study was carried out as part of the centre's efforts and research activities around COVID-19. The study participants participated in a course containing both clinical activities, such as physical training and workshops on dealing with symptoms, and research-related activities with focus on post-COVID-19 rehabilitation needs. Two courses of 4 days each were conducted in August and September 2020.

The study participants were invited through various media and patient organizations. In addition, information about the study was available online on REHPA's website, and written information material was sent to hospitals who were in contact with COVID-19 patients.

The participants were referred by a general practitioner or hospital physician through a referral form with medical information about the course of illness. In addition, the participants completed a personal electronic application form and gave their written consent to participate in the study.

A steering committee and an advisory group were set up to ensure quality in the COVID-19 studies at REHPA. The steering committee primarily contributed with guidance on the direction and aims of the studies. The advisory group primarily contributed with knowledge that ensured the quality of specific methods. The groups included researchers and clinicians as well as persons with post COVID-19 persistent symptoms.

Inclusion Criteria

The research clinic had 10 men and 14 women referred of whom two withdrew their referral as they no longer experienced symptoms and two did not meet the inclusion criteria leaving 20 persons in the study. Persons who had suffered from COVID-19 and had self-perceived rehabilitation needs were included in the study. In the first rehabilitation course, only persons who had been hospitalized with COVID-19 were included. However, as the growing experience with COVID-19 indicated that persons, who had not been hospitalized, also might experience persistent symptoms, we expanded the inclusion criteria to also include persons who had not been hospitalized in the second course. Participants had to be able to care for themselves regarding hygiene, meals etc. It was prioritized to include corresponding to an equal gender distribution. Being an explorative study, this selection was made in order to assemble a diverse group.

Data Collection

Data were collected through PRO, tests of body functions and focus groups including visual drawings.

PRO

The PRO data were collected before the participants arrived at the research clinic. Electronic questionnaires were sent out 3 weeks before the rehabilitation course. PRO measures included The Post COVID-19 Functional Status Scale (PCFS) and the REHPA scale as measures of disability, and the EuroQoL 5-dimensions 5-level (EQ-5D-5L) scale as a measure of quality of life. Sociodemographic information and information about the specific course of illness were included in the electronic questionnaires.

The REHPA Scale of Rehabilitation needs is inspired by the *National Comprehensive Cancer Networks Distress Thermometer and Problem List* (13) and developed at Dallund Rehabilitation center (14). It is used widely in cancer rehabilitation in Denmark but is not validated. The REHPA scale consists of a numeric ranking scale from 0 to 10, on which higher scores symbolize being far from living the life the participants wish and are able to live following COVID-19.

In addition to the numeric ranking scale, participants mark self-perceived causes of their loss of functioning on a 84 item list within the overarching areas *Practical issues, Work or school related issues, Family issues, Psychological issues, Physical issues* and *Spiritual or religious issues.* The participants mark the items they perceive being the ones preventing them from living life as they wish.

PCFS is an ordinal COVID-19 specific status scale used to measure the impact of disability within activity and participation in regards to daily living. This scale does not differentiate between underlying causes (15). The scale ranges from 0 to 5. Higher score indicates greater degree of restrictions.

The EQ-5D-5L includes a visual analog scale, on which participants indicate their self-rated health (16). The scale ranges from 0 to 100, where 100 equals the best imaginable health. In addition, the EQ-5D-5L has five descriptive dimensions: *Mobility*, *Self-care*, *Usual activity, Pain/discomfort* and *Anxiety/depression.* Each dimension has five levels ranging from *no problems* to *extreme problems*.

Tests of Body Functions

In this study we chose to explore the elements of body functions that cover strength and endurance. Tests of strength and endurance were conducted during the rehabilitation course as further basis to describe potential impairments within these domains. As COVID-19 in some areas resembles known respiratory illnesses, it is meaningful to use existing generic and disease-specific tools that are already being used in the rehabilitation of persons with, for example, COPD (17, 18) to assess rehabilitation needs. The present study included the 6-min walk test (6 MWT), the 30-s Sit-To-Stand test (30s-STS) and test of hand grip strength (HGS) measured with dynamometer. The 6 MWT measures the distance (6 MWD) in meters as an indirect surrogate measure of endurance.

The HGS test measures isometric grip strength (in kilograms) as a surrogate measure of strength in the upper extremities.

The 30 s-STS measures the number of times a person can rise from sitting position in 30 s as a surrogate measure of strength in the lower extremities (19, 20). In addition, height and weight was measured in order to calculate reference values for 6 MWT (21).

Focus Groups Including Visual Drawings

Four focus groups were facilitated by the first author of this article (TBA) (22).

TBA and last author developed the interview guide. The guide contained instructions for the interviewer on how to introduce the group session. The questions in the guide focused on facilitating dialogues about impairments and disability during and after COVID-19 with questions regarding:

- The experience of being ill
- Returning to daily living after illness
- Thoughts and experiences on how rehabilitation could bring the wished life within reach

The focus groups contained between 4 and 6 participants where the participants were divided so each group contained both men and women. The focus groups lasted for 75 min each.

TBA introduced the groups to the themes of the interview guide and invited the participants to have an open-minded dialogue with each other about these themes, giving room for different experiences and opinions. During the focus groups the participants were encouraged to elaborate experiences e.g., in regards to how certain symptoms affected activities and participation. In each group, the participants introduced themselves and then spent 5 min on a reflection task, where they drew a timeline on their symptoms from the acute phase of illness to present time. These visual drawings were inspired by the work of Carfì et al. and a Danish taskforce about the journey of being a patient (23, 24). The drawings were the starting point for the dialogue in the focus group.

Data Analysis

Sociodemographic background information, PRO data and results from the tests of body functions were analyzed descriptively. Categorical data are presented as numbers and percentages. Continuous variables are presented as medians showing interquartile ranges (IQR) and the total range of scores. Tests of body functions were divided into gender groups. Data is only shown for subgroups larger than five participants to ensure anonymity. This meant that several subcategories on the items concerning education, occupation and month of diagnosis had to be merged.

All focus groups were recorded and transcripts formed the data for analysis. Thematic analysis, with a focus on meaning and participants' experiences, was conducted by TBA (25). The

TABLE 1 | Participant characteristics (*N* = 20).

Characteristic	*N* (%)	Median (IQR)	Range
Gender			
Women	11 (55)		
Men	9 (45)		
Age in years		51.5 (46–68.5)	35–79
Education			
<3 years of education or no education exceeding primary school (6–16 years of age)	9 (45)		
≥3 years of education following primary school	11 (55)		
Occupational status			
Retired	7 (35)		
Full- or part time employment	9 (45)		
On sick leave	4 (20)		
Month of COVID-19 diagnosis			
03–04/2020	16 (80)		
05–06/2020	4 (20)		
Admitted to hospital due to COVID-19			
Yes	15 (75)		
No	5 (25)		
Days admitted to hospital (*n* = 15)		23 (10–30)	1–58

IQR, interquartile range.

transcripts were coded and divided into overarching themes and sub-themes to identify patterns in the participants' dialogues. Transcripts were worked through several times in order to compare the data, refine coding, and synthesize themes. Themes and subthemes were listed and paired with quotes from across the transcripts.

Ethics and Data Protection

All participants received oral and written information and gave written informed consent to participate. The study was approved and registered by the Region of Southern Denmark: Journal no. 20/30702.The REHPA-database was approved by the Danish Data Protection Agency and approved and registered by the Region of Southern Denmark: Journal no. 18/27843. The Regional Committee on Health Research Ethics for Southern Denmark assessed that the study was not notifiable: Case number 20202000, no. 122

RESULTS

Quantitative Data

Of the 20 participants, 55% were women. The majority (80%) had been diagnosed with COVID-19 in March and April 2020. Additional sociodemographic characteristics of participants are presented in **Table 1**.

TABLE 2 | REHPA scale of rehabilitation needs (*N* = 19).

	Median (IQR)	**Range**
REHPA-scale	**7 (3–9)**	**3–9**
Area	**Item**	***n* (%)**
Practical issues		<5
Work- or school related issues	Own expectations	6 (30)
Psychological issues	Worried	9 (45)
Physical issues	Headache	8 (40)
	Vertigo	7 (35)
	Balance	8 (40)
	Fatigue	16 (80)
	Exhaustion	13 (65)
	Memory	9 (45)
	Concentration	10 (50)
	Impaired mobility	5 (25)
	Decreased muscle strength	8 (40)
	Muscle- and joint pain	8 (40)
	Breathing	11 (55)
	Paraesthesia	5 (25)
Family issues		0
Spiritual or religious issues		0

IQR, interquartile range.

Participants' PRO-data are presented in **Tables 2**, **3**. Participants reported a range of physical-, psychological- and work- and school related issues as frequent causes to loss of functioning (**Table 2**). The median score on the PCFS and the EQ-5D-5L were 2 and 60, respectively (**Table 3**). Tests of body functions are presented in **Table 4**. To differentiate the results these are categorized into gender groups.

Qualitative Data

The visual drawings were the starting point for the dialogues in the focus groups. One participant did not complete the drawing task, but all 20 participated in the following discussion.

When they reflected on the course of the illness, the participants highlighted the following body functions and symptoms on their drawings as the ones that represented limitations in their daily living: concentration (attention), memory, dyspnoea (respiration functions), lack of energy and drive, fatigue and persistent headache. **Figure 1** gives an overview of the symptoms that the participants drew on their timeline, which covered both the acute phase and present time.

The participants referred to their drawings in their dialogue with each other. When interacting with each other in the focus group, several participants recognized symptoms, which they had not inserted in their drawings in the beginning. These symptoms were not added to the drawings (**Figure 1**).

The thematic analysis of the focus groups generated the following themes: *Persistent symptoms, Balancing activities, Uncertainty Powerlessness* and *Hope*.

TABLE 3 | Scales of functioning and health related quality of life (*N* = 20).

		N (%)	Median (IQR)	Range
PCFS,			2 (2, 3)	1–4
EQ-5D-5L			60 (50–65)	15–75
EQ-5D-5L dimensions				
Mobility	No problems	11 (55)		
	Problems	9 (45)		
Self-care	No problems	15 (75)		
	Problems	5 (25)		
Usual activity	No problems	0 (0)		
	Problems	20 (100)		
Pain/discomfort	No problems	3 (15)		
	Problems	17 (85)		
Anxiety/ depression	No problems	6 (30)		
	Problems	14 (70)		

IQR, interquartile range; PCFS, post COVID-19 functional status scale; EQ-5D-5L, EuroQuol 5D five level scale.

TABLE 4 | Tests of body functions (*N* = 20).

	Women (*n* = 11)		Men (*n* = 9)	
	Median (IQR)	Range	Median (IQR)	Range
Age, median (IQR)	48 (44–52)	35–66	72 (55.5–75)	38–79
30 s-STS, median (IQR)	14 (12–24)	7–30	16 (12–18.5)	11–31
HGS, median (IQR)				
Right	33.1 (27.0–35.0)	23.9–41.8	37.6 (28.1–41.75)	24.5–44.8
Left	30.1 (26.2–36.1)	19.5–38.4	37.0 (30.7–44.0)	29.1–48.6
6 MWD, median (IQR)				
Distance (meters)	510 (450–552)	400–623	565 (442.5–587.5)	378–630
Percent of reference	95.5 (82.7–103.3)	73.7–119.3	95.5 (83.3–115.7)	80.1–116.5

IQR, Interquartile range; 30 s-STS, 30 second Sit To Stand test; HGS, hand grip strength; 6 MWD, 6-minute walk distance.

Persistent Symptoms

The participants described how some of the symptoms they had experienced during their course of illness had never subsided. The symptoms that were widely represented in their dialogues were problems with concentration and memory, lack of energy and drive, fatigue and persistent headaches.

One participant described how lack of energy and drive particularly affected the ability to engage in activities that usually would not be difficult to perform such as hanging clothes from the washing machine or cooking dinner:

> *"I haven't had any energy, as I say, I catch myself in sitting down on a chair or in my sofa all the time or (pauses). I actually have lots of plans, and I want to do something, but I constantly catch myself in, like, sitting down."* (Participant FG 2)

In addition to lack of energy and drive, fatigue was highlighted as a substantial impairment. One participant described this as being the primary obstacle in the path of regaining functioning:

> *"Right now it is my main problem preventing me from getting my life back. What is preventing me from getting back to work is fatigue, fatigue and fatigue."* (Participant FG1)

Another participant elaborated on how the fatigue could be provoked in different ways and how this put up limits for activities:

> *"My symptoms, that means fatigue, get worse when I sit and watch television, watch a movie - or when I look too much at the mobile phone or computer screen. So it is not only the physical activity that aggravates… what is it called… my symptoms, it is also mental activity. So, my daily activities are very limited because I simply do not dare to exert myself or exceed the limit. Otherwise, I will be punished with extreme fatigue, and it typically comes late in the evening or the day after."* (Participant FG1)

The participants also elaborated on how problems with memory and concentration affected their ability in regards to both activities and participation especially in regards to planning activities and executing them. One participant described how planning ordinary activities had become unmanageable to the

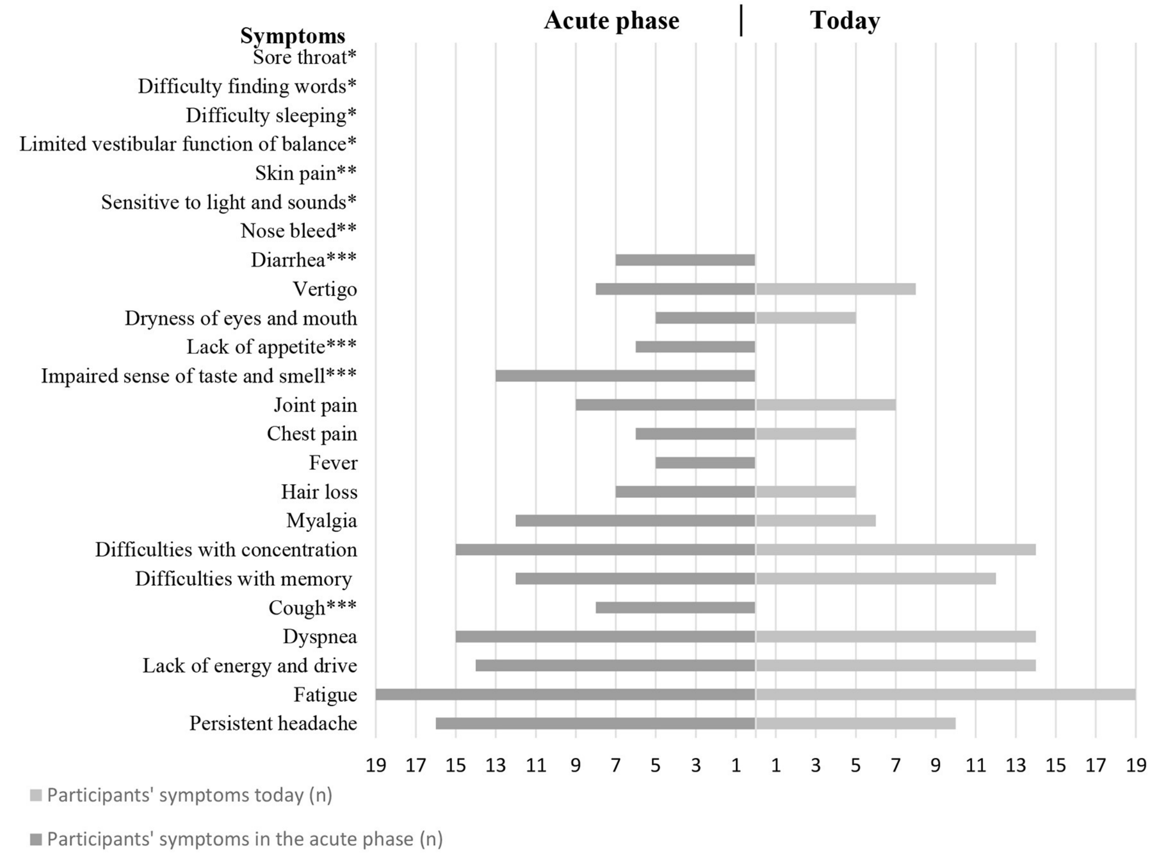

FIGURE 1 | Overview of symptoms marked on the timeline drawings in the focus groups ($N = 19$). * <5 participants experienced these symptoms in both "acute phase" and "today." ** <5 participants experienced these symptoms in "acute phase." *** <5 participants also experienced these symptoms "today."

extent that it results in a large amount of small tasks not being done:

> *"And then I stand in the garden looking at the same weed as yesterday. And it becomes a project in my head, something that maybe takes 5 minutes, I'm just looking at it, and can't get it done"* (Participant FG3).

Another participant described how the execution of activities could be affected by disturbances in the surroundings. The participant elaborated on how engaging in more than one activity at a time made it very difficult to concentrate:

> *"I can't do two things at once. For example, I can't listen to television and crochet at the same time. Then I might as well sit in a carousel."* (Participant FG4)

Finally, several participants also struggled with persistent headaches that affected their ability to concentrate and participate in daily activities:

> *"There are many things which just make the headache worse. I have a hard time concentrating, I cannot sit in front of a computer screen, it has been really difficult for me to drive a car and to go shopping. I can stand in the store, standing in the queue, and I just want to lie down and sleep. Because, it is like, the headache just shuts down my eyes."* (Participant FG4)

Balancing Activities

The focus groups illuminated participants' experience of constantly balancing the amount and the type of activities to avoid aggravating symptoms. They felt that their symptoms and level of disability fluctuated. They had experienced these fluctuations repeatedly and they connected them to specific activities or to exceeding a limit of tolerance. This limit, however, was not visible to them, and they only knew it had been exceeded when their symptoms worsened. One participant described it as follows:

> *"Yeah, the chest pain and headache can also return, if I concentrate too much, if I have too much to do at work. Then the headache also comes. Chest pain can... as late as last week, I felt like...it made me think: "now it really hurts, am I having a heart attack?""*. (Participant FG2)

The participants described that they worried about doing too much, because they had experienced being "punished" by doing too much too fast. Several used the term "dare to" about how they refrained from certain activities or from pushing themselves further toward resuming activities, as this quote illustrates:

> *"So now you could do a lot, so now you could get started, and then you just couldn't. It came back like a hammer the next day. For a long period of time it has been like having to walk on that rocking ground. You had to constantly assess - you have to be careful all the time; what should I throw myself into? What do I dare to throw myself into?"* (Participant FG4)

This problem was described by several of the participants in regards to activities and participation related to social activities, job, activities in the household and fitness activities.

Uncertainty and Powerlessness

In the attempt of regaining functioning, the participants described themselves in need of guidance to proceed toward their goals. They had a clear picture of what they would like to accomplish but sought specific tools to get there. Uncertainty had emerged from the experience of exceeding limits that aggravated their symptoms, and they were unsure about what to do in different situations.

A participant described this uncertainty in regards to resuming physical activity. Before COVID-19, this participant was used to engage in running and exercising. Trying to resume these activities, the participant experienced symptoms during and after the activities that prevented further progression:

> *"We need help to draw a picture of where is it going wrong. What are the things that trigger it? What should your weekly schedule look like? And how can you increase activities next week?".* (Participant FG4)

Another participant described that it is not an issue of identifying goals but rather an issue of not knowing how to reach them:

> *"I can see the lighthouse, but I cannot see the way there. I need someone to help me set the sub-goals I need to proceed."* (Participant FG2)

A participant added to this that access to specific counseling had been scarce, due to a general lack of knowledge about COVID-19. The participants did not blame the healthcare professionals for this, but described the lack of knowledge as an obstacle in their rehabilitation process:

> *"Well that's just that. Nobody knows anything, it doesn't matter where you turn."* (Participant FG3)

The participants described how these experiences left them powerless. They wished for further clinical assessment and referral to rehabilitation. Some participants described the experience of not getting any better and at the same time struggling to find someone that can help.

In addition, the participants experienced being rejected when they tried to contact the health care system. Specifically, one participant described having tried to get help from municipal rehabilitation professionals several times, but had given up. The participant experienced that there was no clear way into municipal interventions. Stories from other persons with post COVID-19 symptoms who had been offered rehabilitation interventions in other municipalities intensified the participants' frustration:

> *"Still, now it doesn't matter. I have soon done it (rehabilitation ed.) myself, but it might have been shortened quite a lot if I had been helped a few months ago. And I think this is a big problem - and I also sense it is different from municipality to municipality.* (Participant FG4)

Hope

Despite the difficulties and impairments that the participants were struggling with, their dialogues also reflected hope for the future. This hope was related to how they pictured their lives. The participants related this to wishing for the best and to specific feelings and experiences of regaining abilities, as the following quote illustrates:

> *"I take one day at a time and hope for the best. I want to be positive. You <u>will</u> get through it and you <u>will</u> manage.* (Participant FG2)

They described how the experience of regaining their abilities step by step gave them energy and courage to continue.

> *"I have more energy, my mood is better because I feel better. So my general condition feels better. And then the other things will come too. Then the clouds disappear from the sun. And I'm more on my feet, I'm not lying on the couch all day."* (Participant FG1)

The participants also described that feeling the effect of physical training gave hope and motivation.

Furthermore, their hope was related to the plans they made before they were ill. For some participants this hope was also related to being able to resume or leave work life and still being perceived as an esteemed employee and colleague.

DISCUSSION

The present study examined functioning and rehabilitation needs among individuals with self-reported disability following COVID-19. The study used a mixed-method design, including PRO, tests of body functions and focus groups with visual drawings.

Key Findings

The quantitative data showed substantial rehabilitation needs among the participants. On the REHPA scale fatigue, exhaustion, breathing and concentration were reported as the primary causes of loss of functioning. In addition, headaches, balance (motor control), decreased muscle strength and muscle- and joint pain were prevalently reported. The participants also showed low health related quality of life (Median EQ-5D-5L: 60).

There was a large variation on the scales indicating that the degree of rehabilitation needs and quality of life varied within the group.

The tests of body functions showed an overall performance as could be expected in healthy persons in the same age range, with the exception of the 30 s-STS where the median is lower than expected (20).

In the focus groups, the participants described that persistent symptoms affected their daily lives including concentration, memory, lack of energy and drive, fatigue and persistent headaches.

The symptoms fluctuated, and the participants attributed fluctuations to specific activities or to having exceeded their own limits. Consequently, they tried to adjust their activities to avoid aggravating symptoms. The participants further expressed a need for guidance to meet their rehabilitation goals. However, they experienced that their wishes for knowledge, clinical assessment and referral to rehabilitation were not met. This left them with a feeling of powerlessness.

Nevertheless, the participants' dialogues reflected hope for the future. This hope was both related to how they pictured their lives and to experiences of functions, they had already regained.

Drawing on the ICF tool, the themes from the focus groups to some extent fit in to the following categories:

Theme 1) *Persistent symptoms,* particularly in regards to categories within body functions: concentration (b140), memory (b144), lack of energy (b130), fatigue (b1308) and headaches (b28010).

Theme 2) *Balancing activities* in daily living with fluctuating symptoms relates to the described persistent symptoms as well as individual environmental- and personal factors among the participants.

Theme 3) *Uncertainty and Powerlessness* included a need for directional guidance in order to regain functioning and unmet needs regarding further clinical assessment of persistent symptoms, referral to rehabilitation and returning to work. This theme refers to both environmental- and personal factors. Imbedded in this theme is the need for support (e355 Health professionals).

Theme 4) *Hope* included the experiences of recovery and hope for the future, which both refers to personal factors and to individual mental functions (e.g., b1265 optimism and b1266 confidence).

Integrated Discussion of Qualitative and Quantitative Findings

Both the quantitative and the qualitative data supported that persons who experience persistent symptoms in the aftermath of COVID-19 struggle with a variety of different symptoms and impairments, which may affect quality of life and functioning.

The PCFS and the REHPA Scale both revealed that the participants had rehabilitation needs regarding regaining functioning and that their quality of life may be affected.

Despite these findings, generally, the participants performed well on tests of body functions, which were almost equivalent to a healthy population within the same age range. The majority of the participants scored higher or close to general references on both the HGS strength test (20) and on the 6 MWT (21, 26). Strength as measured by the 30 s-STS was lower than found in a healthy population (20), but higher than reported in large studies in older populations (27).

This could indicate that the chosen tests of body functions were not sensitive enough or did not target the correct issue. Approximately 40% of the participants indicated difficulties with mobility (EQ-5D-5L) and rehabilitation needs related to balance, decreased muscle strength and muscle- and joint pain (REHPA scale) but the tests of body functions do not reflect difficulties to this extent.

The tests of strength and endurance reflect that the primary causes for limitations in this group may lie within other areas of body functions.

On the drawings, concentration, memory, lack of energy and drive and fatigue are the primary symptoms highlighted which echoes the REHPA scale and the themes from the focus groups.

The highlighted symptoms on the drawings are very much consistent with similar studies (4, 23).

Interestingly dyspnoea is an issue that is not reflected in tests of endurance or in the main themes in the focus groups, although it is prominent in both the visual drawings and on the REHPA scale. In the focus groups, dyspnoea is present but very sparsely addressed as a symptom that affects daily living. It is highlighted in the focus groups that the participants struggle to balance their persistent symptoms to avoid aggravating them. Therefore, they are directing a large amount of their focus in this direction. This indicates a possible cause to why dyspnoea is not more prominent in the participants' dialogues. The participants acknowledge that dyspnoea is present—but this symptom and how it affects daily living might simply not be the main problem when balancing other persistent symptoms.

Nevertheless, some participants presented with significant limitations in tests of body functions. Although these limitations seen in tests of body functions are not prominent among the main themes in the focus groups they could still be highly relevant to investigate clinically also for the purpose of tailoring individual rehabilitation interventions.

From themes in the focus groups, it is also clear that access to professional guidance on how to set goals for their rehabilitation and proceed with specific interventions is crucial for the participants. The participants' experience of need for professional guidance is in line with findings from recent studies (5, 7, 28, 29).

Since data for this study was collected, knowledge on post COVID-19 persistent symptoms has steadily increased. In alignment with our study it is firmly stated, that persons who experience persistent symptoms present with a very broad spectrum of symptoms (4, 23).

Study Strengths and Limitations

The present study has several strengths. The mixed methods design allowed us to examine functioning and disability from different perspectives. While the quantitative data provided information on rehabilitation needs, quality of life and functioning, the qualitative data contributed with rich descriptions of functioning in daily living.

Furthermore, studies from large population- and disease groups were available for comparison of tests of body functions.

The study also has limitations, which need to be taken into account when interpreting the findings. Firstly, in regards to drawing strong statistical conclusions on the quantitative data from the study, a larger population would have been preferable. However, by combining data from both PRO-measures, tests of body functions and qualitative data, the study enhances and deepens our understanding of functioning and rehabilitation needs after COVID-19.

Further, participants may not be representative of the larger population of persons with persistent symptoms after COVID-19: The referral and application procedure may have introduced selection bias. There may also be a healthy volunteer bias, i.e., persons applying for the rehabilitation course may be those with less COVID-19 persistent symptoms. However, all participants in this study present with self-perceived rehabilitation needs, and the study likely contributes to a picture of what clinicians are facing when working with persons with post COVID-19 persistent symptoms.

Finally, the interaction in the focus groups may have drawn participants' attention to a selection of prominent symptoms. This is a weakness, if some participants did not get the opportunity to highlight other symptoms and themes e.g., those regarding symptoms that the other participants did not experience. Individual interviews could have given each participant greater opportunity to elaborate on individual perspectives. However, probing questions were used to assure that participants had the opportunity to mention all relevant issues.

CONCLUSION AND CLINICAL IMPLICATIONS

This study highlights that persons with persistent symptoms after COVID-19 may experience a range of symptoms and limitations in their daily living. This points toward a need for individual assessment and guidance to help persons with persistent symptoms regain functioning or cope with possible disability in daily activities and participation. Professional guidance could also support persons with persistent symptoms in dealing with feelings of uncertainty and powerlessness and support hope and goalsetting in the rehabilitation process.

Guidelines on how to conduct evidence-based post COVID-19 rehabilitation interventions have emerged over the course of the pandemic (2, 8, 17), and the present study contributes to this knowledge base by pointing to elements that interventions can include to target the rehabilitation needs of their patients.

At a group level, it would be important to address coping with the common symptoms fatigue, memory and concentration problems. At the same time, the study results point to the importance of an individual approach to rehabilitation, as patients may present with a wide range of symptoms. This calls for a specialized approach based on systematic screening procedures addressing a broad spectrum of potential impairments. This study also indicates that it would be relevant to include components within the mental functions in examining body functions.

When referring people with persistent symptoms after COVID-19 to relevant rehabilitation interventions scales to assess specific rehabilitation needs might be useful for the professionals involved. The scales used in this study represent possible assessment tools that could be used as initial guidance for professionals to prepare and tailor further individual assessments and interventions.

Further research could preferably elaborate on the mechanisms behind COVID-19 persistent symptoms and in more detail examine impairment of mental functions and how these can be assessed.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, upon reasonable request, without undue reservation. Note that all qualitative data are only available in Danish.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by The Regional Committee on Health Research Ethics for Southern Denmark: Case number 20202000, no. 122. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

TB, A-DZ, and NR: study design. TB: data collection and analysis and manuscript writing. TB, TM, A-DZ, JR, and NR interpretation and manuscript revisions. All authors contributed to the article and approved the submitted version.

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BRIEF RESEARCH REPORT
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The Nottwil Standard-Development and Implementation of an International Classification of Functioning, Disability and Health-Based Clinical Standard Assessment for Post-acute Rehabilitation After Newly Acquired Spinal Cord Injury

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Introduction: Assessments during rehabilitation of spinal cord injury (SCI) align with the World Health Organization's classifications and national quality requirements. This paper aims to report on the development and first implementation experiences of an institutional standard of assessments performed after newly acquired SCI.

Setting: Specialized SCI acute care and post-acute rehabilitation clinic in Switzerland.

Methods: A situation analysis of an interdisciplinary post-acute SCI rehabilitation program was performed. The results informed a subsequent consensus-based selection of assessments, and an information and implementation strategy. Linking to the ICF Core Set for SCI in post-acute settings and ICF Generic-30 Set was performed. The Nottwil Standard was piloted for 18 months.

Results: Situation analysis: A battery of 41 assessments were irregularly performed during initial rehabilitation after newly aquired SCI. Selection of assessments: A multidisciplinary group of clinicians agreed on 10 examinations, 23 assessments and two questionnaires that make up the Nottwil Standard. In total, 55 ICF categories are covered, including most of the ICF Generic-30 Set categories. The implementation strategy included Executive Board commitment, a structured improvement project, guidelines for documentation and assessments, a manual controlling system, and staff training on the Nottwil Standard. Pilot phase: 54 persons with paraplegia and 42 with tetraplegia (75 male; 21 female) were included. Twenty-seven assessments out of 33 assessments were performed in more than 80% of all observed patients' rehabilitation.

Conclusion: Implementation of a standard assessment schedule was feasible but required a well-structured process with good communication strategy and controlling mechanism, and full engagement of involved professions.

Keywords: rehabilitation, post-acute care, spinal cord injury, international classification of functioning, disability and health, functioning, assessment 2

INTRODUCTION

Quality clinical care of persons with spinal cord injury (SCI) after a newly acquired SCI demands a comprehensive and accurate assessment of their medical and functioning needs (1–4). A major challenge is determining the assessment tools, clinical examinations and other sources of information (collectively referred to as "assessment tools" from now on) to employ in the assessment. Ideally, such a battery of assessment tools is part of standard assessment procedures and reflects current rehabilitation practice. The development of such a standard should rely on a number of principles that guide its development.

Guiding Principles

The first guiding principle is the application of WHO classifications, specifically the International Classification of Diseases (ICD) (5) and the International Classification of Functioning, Disability and Health (ICF) (6), to meet the objective of SCI rehabilitation, i.e., optimization of the person's functioning (2, 7). The ICF is central to the development of an assessment standard that relies on a four-step approach of standardized documentation of functioning (8). While the ICD can be used to diagnose disease and injury, the ICF can be used to describe the functioning of a person from a bio-psycho-social perspective. The ICF encompasses categories that are hiearchically organized under the following components: body functions (e.g., shoulder pain, muscle tone functions in wheelchair-using patients with SCI), body structures (e.g., shoulder joint or arms), activities and participation (e.g., moving around using a wheelchair, work, participation in wheelchair sports) and environmental factors (e.g., barrier-free buildings). ICF categories contain a letter, i.e., b for body functions, s for body structures, d for activities and participation and e for environmental factors) and a series of numbers representing the four levels of detail in the hierarchy, from least detailed chapter level (e.g., b2 Sensory functions and pain) to the most detailed fourth level (e.g., b28014 Pain in upper limb) (6).

The four-step approach encompasses deciding on (1) what ICF domains (or categories) to document; (2) what perspective to take; (3) what data collection tools to apply; and 4) which approach to use for reporting. ICF Core Sets, short lists of ICF categories for specific health conditions and settings (9, 10), can be used to define what to document. The ICF Generic-7 and Generic-30 Sets as a minimum set of categories independent of health condition and setting, can also be used in the first step and across the care continuum (11, 12). For the rehabilitation care of persons with newly acquired SCI, the ICF Core Set for SCI in post-acute care (13) would be most appropriate to use. This ICF Core Set was developed in a multiple stage consensus process in which experienced SCI specialists from different professions and countries across the world defined the most relevant categories that can be used during this rehabilitation phase.

The ICF is also key to the second principle, i.e., aligning with international initiatives to scale up rehabilitation. A trailblazing initiative has been led by the Physical and Rehabilitation Medicine (PRM) Section and Board of the European Union of Medical Specialists (UEMS-PRM) that reflects the crucial interaction between practice, science and governance (policy) (14). The UEMS-PRM implementation action plan calls for, among other things, the "identification of data collection tools that cover the ICF domains included in the clinical assessment schedules [CLAS] of specific rehabilitation service [types]" (14–16). Aligned with the aforementioned four-steps approach, a CLAS is the specification of functioning aspects to document [using ICF Core Sets (9, 10) and ICF Generic Sets (11, 12)], for whom and when, and the data collection tools to employ (16, 17). Given that a CLAS designated for a specific health condition should cover all relevant aspects of functioning and contextual factors relevant for persons with that health condition, the ICF Core Set for SCI in post-acute care should be used for specifying the CLAS for the rehabilitation of persons with newly acquired SCI. Assessment tools should be administered as soon as possible at the beginning and at the end of an intervention (17). The UEMS-PRM action plan also calls for developing national ICF-based rehabilitation quality management strategies that are consistent with existing clinical quality management systems (14). This is related to the third principle.

The third principle is the consideration of national clinical quality management requirements for the reporting of health data. In Switzerland, functioning data from rehabilitation institutions are reported to the Swiss National Association for Quality Development in Hospitals and Clinics (ANQ) [https://www.anq.ch/de/fachbereiche/rehabilitation/]. In addition to functioning data, health condition(s), the Swiss Classification of Operations (CHOP) codes for interventions and procedures (18, 19), and the definition and achievement of rehabilitation goals according to ANQ criteria (20).

The fourth principle is the consideration of evidence provided by the SCI-specific cohort studies, e.g., Swiss SCI cohort study (SwiSCI; https://www.swisci.ch) and the European Spinal Cord Injury cohort study (EMSCI; https://www.emsci.org), and SCI-specific research platforms and resources on outcomes, e.g., the Spinal Cord Injury Research Evidence (https://scireproject.com/ and) or the Spinal Cord Outcomes Partnership Endeavor

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Abbreviations: SCI, Spinal cord injury.

(SCOPE) (21, 22) in developing robust assessment standards. Especially relevant for developing standards for the assessment of persons with newly acquired SCI are the S2e guidelines for outcome measures in initial rehabilitation after the onset of a SCI (23, 24) led by the German-speaking Medical Society of Paraplegia (DMGP). Scientific evidence also encompasses information about validity and reliability of assessment tools (25).

The fifth principle relates to the implementation of the assessment standard. For an assessment standard to be feasibly implemented, it should adhere to the requirements of insurers, i.e., that the provision of care is suitable, feasible, cost-efficient and is based on scientific evidence (26). Essential for effective implementation of an assessment standard are health professionals trained in applying the tools contained in the assessment standard, including knowing the appropriate timing for applying specific assessment tools (27), as well as care provider leaders who support its implementation (28). Moreover, the feasibility of implementating an assessment standard is enhanced with the availability of a supportive infrastructure, e.g., health information system (HIS) and administrative support (28).

Initiating the Project

The impetus for developing the Nottwil Standard is illustrative of what UEMS-PRM highlights as the interaction between practice, science and governance (policy). The clinic's decision-makers recognized the need to implement international recommendations for outcome measures and evidence-based rehabilitation of persons with newly acquired SCI (practice), and to meet requirements of financing-relevant stakeholders (e.g., insurances) for rehabilitation quality as well legal requirements (governance/policy). Furthermore, the clinic and its partner research institute envisioned the translation of cohort study results, namely from SwiSCI and EMSCI in rehabilitation quality management. The decision to initiate the project was made at a workshop of clinic and research institute leaders in 2015. Subsequently, a workshop was held in January 2016 at the research institute, during which the UEMS-PRM implementation action plan was developed (14).

The objective of this paper is to report on the development of an assessment standard (called Nottwil Standard) for use in the rehabilitation of persons after newly acquired SCI according to the guiding principles and to report on the first experiences in implementing it.

METHODS

Design

This study is an implementation study starting with an observational situational analysis, presenting the participatory consensus process and ending with an observational analysis after the implementation of the newly developed standard.

Setting

This project took place in an acute inpatient rehabilitation and outpatient clinic specialized for SCI and under the auspices of its integrated quality management and multiproject management unit. The clinic is part of a larger organization that also includes a research institute and is governed by a foundation. Since 2006 the clinic has been developing an ICF-oriented culture, striving to increasingly implement ICF elements in interprofessional clinical management.

Preparatory Activities

Situation Analysis

An observational study, a situation analysis was conducted that involved an analysis of retrospective data from patients (adults ≥18 years old) admitted for rehabilitation after newly acquired SCI from December 2014 to December 2015 (3, 27). Among the data analyzed were the assessment tools used by physicians, physiotherapists, occupational therapists and nurses, and assessment procedures, including adherence to administration recommendations (e.g., timing). The situation analysis results were considered in the development of the Nottwil Standard.

Developing the Nottwil Standard

The project was led by a rehabilitation physician with experience in rehabilitation quality management research methodology and conducted by a multidisciplinary core project team (CPT) consisting of the project leader, the rehabilitation department head, the chief physician of rehabilitation, the head of corporate development and scientific assistant. The CPT was supported by an expanded project team (EPT) representing all relevant professions involved in the routine SCI rehabilitation process, including peer counselors, who represented the perspective of a person with SCI. The development of the Nottwil Standard was driven by an inclusive and consensus-based approach. Content and milestones were discussed, revised and approved by the CPT and EPT. The overall project proceeded in alignment with the CLAS concept (16, 17) and the four-step approach (8).

Step 1: Defining the Domains to Document

In a first step, the CPT defined the domains (or ICF categories) based on the ICF Generic-7 and—30 Sets (11, 12), the results of the situation analysis (3, 27) and in line with the guidelines on outcome measures of the DMGP. (23, 24). The CPT and the EPT decided to select assessment tools that are able to measure the defined ICF categories. If no assessments were available to cover specific categories, the patient's status in that category would be narratively described.

Step 2: Deciding What Perspective to Take

The CPT and EPT prioritized clinical and health care professional (HCP)-administered assessment tools to measure the ICF category, as these were deemed objective measures of functioning. To reflect the patient's perspective, patient-reported outcome measures (PROMs) were also selected. Associated with perspective is the decision about which profession(s) are responsible for assessing which aspect of functioning. In turn, this also guided the decision on the assessment tools to include. In some cases, more than one profession was defined as responsible.

Step 3: Identifying What Data Collection Tools to Apply

Identifying the data collection tools to apply mirrors the project's aim, i.e., to develop the Nottwil Standard. In addition to applying the results of steps 1 and 2, this step considered the results of the situational analysis, specifically which assessment tools were employed to measure different aspects of patient functioning and health, how and how often assessment tools were used, as well as the recommended toolkit defined in the DMGP guidelines (24) and the assessment tools recommended in the SwiSCI and EMSCI studies. Furthermore, suggestions for additional assessment tools recommended by HCPs based on recent scientific evidence were also considered.

Step 4: Deciding on When to Assess

The CPT defined the timepoint for assessment with the CLAS recommendation of the UEMS-PRM (16), the recommended timepoints from the SwiSCI (4, 12, 24 weeks post-injury and discharge) (29) and the EMSCI (1, 4, 12, 24, 48 weeks post-injury) (30) studies in mind.

Toward Implementation of the Nottwil Standard

The implementation of the Nottwil Standard was documented in an implementation plan that outlined its integration in routine practice and in the existing documentation system, and the meetings with the EPT and all involved professional groups (physicians, therapists and nurses). To facilitate the integration of the Nottwil Standard in the clinic's electronic documentation system, documentation and process-based management representatives of the clinic's information technology department were also involved.

As Switzerland is a multi-language country, language diversity in the development of the Nottwil Standard was deemed important. Thus, where possible, PROMs in the Swiss languages of German, French, and Italian or English were included in the Nottwil Standard. These are the same languages used in the SwiSCI study (31).

To ensure the smooth implementation of the Nottwil Standard, a 1-year pilot study was conducted.

Pilot Study

The pilot study was approved by the ethical committee (EKNZ Req-2020-01416) as a quality assurance project. The aim of the pilot implementation and quality assurance project was to evaluate the compliance with the standard. Data collection took place and included all patients admitted for initial rehabilitation after 1 July 2019 and discharged before 31 December 2020. Baseline patient characteristics, e.g., gender, age, completeness and level of lesion, as well as admission data, e.g., date of SCI onset and time of assessment, were recorded by the scientific assistant.

During the pilot study, the CPT regularly collected feedback and suggestions for improvement from the clinical staff beyond the EPT. The CPT and EPT discussed the collected input in two half-year feedback meetings, and the Nottwil Standard was adapted accordingly. The CPT and EPT regularly informed their respective clinical teams about changes that impacted the application of the Nottwil Standard during the pilot study.

RESULTS

Situation Analysis

In total, 41 assessment tools were administered, 10 of which were administered more than once per patient. Of these 10 tools, the most frequently used were Spinal Cord Independence Measure III (SCIM) (32, 33), skin assessment and the Manual Muscle Test (34). The results show that outcome measures for motor activity, mobility and self-care were administered regularly, while measures for the autonomous nervous system, mental health and participation were not. Furthermore, neurological assessments like the International Standards for Neurological Classifications of SCI (ISNCSCI) (35) were not administered consequently nor at the recommended time points. Furthermore, the battery of assessment tools at the time did not cover the spectrum of categories of the ICF Core Set for post-acute care (3, 27).

Defining the Domains to Document

The included ICF categories are presented in **Table 1**.

The Nottwil Standard does not contain assessment tools that cover the following categories of the ICF Generic-30 Set and ICF Core Set for SCI in post-acute care due to the lack of adequate and established assessment tools that measure these categories: d230 Carrying out daily routine, d240 Handling stress and other psychological demands, d570 Looking after one's health, d640 Doing housework, d660 Assisting others, d710 Basic interpersonal interactions and d770 Intimate relationships.

Deciding What Perspective to Take

The following professions were defined as those responsible for administering the Nottwil Standard: physicians (paraplegiology, neurology, urology, radiology, gynecology, pain management, hand surgery), nursing, physiotherapy, occupational therapy, psychology, social service, speech therapy, nutritional therapy, vocational counselor. See **Table 2** for the list of assessment tools and responsible professions. Two PROMs, the Hospital Anxiety and Depression Scale (HADS) (36) and the SCI Quality of Life Basic Data Set (37), were also included in the Nottwil Standard.

Identifying What Data Collection Tools to Apply

The Nottwil Standard version used for the pilot study contained 10 clinical examinations, 23 assessment instruments and two questionnaires. In addition, 7 tools were added specifically for the assessment of patients with tetraplegia (**Table 3**) and 5 tools to assess patients with walking ability (**Table 4**). Several assessment tools recommended in the DGMP guidelines and by the HCPs were also included: the International Standard of Autonomic Function in Spinal Cord Injury (ISAFSCI) (38), Spinal Cord Injury Pain Instrument (SCIPI) (39), International Spinal Cord Injury Pain classification (ISCIP) (40), 10 Meter Walk Test for Spinal Cord Injury (10 MWT) (41, 42) and WHO-QoL BREF (43), the Aktivitätstest zur Mobilität im Rollstuhl (activity test for mobility in wheelchair; AMR) (44, 45), the Bogenhausener

TABLE 1 | Overview of the categories of the ICF Generic-30 Set (12). Post-acute SCI Set (13), and categories resulting from linking the Nottwil Standard to the ICF.

	ICF Code and Label **(G) = Category of the ICF Generic-7 Set (11)**	**ICF generic-30 Set**	**SCI Post-acute Brief**	**SCI post-acute comprehensive**	**Nottwil standard**
***N* =**		**30**	**27**	**52**	**61**
b114	Orientation functions				1
b126	Temperament and personality functions				1
b130	Energy and drive functions (G)	1		1	1
b134	Sleep functions	1		1	1
b137	Muscle power functions				1
b140	Attention functions				1
b144	Memory functions				1
b147	Psychomotor functions				1
b152	Emotional functions (G)	1	1	1	1
b156	Perceptual functions				1
b160	Thought functions				1
b164	Higher-level cognitive functions				1
b176	Mental function of sequencing				1
b180	Experience of self and time functions				1
b260	Proprioceptive function				1
b280	Sensation of pain (G)	1	1	1	1
b410	Heart functions				1
b415	Blood vessel functions				1
b420	Blood pressure functions				1
b430	Hematological system functions				1
b440	Respiration functions		1	1	1
b455	Exercise tolerance functions	1		1	1
b510	Ingestion functions				1
b525	Defecation functions		1	1	1
b530	Weight maintenance functions				1
b535	Sensations associated with the digestive system				1
b550	Thermoregulatory functions				1
b620	Urination functions	1	1	1	1
b640	Sexual functions	1		1	1
b665	Touch function				1
b710	Mobility of joint functions	1		1	1
b730	Muscle power functions	1	1	1	1
b735	Muscle tone functions		1	1	1
b770	Gait pattern functions				1
b810	Protective functions of the skin		1	1	1
d230	Carrying out daily routine (G)	1	1	1	
d240	Handling stress and other psychological demands	1	1	1	
d410	Changing basic body position	1	1	1	1
d415	Maintaining a body position	1	1	1	1
d420	Transferring oneself	1		1	1
d440	Fine hand use				1
d445	Hand and arm use		1	1	1
d450	Walking (G)	1	1	1	1
d455	Moving around (G)	1		1	1
d460	Moving around in different locations				1
d465	Moving around using equipment	1		1	1
d470	Using transportation	1		1	1
d475	Driving				1
d480	Riding animals for transportation				1

(Continued)

TABLE 1 | Continued

	ICF Code and Label (G) = Category of the ICF Generic-7 Set (11)	ICF generic-30 Set	SCI Post-acute Brief	SCI post-acute comprehensive	Nottwil standard
d510	Washing oneself	1	1	1	1
d520	Caring for body parts	1		1	1
d530	Toileting	1	1	1	1
d540	Dressing	1	1	1	1
d550	Eating	1	1	1	1
d560	Drinking		1	1	
d570	Looking after one's health	1		1	
d640	Doing housework	1		1	
d660	Assisting others	1		1	
d710	Basic interpersonal interactions	1		1	
d770	Intimate relationships	1		1	
d850	Remunerative employment (G)	1		1	1
d920	Recreation and leisure	1		1	1
e110	Products or substances for personal consumption			1	
e115	Products and technology for personal use in daily living		1	1	1
e120	Products and technology for personal indoor and outdoor mobility and transportation		1	1	1
e135	Products and technology for employment			1	
e150	Design, construction and building products and technology of buildings for public use			1	
e155	Design, construction and building products and technology of buildings for private use			1	
e225	Climate			1	
e310	Immediate family		1	1	
e320	Friends			1	
e340	Personal care providers and personal assistants		1	1	
e355	Health professionals		1	1	
e450	Individual attitudes of health professionals			1	
e580	Health services, systems and policies			1	1
e650	Financial assets				1
s110	Structure of brain				1
s120	Spinal cord and related structures		1	1	1
s430	Structure of respiratory system		1	1	1
s610	Structure of urinary system		1	1	1
s710	Structure of head and neck region				1
s720	Structure of shoulder region				1
s730	Structure of upper extremity				1
	TOTAL	30	27	52	63

Dysphagia Score (BODS) (46), and magnetic resonance imaging (MRI) of the brain and spinal cord. The Nottwil Standard tools were organized according to the ICF components of body functions and structures and activities and participation and ICF categories, and quality of life. See **Tables 2–4**.

Deciding on When to Assess

The time points for conducting the assessment were defined as follows: admission (0–2 weeks after admission) and discharge (0–3 weeks before discharge). For specific assessment tools, additional time points were considered clinically relevant. See **Table 2**.

Toward Implementation of the Nottwil Standard

Other than the assessment tools recommended by the DMGP guidelines (i.e., ISAFSCI, SCIPI, ISCIP, 10 MWT, WHO-QoL BREF) or the HCPs (i.e., AMR, BODS and MRI), the assessment tools included in the Nottwil Standard had already been in routine use in the clinic and integrated in the HIS. The newly introduced assessments were initially introduced in paper form. The ISAFSCI was later integrated into the clinic's HIS.

In terms of the controlling mechanism during the pilot study, when an assessment was not conducted as described in the Nottwil Standard, reminders were manually sent to

TABLE 2 | The Nottwil Standard assessment tools, responsible professions and compliance of all assessments during the pilot study.

ICF Title	Diagnosis	Profession	Administered admission total (%)	Administered ITP total (%)	Administered discharge total (%)	Total adherence (%)
NC	Etiology	Physician (Paraplegiology)	96 (100)			100
s120 Spinal cord and related structures	Lesion level	Physician (Paraplegiology)	96 (100)			100
ICF Title	**Structure/Function**	**Profession**	**Administered admission total (%)**	**Administered ITP Total (%)**	**Administered discharge total (%)**	**Total adherence (%)**
b665 Touch function b280 Sensation of pain b137 Muscle power function	ISNCSCI	Physician (Paraplegiology/ Neurology)	96 (100)		94 (98)	>95
b410 Heart functions b415 Blood vessel functions b420 Blood pressure functions b620 Urination functions b525 Defecation functions b550 Thermoregulatory functions b640 Sexual functions	ISAFSCI	Physician (Paraplegiology/ Neurology/Urology)		22 (23)	33 (34)	>25
b420 Blood pressure functions	Tilt table test (over Th10)	Physician (Paraplegiology/Neurology)		27 (39)		>35
b525 Defecation functions b535 Sensations associated with the digestive system d530 Toileting	Defecation method (SCI Bowel Function Basic Data Set)	Physician (Paraplegiology/Urology) Nurse				
b610 Urinary excretory functions b620 Urination functions b630 Sensations associated with urinary functions d530 Toileting	Bladder emptying (SCI Lower Urinary Tract Function Basic Data Set)	Physician (Paraplegiology/Urology) Nurse				
b620 Urination functions	Urodynamics/Uroflowmetry	Physician (Urology)		81 (84) 95 (99)		>90
s610 Structure of urinary system	Ultrasound Bladder/Kidney	Physician (Urology)		95 (99)		>95
s120 Spinal cord and related structures	Electrophysiology	Physician (Neurology)		95 (99)		>95
b710 Mobility of joint functions	Range of Motion Lower Extremities	Physiotherapist	95 (99)		90 (94)	>95
b710 Mobility of joint functions	Range of Motion Upper Extremities	Physiotherapist	88 (92)		86 (90)	>90
b730 Muscle power functions	Manual Muscle Test Lower Extremities	Physiotherapist	95 (99)		87 (91)	>90

(Continued)

TABLE 2 | Continued

ICF Title	Structure/Function	Profession	Administered admission total (%)	Administered ITP Total (%)	Administered discharge total (%)	Total adherence (%)
b280 Sensation of pain s720 Structure of shoulder region d420 Transferring oneself d460 Moving around in different locations d465 Moving around using equipment	WUSPI	Physiotherapist			54 (56)	>50
b114 Orientation functions b140 Attention functions b144 Memory functions b156 Perceptual functions b160 Thought functions b164 Higher-level cognitive functions b176 Mental function of sequencing complex movements	MoCA	Physician (Paraplegiology) Neuropsychology		71 (74)		>70
b410 Heart functions	ECG	Physician (Paraplegiology)	93 (97)			>95
b420 Blood pressure functions	Blood Pressure	Physician (Paraplegiology)	96 (100)		96 (100)	100
b440 Respiration functions	Lung Function: Spirometry/Bodyplethismography	Physician (Paraplegiology)		74 (77) 18 (19)		>40
s120 Spinal cord and related structures	MRI (whole spine)	Physician (Paraplegiology/Radiology)		87 (91)		>90
s710 Structure of head and neck region	MRI (head)	Physician (Paraplegiology/Radiology)		71 (74)		>70
NC	Height	Nurse	79 (82)			>80
b530 Weight maintenance functions	Body Weight	Nurse	86 (90)		86 (90)	>90
NC	Leg Circumference	Nurse	96 (100)		95 (99)	>95
b810 Protective functions of the skin	Pressure Injury (yes/no)	Physician (Paraplegiology)				
b280 Sensation of pain	NRS Pain	Physician (Paraplegiology)		*17times applied	91 (94.79)	
b280 Sensation of pain	ISCIP	Physician (Paraplegiology)		11 (64.71)	95 (98.96)	
b280 Sensation of pain	SCIPI	Physician (Paraplegiology)		11 (64.71)	95 (98.96)	
b735 Muscle tone functions	Modified Ashworth Scale	Physiotherapist		30 (31.25)	57 (59)	
s770 Additional musculoskeletal structures related to movement	Osteoporosis/Densitometry und Bodycomposition	Physician (Paraplegiology/Radiology)		54 (56)		>50
NC	Vitamin D Status	Physician (Paraplegiology)		95 (99)		>95
b530 Weight maintenance functions	SNST	Nutrition Therapy	79 (82)			>80

(Continued)

TABLE 2 | Continued

ICF Title	Activity/Participation	Profession	Administered admission total (%)	Administered ITP total (%)	Administered discharge total (%)	Total adherence (%)
See below	SCIM III	Nurse/Physiotherapist/ Occupational Therapist	96 (100)		96 (100)	100
d510 Washing oneself d520 Caring for body parts d540 Dressing d550 Eating	Self-Care	Nurse	96 (100)		96 (100)	
b620 Urination functions b525 Defecation functions d530 Toileting	Respiration and sphincter management	Nurse	96 (100)		96 (100)	
d420 Transferring oneself d450 Walking d455 Moving around d460 Moving around in different locations	Mobility (Room and Toilet)	Occupational therapist	96 (100)		96 (100)	
d420 Transferring oneself d450 Walking d455 Moving around d460 Moving around in different locations	Mobility (Indoors and Outdoors, on even Surface)	Physiotherapist	96 (100)		96 (100)	
b770 Gait pattern functions d450 Walking	WISCI II	Physiotherapist			59 (61)	>60
d465 Moving around using equipment	AMR (if in wheelchair)	Physiotherapist			47 (48.96)	>50
b455 Exercise tolerance functions	Endurance test	Sports medicine		41 (43) 25 (26)		>30
e115 Products and technology for personal use in daily living e120 Products and technology for personal indoor and outdoor mobility and transportation d850 Remunerative employment	ANQ Goals	Physician (Paraplegiology)	96 (100)			100
ICF Title	**Quality of life**	**Profession**	**Administered admission total (%)**	**Administered ITP total (%**	**Administered discharge total (%)**	**Total adherence (%)**
b130 Energy and drive functions b126 Temperament and personality functions b152 Emotional functions b147 Psychomotor functions b160 Thought functions b180 Experience of self and time functions	HADS	Psychology			40 (42)	>40

NC, Not covered by the ICF; ISNCSCI, International Standards for Neurological Classification of SCI; ISAFSCI, International Standard of Autonomic Function in Spinal Cord Injury; WUSPI, Wheelchair User's Shoulder Pain Index; MoCA, Montreal Cognitive Assessment; ECG, Electrocardiogram; MRI, Magnetic Resonance Imaging; NRS, Numeric Rating Scale; ISCIP, International Spinal Cord Injury Pain classification; SCIPI, Spinal Cord Injury Pain Instrument; SNST, Spinal Nutrition Screening Tool; SCIM, Spinal Cord Independence Measure; WISCI, Walking Index for Spinal Cord Injury; AMR, Aktivitätstest zur Mobilität im Rollstuhl (Activity test for Mobility in Wheelchair); ANQ, Swiss National Association for Quality Development in Hospitals and Clinics; HADS, Hospital Anxiety and Depression Scale; WHOQoL-BREF, World Health Organization Quality of Life.

**Real number without complete screening of pain incidence.*

TABLE 3 | The Nottwil Standard assessment tools, responsible professions and compliance of all assessments for 42 patients with tetraplegia during pilot study.

ICF Title	Structure/Function	Profession	Administered admission total (%)	Administered ITP total (%)	Administered discharge total (%)	Total adherence (%)
b730 Muscle power functions	Manual muscle test upper extremities	Occupational therapist	42 (100)		41 (98)	>95
b730 Muscle power functions s730 Structure of upper extremity d445 Hand and arm use	ICSHT	Hand surgery		36 (89)		>85
b710 Mobility of joint functions s730 Structure of upper extremity	Range of motion wrist-finger	Occupational therapist	41 (98)		33 (84)	>90
b730 Muscle power functions s730 Structure of upper extremity	Jamar hand dynamometer	Occupational therapist	23 (41.82)		19 (34.55)	
s730 Structure of upper extremity d440 Fine hand use d445 Hand and arm use	GRASSP 2	Occupational therapist	42 (100)		37 (91)	>95
b430 Hematological system functions	Pulse oximetry	Physician (Paraplegiology)	41 (98)			>95
b510 Ingestion functions	BODS	Physician (Paraplegiology) Logopedics	41 (98)		40 (96)	>95

ICSHT, International Classification for Surgery of the Hand in Tetraplegia; GRASSP, Graded Redefined Assessment of Strength, Sensibility and Prehension; BODS, Bogenhausener Dysphagia Score.

TABLE 4 | The Nottwil Standard assessment tools, responsible professions and compliance of all assessments for patients with walking ability during the pilot study.

ICF Title	Structure/Function	Profession	Administered admission total (%)	Administered ITP total (%)	Administered discharge total (%)	Total adherence (%)
b260 Proprioceptive function	Deep proprioceptive sensitivity	Physician (Paraplegiology/Neurology)				
b770 Gait pattern functions d450 Walking	10 meter walk test	Physiotherapist			13 (42)	>40
b770 Gait pattern functions d450 Walking	Six-minute walk test	Physiotherapist			28 (90)	>90
d410 Changing basic body position d450 Walking	Timed up and go test	Physiotherapist			22 (71)	>70
b770 Gait pattern functions	Gait analysis	Physiotherapist/Neurology				

the responsible person(s), and reasons for non-performance were documented in the HIS for the specific patient. This documentation was visible to all clinical staff involved in the rehabilitation of that patient. The development of an automated reminder system is planned.

Pilot Study

Forty-two patients with tetraplegia and 54 patients with paraplegia (75 were male and 21 female) were included in the pilot study.

All senior ($n = 10$) and junior ($n = 19$) physicians, 40 physiotherapists, 20 occupational therapists, 8 psychologists, 5 nutrition specialists, 6 social workers participated in the training on the Nottwil Standard. While many of the assessment tools were already in routine use, physicians had to learn to use the ISAFSCI, ISCIP and SCIPI, and physiotherapists had to be trained to use the 10 MWT.

The following assessments were administered at a 100% compliance level in accordance with the Nottwil Standard recommendations: ISNCSCI, urological examination, manual muscle tests, range of motion testing and SCIM III. See **Table 2**. The lowest compliance rates were observed for ISAFSCI (35%), ISCIP (35%), SCIPI (35%), (HADS 41%). Assessments using WHOQOL BREF was not implemented at all.

In summary, the Nottwil Standard (see **Tables 2–4**) covers the complexity of functioning associated with SCI, including but not limited to neuromuscular functions (e.g., 10 MWT, manual muscle test), functions of the autonomic nervous system (e.g., ISAFSCI, blood pressure), pain (e.g., numeric rating scale for pain), mental/psychological functions (e.g., HADS), bladder and bowel management (e.g., SCIM III), mobility (e.g., AMR), participation in work and social life (e.g., SCIM III, ANQ goals), influence of assistive devices (e.g., ANQ goals). Since the functioning of persons with SCI can differ greatly depending on whether the person is living with paraplegia or tetraplegia, or can or cannot walk, the Nottwil Standard also contains specific assessment tools for these sub-populations of persons with SCI.

DISCUSSION

In this paper, we reported on the development of the Nottwil Standard, an ICF-based assessment standard for use in the rehabilitation of persons after newly acquired SCI and on the first experiences in implementing it. Developing the Nottwil Standard not only met the challenge of determining a battery of tools that support a comprehensive and accurate assessment of health and functioning of patients with SCI, it showed that it is feasible to develop and implement it in an interprofessional and participatory manner. Furthermore, this project reflects the potential for real-life clinical application of the ICF that also promotes the clinical quality management.

Potential for Real-Life Clinical Application of the ICF

Although the ICF was launched in 2001, the implementation of the ICF in the clinical management of individuals with SCI took over a decade. This is consistent with findings of a mixed method examination of the extent of ICF diffusion in clinical rehabilitation (not only SCI) between 2001 and 2010. This study showed that clinical implementation of the ICF at the time was rare and called for more large-scale research to address the need for best practice recommendations implementing the ICF in clinical rehabilitation (47). In terms of SCI care, there were early implementation efforts, e.g., in developing an ICF-based electronic tool for use in the long-term clinical follow-up of patients with SCI (48). The ICF has also been key in framing outcomes in SCI care, including the International SCI data sets (49). Efforts to implement the ICF in SCI rehabilitation gained momentum with the development of the ICF Core Set for SCI for the post-acute care and the ICF Generic-30 Set (12, 13), For example, the DGMP guidelines for outcome measures in inital rehabilitation after the onset of a SCI calls for using the ICF Core Set for SCI in post-acute care in selecting the outcome measures to use (24). This was one of the drivers for developing the Nottwil Standard.

The ICF and its underlying comprehensive biopsychosocial perspective also stimulated the decision to include the additional assessment tools suggested by the HCP, i.e., ISAFSCI for autonomic functioning, SCIPI and ISCIP for pain examination, AMR for wheelchair mobility, BODS for swallowing function, the brain and spinal MRI for nerve structural changes, the Montreal Cognitive Assessment for neurocognitive functioning (50) and WHO-QoL for the quality of life evaluation. This helped to ensure that the Nottwil Standard comprehensively covered as many SCI-relevant functioning areas as possible. Ultimately, the aim of establishing such a comprehensive standard for assessing functioning and health of patients with SCI is to improve quality of care.

Quality Management in SCI Rehabilitation

The value of employing the ICF in clinical quality management has been recognized at the national and international level. At the international level, the UEMS-PRM has developed the European Framework for rehabilitation service types and corresponding CLAS as ICF-based standards for improving rehabilitation quality in Europe (14–16). At the national level, the ANQ, the national organization responsible for ensuring quality hospitals and clinics in Switzerland, calls for using the ICF in participation goal-setting (20). For this reason, the Nottwil Standard includes participation goal-setting based on ANQ criteria. The ANQ also calls for employing specific functioning-based instruments for reporting outcomes to the ANQ for further developing and improving quality in Swiss hospitals and clinics. These instruments reflect concrete ICF categories (51).

Ensuring clinical quality in SCI rehabilitation goes beyond ICF implementation. The pilot study showed that the successful implementation of the Nottwil Standard requires the commitment at the institutional level, active involvement of clinicians and an effective information-sharing strategy. Active involvement of the clinicians encompassed training on the Nottwil Standard and continuous discussion, evaluation and adaptation of its use (ongoing). These discussions, the controlling mechanism put in place during the pilot study and the dissemination of information on the status of the pilot study and planned adaptations of the Nottwil Standard were all elements of the information-sharing strategy.

Culture of Change

The implementation of the Nottwil Standard constitutes a change in the way assessments are done in the rehabilitation of newly injury patients with SCI. Managing change as a result of the Nottwil Standard can be viewed from the perspective of Kotter's eight steps of change management in health care: "increase urgency, building guiding teams, get the vision right, communicate for buy-in, enable action, create short-term wins, don't let up, make it stick" (52). The sense of urgency to develop and implement the Nottwil Standard has its roots in the DGMP guidelines (24) for outcome measures and ANQ goal-setting and outcomes reporting criteria (20), which promotes ICF implementation in rehabilitation, and has been building up with the results of the situation analysis (3, 27). Building guiding teams was satisfied with the establishment of a cohesive coalition between the CPT and the EPT and involving all relevant professions. Getting the vision right and communicating for buy-in are related. Clearly communicating the reasons for the Nottwil Standard and regularly communicating the status of the implementation plan were deemed as important and realized through regular meetings and information-sharing with clinical staff. Regular information-sharing and the active involvement in implementing the Nottwil Standard was the opportunity for clinical staff to connect the results of the assessments and the impact on clinical management. The HCP also had to learn that the Nottwil Standard does not hinder individualized management but rather promotes a comprehensive assessment of the patient while simplifying the complexity of the patient's health and functioning. Enabling action was reflected in the support of the clinic's management by investing necessary resources (setting up the CPT and EPT, time for meetings, engaging the IT department) in the project. Creating short-term wins can be seen in the acknowledgment of clinical staff that routine data-based assessments according to the Nottwil Standard was possible. The last two steps (don't let up, making change stick) are ongoing. The Nottwil Standard must undergo continuous improvement based on scientific developments and an evolving clinical and organization environment (7, 53, 54).

LIMITATIONS

Some limitations are noteworthy to mention. First, despite efforts to achieve comprehensiveness of the Nottwil Standard by including assessment tools that cover as many SCI-relevant ICF categories as possible, no adequate assessment tools were found for seven categories of the combined ICF Generic-30 Set and ICF Core Set for SCI in post-acute care. Alternatives to established assessment tools for assessing these categories, e.g., single item-questions, will be explored. Second, the Nottwil Standard was developed for implementation in a specific rehabilitation facility. Applying the Nottwil Standard to other hospitals and clinics will require additional testing and possible adaptation. Nevertheless, the principles of continuous improvement can be used in different settings. Lastly, the controlling mechanism nor all the assessment tools had been integrated in the HIS during the pilot study. Thus, the results of the pilot study may have been influenced by this lack of an automated reminder system, as well as the inability to electronically extract relevant data from performed assessments. Respective updates to the HIS are ongoing.

CONCLUSION

The Nottwil Standard is an ICF-based assessment standard for a comprehensive and accurate assessment of health and functioning of persons after newly acquired SCI. It was developed by an interprofessional group of rehabilitation professionals in a consensus-oriented collaborative process and guided by a set of principles. The Nottwil Standard can be feasibly integrated in routine practice and in the existing HIS. Implementation also requires a well-structured process with a good communication strategy and controlling mechanism, and full engagement of the involved multiprofessional clinical staff. Further development activities include the integration of all the Nottwil Standard assessment tools in the clinic's HIS and deciding on how to assess the SCI-relevant ICF categories that the Nottwil Standard should cover but for which no assessment tool had yet been found. Lastly, since the ultimate aim of the Nottwil Standard is the continuous improvement of rehabilitation quality, an evaluation of impact of the Nottwil Standard on care quality, for example in terms of patient and staff satisfaction, is warranted.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

ETHICS STATEMENT

The ethical committee Ethikkommission Nordwestschweiz (EKNZ Req-2020-01416) approved the study. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

PL and AS-S collected the data and were responsible for the methodological quality. MS, PL, and AS-S drafted the first version of the manuscript and all authors approved the last version and gave feedback to the final manuscript. All authors drafted the study, the development and implementation of the Nottwil standard.

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Mapping of the GEVA Items to the ICF: Preliminary Results Based on the Content of a Tool Guide Used to Assess the Needs of Persons With Disabilities in France

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The aim of this research is two-fold. Firstly, mapping the GEVA items on to the ICF will allow identifying those items that are covered by the ICF and assist in improving the data collection process. Secondly this work will provide a first exploration of the items that are not covered by the ICF and that could lead to potential proposals for updating the ICF. The preliminary results show that the items of the GEVA 2008 general version are partly covered by the ICF 2017 Browser version categories. In every section of the GEVA, some of the items might be coded with ICF codes coming from the following ICF components: Body functions, Activities and Participation, Environmental factors, Personal factors. The items of the section 6 remains those mostly covered by the ICF. Throughout the GEVA, many environmental factors are documented. Although further analysis is needed to better inform the use of qualifiers (performance, capacity, satisfaction) together with the activities and the environmental factors, the identified ICF codes could assist in improving the data collection process. Finally, some items might be discussed to become potential ICF updates proposals.

Keywords: ICF, assessment, mapping, France, GEVA disability assessment tool

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INTRODUCTION

How should the needs of persons with disabilities be assessed so as to enable to live with optimum independence, and the means to live and participate in accordance to their wishes? In the last 50 years, France has developed a succession of laws progressively building a legal framework that aims to ensure the rights to individualized compensation measures and the rights for general accessibility to all.

The main concepts, principles, values, and rights are well-known and accepted. However, their implementation may be considered as an on-going search for improvements.

France has been involved in several international processes such as (1) the work related to the concept of disability. This includes the collaboration with WHO during the revision of the International Classification of Impairments, Disabilities, and Handicaps (1980), and the on-going maintenance of the International Classification of Functioning, Disability, and Health (ICF, WHO, 2001) and (2) the work related to the UN Convention on the rights of persons with disabilities (2006) development process. In 2010, France, together with the European Union, ratified the UN Convention.

France may broadly be described as a welfare state, and accordingly the provision for persons with disabilities needs is based on the recognition of an administrative status, namely "persons with disabilities." The administrative system is complex and depends on the origin of the impairments or disabilities (work, health, army, life accident, etc.), and different allowances may be granted.

The 2005-102 Law "For equal rights and opportunities, participation and citizenship of persons with disabilities" has provided a new framework focusing on the right for compensation and accessibility. Firstly, this law gives a definition of disability as: "any limitation to activity or restriction to participation to life in society, that one may undergo in one's environment, due to substantial, long-term or permanent alteration of one or more physical, sensory, mental or cognitive functions, severe multiple and profound disabilities or a disabling health condition." Although this definition does contain the concepts found in the ICF, as underlined by the UN Special Rapporteur on the rights of persons with disabilities (1): "[...] the definition of disability [...] focuses on the impairment, instead of a person's interaction with the environment and existing barriers, and should therefore be revised." Hence, the implementation of the concepts might be improved.

Nevertheless, this law has led to the set-up of, in each of the 102 French administrative territorial entities, a one-stop counter [Maison Départementale des Personnes Handicapées (MDPH)] that manages the granting of several different disability benefits, one of which being the Prestation de compensation du handicap "PCH" for citizens aged under 60 years. The MDPHs are in charge of assessing the situations and needs for the compensatory support of persons with disabilities. Each is composed of two bodies: (1) a multidisciplinary team (medical doctors, occupational therapists, psychologists, social workers, etc.) in charge of the assessment of the needs; (2) an executive board, the "Commission for the rights and independence of persons with disabilities," composed of professionals as well as the representatives of organizations of persons with disabilities. These commissions make all decisions related to the provision of financial, technical, and human aid based on the multidisciplinary assessment, related to the development of a personalized compensation plan. The network of local authorities is supported by a national central authority (national fund of solidarity for autonomy—Caisse Nationale de Solidarité pour l'Autonomie (2) in charge of the implementation of a disability policy throughout the country.

In 2008, a national decree (2008-110, February 6, 2008) provided a guide "Guide d'évaluation multidimensionnelle" (GEVA), for the multidimensional assessment of the needs of persons with disabilities. The aim is to ensure, to the greatest extent possible, equality in the treatment of requests of individuals, equity in granting benefits, and a harmonized countrywide assessment of the situation of persons with disabilities in drawing up individualized support plans. It allows the gathering of information about the situation of an individual, summarizes the main key points of the assessment, and supports the decision process. Section 6 of GEVA aiming at supporting the decision taken to allocate the PCH has been explicitly built based on ICF categories and qualifiers.

The general version of this guide, 40 pages, has been developed in 2008 (2) and was first designed to assess the needs of adults aged under 60 years. Several complementary versions do exist, especially some focusing on education and children. As mentioned in a 2014 national study, "Generally speaking, the GEVA is used as a reference framework, but many MDPH have adapted it making their own and simplified versions. Professionals involved in assessment use the sections that seem most relevant and useful to them in relation to the situation. [...] A majority of the MDPH use a tool for gathering information at the individual's home. Half of these tools are *ad-hoc* tools that contain GEVA items" [(3), p. 36, Translation M. Cuenot].

This initial version provided to the professionals contains no codes and no formal procedure designed to be used for data collection. Only in the annex of the 2008 decree, some hierarchical *ad hoc* codes are provided for each item and each possible response. The hierarchy is organized by the order of GEVA sections.

The aim of this research is two-fold. Firstly, mapping of the GEVA items onto the ICF will allow to identify those items that are covered by the ICF and assist in improving the data collection process. Secondly, this work will provide the first exploration of the items that are not covered by the ICF, and then could lead to potential additional proposals for updating the ICF. After introducing the method used for this mapping, some preliminary results will be described and then discussed.

METHODS

The items of the general 2008 paper-based version of the GEVA have been used as a reference version for this mapping (2). They have been translated into English by the author of this paper. **Table 1** gives an overview of the content divided up into eight sections. Our analysis did not only take into account the GEVA Section 6 explicitly related to Activities, but also the GEVA Sections 1–5, the Sections 7 and 8 being merely the summaries of the other sections. We hypothesized that some other sections could also be coded with the ICF.

The linking rules formulated by Cieza et al. (4, 5) have guided the mapping work. The ICF 2017 browser version, currently available online, has been used as the reference ICF version for this work. In a general statistic approach, every different GEVA item has been counted in Sections 1–6, thus not including duplicated ones and counting only one ICF category for one GEVA item. The main results presented here are based on a qualitative analysis of the content of the GEVA for the aim is rather showing which ICF categories may be used to code the GEVA items than showing how many GEVA items are coded (several GEVA items may correspond to one same ICF category or are duplicated several times throughout the GEVA).

RESULTS

Preliminary results show that the GEVA items are partly covered by the ICF. The general statistic approach allows to estimate that 80% (343 of 435) of the GEVA items can be covered by the ICF

TABLE 1 | Overview of the GEVA 2008 sections and corresponding covered ICF components.

Sections	Overview of content	ICF components
Identification:	Title; Name; ID; Initial reasons of assessment; Life project and wishes of the person; Acquaintances' or legal representative's opinion	PF
Section 1: Family, social, and financial situation	Family status; List of persons currently in the household Social situation in relation to education or employment, including child care arrangements for young children Individual financial resources Elective offices; related needs for human assistance.	PF; D; E
Section 2: Housing and living conditions	Housing: accommodation, housing types and characteristics (accessibility; comfort) Services and building accessibility Transportation: school; human assistance and adaptations	PF; D; E
Section 3: Training and professional path	Education path: background and orientation; learning assesment and adaptations; professionals' opinion Professional path: plan; situation; status; workstation and working conditions arrangements; job coach or psychologist's opinion; arrangements for maintaining a job; skills assessment.	PF; D; E
Section 4: Medical information	Pathological origin of the disabilities; medical background; clinical information (vision; hearing); symptoms; foreseeable evolution Impairments (see regulatory framework); healthcare provision Constraints: personal assistive devices; food; natural environment	(ICD-10) B; PF; D; E
Section 5: Psychological assessment	(Neuro-)Psychological and/or memory assessment	PF
Section 6: Activities	1. General tasks and demands, and interpersonal relationships 2. Mobility 3. Self-care 4. Communication 5. Domestic and daily life 6. Applying knowledge and learning 7. Tasks and demands related to education 8. Tasks and demands related to employment	B; D; E
Section 7: Assistance and care provided	Human assistance (acquaintances, professionnals, joint collaboration) Organization of a usual day and week Professionals related to the education project Summary-Key points to be emphasized Discussion with the concerned person about the assessment Eligibility criteria (severe and complete difficulties identified) Identified needs in relation to different activities	PF; B; D; E
Section 8: Assessment summary	Summary of assessment, intended to the Commission's attention	PF; B; D; E

categories. In each of the six considered sections of the GEVA, some of the items may be coded with the ICF codes. Hence, not only the items of the Section 6 of the GEVA explicitly relate to Activities but also some items of the other GEVA Sections 1–5 belong to the universe of the ICF. The covered items are related to the following ICF components: Body functions (B), Activities and Participation (D), Environmental factors (E), and Personal factors (PF).

Some items are covered by other international classifications. In Section 4, the information related to diseases and rare diseases and to hearing and vision could be coded with ICD-10 codes. Some items may also be covered by the 1980 ICIDH categories. Indeed, some parts of the national regulatory framework still use impairments and disabilities to specifically fix the disability rates (Guide-barème). These impairment-related items may be mapped onto some ICF B categories and a related qualifier (**Table 2**).

The section in which the GEVA items are mostly covered by the ICF D chapters remains Section 6 (**Table 2**). Each item of this section is explicitly intended to be assessed through the two qualifiers: functional capacity and performance. Functional capacity should be assessed with the following scale, which is similar to the one recommended for the ICF: "0": No difficulty; "1": Mild difficulty; "2": Moderate difficulty; "3": Severe difficulty; "4": Total difficulty; and "9": Non-applicable. Performance should be assessed with another scale: a-activity performed alone; b-activity partially performed with human assistance; c-activity performed with continued assistance; and d-activity not performed.

This performance scale provides the information about the environment, especially mentioning the potential impact of human assistance on the performed activity. This means that conceptually the data that might be collected at that stage should contain one related to D and one related to E. The following general five types of E are required to be documented as facilitators or barriers during the performance assessment: human environment [ICF chapter e3 Support and relationships]; technical assistance [e1 Products and technology] housing

TABLE 2 | GEVA items covered by ICF categories (exact matches).

GEVA item	ICF 2nd or 3rd-level codes
Section 4	**B**
Intellectual and cognitive impairments	b1 Mental functions + qualifiers
Mental impairments	b1 Mental functions + qualifiers
Hearing impairments	b230 Hearing functions + qualifiers
Language impairments	b3 Voice and speech functions + qualifiers
Vision impairments	b210 Seeing functions + qualifiers
Visceral impairments	Functions related to the digestive system (b510-b539) + qualifiers
Motor impairments	b7 Neuromusculoskeletal and movement-related functions + qualifiers
Section 6	**B**
1.1 Orientation to time	b1140 Orientation to time
1.2 Orientation to space	b1144 Orientation to space
1.4 Memorize	b144 Memory functions
4.2.1 Hearing sounds	b2300 Sound detection
4.2.5 Localization of sound source	b2302 Localization of sound source
4.3 Seeing	b210 Seeing functions
8.8.1 Seeing colors	b21021 Color vision
8.8.2 Depth perception	b21000 Binocular acuity of distant vision
3.6.1 Using one's respiratory functions	b440 Respiration functions
2.15 Two-hand coordination	b7602 Coordination of voluntary movements
Section 2	d850 Remunerative employment
Section 6	**D**
1.3 Focusing attention	d160 Focusing attention
1.5 Making decisions	d177 Making decisions
1.6 Taking initiatives	d177 Making decisions
1.6.2 Spontaneously forming relationships	d7200 Forming relationships
1.6.3 Spontaneously undertaking a simple activity	d2100 Undertaking a simple task
1.6.4 Spontaneously undertaking a complex activity	d2101 Undertaking a complex task
1.7 Managing one's own safety 1.7.1 Not endangering other's life or one's own life	d570 Looking after one's health
1.7.2 Adapted reaction in a hazardous situation	d240 Handling stress and other psychological demands
1.8 Respecting social rules 1.9 Relating to others according to social rules	d7203 Interacting according to social rules
1.10 Control one's behavior in interactions with others	d7202 Regulating behaviors within interactions
1.11 Relating with peers	d7402 Relating with equals
1.12 Having intimate relationships	d770 Intimate relationships
2.1 Standing	d4104 Standing
2.1.1 Lying down	d4100 Lying down
2.1.2 Sitting	d4103 Sitting
2.2 Transferring oneself	d420 Transferring oneself
2.3 Shifting the point of support	d4106 Shifting the body's center of gravity
2.4 Maintaining a sitting position	d4153 Maintaining a sitting position
2.5 Maintaining a standing position	d4154 Maintaining a standing position
2.6 Walking	d450 Walking
2.7.1 Moving around within the home	d4600 Moving around within the home
2.7.2 Moving around outside the home	d4602 Moving around outside the home and other buildings
2.8 Climbing stairs	d4551 Climbing
2.9 Using public transportation	d4702 Using public motorized transportation
2.10 Using one's own vehicle	d4701 Using private motorized transportation
2.11 Driving a vehicle	d475 Driving
2.14 Fine hand use	d440 Fine hand use
2.16 Lifting and carrying objects (including while moving around)	d430 Lifting and carrying objects

(Continued)

TABLE 2 | Continued

GEVA item	ICF 2nd or 3rd-level codes
3.1 Washing oneself	d510 Washing oneself
3.2 Caring for body	d520 Caring for body parts
3.3 Toileting and using the toilets	d530 Toileting
3.4 Putting on and taking off clothes	d5400 Putting on clothes; d5401 Taking off clothes
3.5 Eating, drinking	d550 Eating; d560 Drinking
3.6 Looking after one's health	d570 Looking after one's health
3.6.2 Caring for oneself	d5702 Maintaining one's health
3.6.4 Monitoring one's own diet	d5701 Managing diet and fitness
4.1 Speaking	d330 Speaking
4.2.2 /0.3 /0.4 Understanding others' speaking face to face/in a group/in a noisy environment	d310 Communicating with—receiving—spoken messages
4.4 Using communication devices and techniques	d360 Using communication devices and techniques
4.4.1 Using a phone	d3600 Using telecommunication devices
4.4.2 Using other communication devices and techniques	d3609 Using communication devices and techniques, unspecified
4.5 Understanding a simple sentence	d3100 Communicating with - receiving - simple spoken messages
4.6 Maintaining a conversation	d350 Conversation
4.7 Producing and receiving non-verbal messages	d315 Communicating with - receiving - nonverbal messages; d335 Producing non-verbal messages
5.1 Shopping	d6200 Shopping
5.2 Preparing a simple meal	d6300 Preparing simple meals
5.3 Doing housework	d640 Doing housework
5.4 Taking care of clothes and garments	d6400 Washing and drying clothes and garments
5.5 Taking care of one's own family	d660 Assisting others
5.6 / 5.6.1 Managing one's own money daily and administrative tasks	d860 Basic economic transactions (managing one's budget, administrative tasks)
5.6.2 Managing one's bank account	d865 Complex economic transactions (managing one's bank account)
5.8 Having informal relationships with neighbors	d7501 Informal relationships with neighbors
5.9 Participating in community, social and civic life	d9 Community, social and civic life
5.9.3 Participating in local life	d950 Political life and citizenship
6.1 Reading	d166 Reading
6.2 Writing	d170 Writing
6.3 Calculating	d172 Calculating
6.4 Acquiring know-how skills; 6.5 Applying know-how skills	d155 Acquiring skills
7.1 Learning to read	d140 Learning to read
7.2 Learning to write	d145 Learning to write
7.3 Learning to calculate	d150 Learning to calculate
7.6 / 8.1/ 7.6.9 Respecting basic rules in relation to education/employment; Respecting school rules	d7203 Interacting according to social rules
7.6.8 / 8.6 Working with a team, in relation to education/employment	d7402 Relating with equals
8.1.3 Respecting hierarchical relations	d8451 Maintaining a job
8.1.4 Participating in meetings	d3551 Discussion with many people
8.7 / 8.7.1 Physical tasks/Lifting and moving heavy objects	d430 Lifting and carrying objects
8.7.2 Trunk twisting while working	d4305 Putting down objects
8.7.3 Working in various positions	d4309 Lifting and carrying, unspecified
8.7.4 Working in a squatting position	d4151 Maintaining a squatting position
8.7.9 Using one's feet to use a machine	d4350 Pushing with lower extremities

adaptations [e1158 Products and technology for personal use in daily living, other specified]; services [e5 Services, systems, and policies]; and animal assistance [e350 Domesticated animals]. Additionally, in this GEVA Section 6, a list of items are given for a more in-depth assessment of the human, technical, and animal assistance provided in each life domain. A related satisfaction assessment scale is eventually included to collect the point of view of the individual about the situation: complete satisfaction; satisfaction; mild satisfaction; and no satisfaction.

Hence, throughout the GEVA sections, many E are listed that may be documented. **Table 3** presents the corresponding ICF E categories that are covered. Some require additional information

TABLE 3 | ICF Environmental factors documented throughout the GEVA and related GEVA sections.

E1 Products and technology	6: General Environmental factor technical environment
e1101 Drugs	4: Regular treatments
e1108 Products or substances for personal consumption, other specified	4: Food constraints
e1151 Assistive products and technology for personal use in daily living	4: Urinary ostomy and catheter, digestive ostomy, gastrostomy, jejunostomy, tracheotomy, ventilation unit
e1158 Products and technology for personal use in daily living, other specified	4: Dependence on another machine 6: General Environmental factor housing
e120 Products and technology for personal indoor and outdoor mobility and transportation	2: Adapted vehicule
e1201 Assistive products and technology for personal indoor and outdoor mobility and transportation	4: Walking sticks, wheelchair
e1251 Assistive products and technology for communication	4: Hearing aid
e130 Products and technology for education	3: Adaptations during school assessments
e1301 Assistive products and technology for education	6: Adapted teaching material, computers
e135 Products and technology for employment	3: Workstation accommodation
e150 Design, construction and building products and technology of buildings for public use;	2: Accessibility of postal, and education facilities and services
e1500 Design, construction and building products and technology for entering and exiting buildings for public use	2: Accessibility of the housing
e1501 Design, construction and building products and technology for gaining access to facilities inside buildings for public use	2: Lift in the housing
e1508 Design, construction and building products and technology of buildings for public use, other specified	2: Other elements of accessibility of the housing
e1550 Design, construction and building products and technology for entering and exiting of buildings for private use	2: Accessibility of shops, banks
e1551 Design, construction and building products and technology for gaining access to facilities in buildings for private use	2: Accessibility of living room, kitchen, bedroom, toilets, bathroom, vertical and horizontal inside circulation
e1650 Assets	2: Owner of housing
e198 Products and technology, other specified	4: Equipment
e225 Climate	4: Weather
e2250 Temperature	4: Cold, heat
e2251 Humidity	4: Humidity
e240 Light	4: Light
e2450 Day/night cycles	6: Night work
e2458 Time-related changes, other specified	6: Working assuming schedules modifications
e250 Sound	4: Noise
e2500 Sound intensity	6: Working in a noisy environment
e255 Vibration	6: Working in an environment with vibrations
e260 Air quality	6: Working in specific respiratory environments
e2601 Outdoor air quality	4: Dust, chemical agents
e298 Natural environment and human-made changes to environment, other specified	4: Other external factor constraints
e3 Support and Relationships	6: General Environmental factor human environment
e310 Immediate family	6: Spouse, child, parent, brother/sister, other parent
e325 Acquaintances, peers, colleagues, neighbors and community members	6: Friend, neighbor, mutual support group
e340 Personal care providers and personal assistants	3: Human assistance during school assessments 4: Personal care assistant 6: Personal assistant at school
e350 Domesticated animals	6: General Environmental factor animal environment
e355 Health professionals	4: PT, OT, nurse, speech therapist, psychologist
e398 Support and relationships, other specified	6: Cued speech interpreters, technicians in writing, sign language interpreters
e399 Support and relationships, unspecified	6: Associated to the general performance qualifier levels b and c

(Continued)

TABLE 3 | Continued

e5 Services, systems and policies	6: General Environmental factor services
e5250 Housing services	6: Types of housing facilities
e5258 Housing services, systems and policies, other specified	6: Different types of medico-social facilities
e5300 Utilities services	2: Heat, gaz, water, electricity, other
e5350 Communication services	2: Accessibility of postal services
e5400 Transportation services	2: Accessibility of transportation facilities
e5500 Legal services	6: Legal protection
e5550 Associations and organizational services	2: Accessibility of cultural and leisure services and facilities
e5650 Economic services	2: Accessibility of bank services
e5652 Economic policies	2: Insurance premiums and restrictions
e5758 General social support services, systems and policies, other specified	6: Different types of medico-social supports
e580 Health services, systems and policies	4: Healthcare and night care provision, meals delivery services 6: Different types of medico-social supports
e5808 Health services, systems and policies, other specified	6: Different types of hospitalization
e585 Education and training services, systems and policies	3: Types of schooling/training/examination facilities and services 6: Remote learning and home schooling services, specialized assistance services for pupils, homework support services
e5850 Education and training services	2: Accessibility of school, pre-school, kindergarden services
e590 Labor and employment services, systems and policies	3: Types of working conditions and workstation arrangements 6: Job seeking and support services
e5908 Labor and employment services, systems and policies, other specified	6: Support and work institutions
e598 Services, systems and policies, other specified	2: Accessibility of other services

to know whether they have an impact on the individual situation, as a facilitator or an obstacle. Others only require to be identified as being provided or not. A more in-depth analysis would allow more information on how they are formulated in relation to the ICF E qualifiers. Nevertheless, these preliminary results show that the ICF E Chapters 1, 2, 3, and 5 are documented throughout the GEVA items. The categories of Chapter 4 related to Attitudes are not represented as such.

Throughout the GEVA, some items are also related to PF. Some additional qualitative information is listed in the GEVA and relates to proxy and points of view of professionals about the situation of an individual (psychological, medical, educational, apprenticeship, and professional).

Finally, some GEVA items might be covered by the ICF but no exact match is really possible. **Table 4** presents them together with the potentially lacking concept. They are mainly related to D and E. Other GEVA items cannot at all be coded with the ICF for they require qualitative information, either the point of view of other persons in relation to the main one asking for an assessment, or administrative information about some applications in progress and time-related information. The satisfaction qualifier is also not a part of the ICF.

DISCUSSION

These preliminary results of this GEVA-ICF mapping provides a first overview of the ICF coverage potential. The categories stemming from the D chapters and the Environmental chapters, together with the corresponding qualifiers, are well-represented. Not completely covered items deal in particular with education and employment (see **Table 4**). They raise some issues on how to better implement specific adaptations in these two areas and others so as to facilitate the coding and collection of some precise information.

This also underlines the needs to better document the way of interaction of these components together in some specific areas, in particular such as education or employment, which are the two major areas in the individual life project.

In the ICF education category (d820), additional information could then be added in relation to assessment/examination criteria, organizing and checking one's own work, getting organized in the classroom, getting used to school life, using learning (adapted) materials, taking notes, and participating in after-school activities. Several GEVA items also relate to the learning process: learning how to use communication techniques, or basic social rules, asking for help or assistance.

In the employment area, additional information could be added about organizing and checking one's work, working at height, working with the dominant/non-dominant arm, and working in hazardous environments.

Furthermore, the GEVA satisfaction qualifier is currently used and allows a better understanding of the impact of the E. A more in-depth analysis is needed to firstly better inform the use of qualifiers together with E and secondly to improve the identification of the items directly covered by the ICF definition of PF and others that might not be covered but which provided relevant information for a better understanding of the situation and project of an individual.

TABLE 4 | GEVA items not completely covered by the ICF.

GEVA item and related GEVA Section	Most precise ICF categories	Potential additional concepts related to ICF chapters
Section 1		
Childcare related services	e5850 Education and training services	Child care facilities (e)
- Engaging in political life - Participation in councils where DPO's representatives are appointed as members by law: Local councils; national or European parliament; other	d950 Political life and citizenship	Local National Transnational Other specified
Human assistance required in relation to political life; Other needs	e340 Personal care providers and personal assistants e5950 Political services	Human assistance related to political engagement (e)
Section 3–4		
School assessment criteria (adaptations, additional time)	d820 School education	Learning assessment criteria
Additional time necessary for care provision	e580 Health services, systems and policies	Additional time
Infectious agents	e2201 Animals	Infectious agents (e)
Section 6		
1.6.1 Spontaneously asking for help 3.6.3 Expression of a need for healthcare 5.9.2 Expression of a request for help in relation to one's own rights	d570 Looking after one's health d940 Human rights	Asking for help or assistance
2.12 / 13 Grasping using the dominant hand/non-dominant hand	d4401 Grasping	Dominant hand/Non-dominant hand
3.6.5 Managing one's daily rest	d570 Looking after one's health	Managing one's need for some rest
5.9.1 Managing one's free time, participating in cultural or sport activities	d920 Recreation and leisure	Managing one's free time
5.10 Going on holiday	d9208 Recreation and leisure, other specified	Going on holiday
7.4 Learning communication techniques	d3608 Using communication devices and techniques, other specified	Learning how to use communication techniques
7.5 Learning basic social rules	d7208 Complex interpersonal interactions, other specified	Learning basic social rules
7.6.3/8.2 Organizing one's work 7.6.4/8.3 Checking one's work 7.7 Getting organized in the classroom	d820 School education d8451 Maintaining a job	Organizing one's work Checking one's work Getting organized in the classroom In relation to education In relation to employment
7.6.7 Adaptation to school life	d820 School education	Getting used to school life
7.8 Using learning materials 7.9 Using materials adapted to one's disabilities	d820 School education	Using learning materials Using materials adapted to one's disabilities
7.10 Taking notes	d820 School education	Taking notes
7.11 Adaptation to examination and assessment conditions	d820 School education	Adaptation to examination and assessment conditions
7.12 Participating in after-school activities	d820 School education	Participating in after-school activities
8.7.5/8.7.6 Working at height (scale, roof)	d4158 Maintaining a body position, other specified	Working at height
8.7.7 Working with the dominant arm above the shoulders' height 8.7.8/non-dominant	d4308 Lifting and carrying, other specified	Working with the dominant/non-dominant arm above the shoulders' height
8.8.5 Using hazardous tools or machines	d2402 Handling crisis	Using hazardous tools or machines
8.8.9 Working in environments with risks for the skin	d2402 Handling crisis	Risks in relation to the skin

In relation to E and PF, there is also a need to distinguish on one hand the content directly inspired by the French regulatory framework and on the other hand the content based on the ICF concepts and implementation rules. The GEVA has been designed in accordance with the French legal framework and not its whole content may be applied to other social and cultural contexts without adaptation.

The GEVA items not completely covered by the ICF might benefit from the discussions with other ICF experts so as to better evaluate them as potential ICF update proposals.

CONCLUSION

This mapping approach shows that firstly the items of the GEVA 2008 general version are partly covered by the ICF 2017 Browser version categories. In every section of the GEVA, some of the items might be coded with the ICF codes obtained from the following ICF components: B, D, E, and PF. The items of Section 6 remains those mostly covered by the ICF. Throughout the GEVA, many E factors are documented. Although further analysis is needed to better inform the use of qualifiers (performance, capacity, and satisfaction) together with the D, and the E, the identified ICF codes could assist in improving the data collection process. Finally, some items might be discussed to become potential ICF update proposals.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

AUTHOR CONTRIBUTIONS

The author confirms being the sole contributor of this work and has approved it for publication.

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Using ICF to Describe Problems With Functioning in Everyday Life for Children Who Completed Treatment for Brain Tumor: An Analysis Based on Professionals' Documentation

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Background: Children treated for brain tumors often experience persistent problems affecting their activity performance and participation in everyday life, especially in school. Linking these problems to the International Classification of Functioning, Disability and Health (ICF) classification system can be described as affecting body function, activity performance, and/or participation. Services involved in the everyday life of the child have different focus and goals when meeting the child in context, which advantage the use of ICF to overcome this impediment to follow-up and provide comprehensive support for children who have completed treatment for a brain tumor.

Aim: The aim of the study was to use the ICF classification system to describe how professionals in healthcare, habilitation, and school document problems with everyday life functioning at body, activity, and participation levels for children who completed treatment for a brain tumor.

Materials and Methods: A retrospective review of records from healthcare, habilitation, and school concerning nine children completed treatment for brain tumor was implemented. Identified problems in everyday life were linked to ICF codes. Descriptive statistics of ICF-linked code frequency supplemented by network visualization diagrams viewing the co-occurrence between codes within the body, activity participation, and environmental components were performed.

Results: Most documented problems were found in healthcare records, whereas the documentation in habilitation and school was sparse. The frequently occurring codes, independent of record source, were linked to the body function component, and ICF-linked problems in habilitation and school were salient in the activity and participation component. To gain a holistic picture of relations between ICF codes and problems, network visualization diagrams were used to illustrate clusters of problems.

Conclusion: Code prevalence likely reflects where healthcare professionals and educators focus their attention when meeting the needs of children treated for a brain tumor in context. To maximize the comprehensive view of functioning and participation of children in everyday life, the full range of difficulties regarding body impairments, activity limitations, and participation restrictions must be identified and linked to each other in patterns of co-occurrence, which the ICF facilitate. However, ICF provides no guidance on how to identify networks of problems within the body, activity, and participation. Identifying such networks is important for building comprehensive interventions for children.

Keywords: child, brain tumor, ICF, documentation, problem, everyday life

INTRODUCTION

Many children treated for brain tumors experience late effects that influence their ability to participate in everyday life (1). Diminished ability to take part in everyday life affects the health of the child, as human health is related to the ability to perform vital activities and participate in everyday life in supportive environments (2). In Sweden, brain tumor accounts for about one-third of childhood malignancies per annum, and many children with such diagnosis are expected to be long-term survivors (3). Despite being "cured" of their malignancy (4, 5), these children exhibit life-long problems in everyday life functioning. These problems can be related to cancer or its treatment and affect the psychosocial and cognitive abilities of a child (6–9). Compared to healthy peers and other cancer groups, children treated for brain tumors report poorer health-related quality of life (10, 11). Common symptoms include fatigue, which is often described as a distressing state (12), sleep disturbance, and headache (13). These children also experience scholastic difficulties with reading, writing, and doing math (14), impaired abilities to concentrate (15) and control their behavior (16, 17), and inattentiveness to social cues, which can lead to social exclusion by peers (18). School absence is more common among this group of children (19), and studies report that they have a poorer academic achievement compared to healthy peers (20–22).

For children returning to school after brain tumor treatment, informational exchanges between healthcare and school professionals are needed (8, 9). Professionals in healthcare, habilitation, and school (23, 24) are required by law to document the needs and support provided for a child. In healthcare and habilitation services, the planned and provided care, evaluations of the results, and recommended adaptations to improve outcomes are documented in the medical record of the child (23). In school, the developmental and learning needs of a child are documented in the individual education plan of the child. If a child is at risk of not achieving the overall educational goals, a written action plan with interventions and follow-up must be developed, with environmental adaptions included (25). The health and welfare team of the school also documents the difficulties and needs of the child (26). However, the documentation within healthcare almost exclusively focuses on medical aspects of the child's functioning (27), and the school documentation is fragmented. Moreover, linkages between problems described and actions planned are usually not as explicit in school documentation as within healthcare documentation (28). Providing comprehensive support to children treated for a brain tumor requires that users of the records not only read the information provided by their own services, but also link that information to the information provided by other services. Useful services require that the difficulties of the child are described and explained within the context in which the difficulties are being expressed and the support is to be provided (29, 30). A coherent plan for multilevel interventions to support children with brain tumors requires professionals across healthcare, habilitation, and school settings to understand how problems are transformed and linked when moving from body function to participation in school activities and other aspects of everyday life (31). Therefore, the co-occurrence of problems and the relationship between problems are just as important as single problems when providing services. Different services must identify strategies to enhance communication and collaboration to facilitate a comprehensive view of the child. By using the WHO's International Classification of Functioning, Disability and Health (ICF) (32), the understanding of the child's reality can be increased (33, 34) as the ICF goes beyond medical diseases presented in the International Classification of Disease (ICD-10) (35). The ICF uses a universal frame of language to holistically describe the functioning and health of the person with a possibility to use across disciplines and settings (33).

A common use for ICF is to analyze patterns in what information professionals tend to look for when assessing functioning. This is done by linking items from existing assessment instruments to ICF using established linking rules (36), even if the instruments not originally were developed based on the ICF. Further, Klang Ibragimova et al. (37) linked free texts from habilitation plans not originally based on ICF, to ICF codes as in the present study. In this study, the codes were applied to healthcare, habilitation, and school documents to describe what professionals within different services have focused on when documenting problems that children treated for brain tumors experience in their everyday life. Although the ICF manual (2001, 2021) provides guidance in how to code functioning into components and codes, the manual provides no guidance in how to analyze relations between components and codes within components, i.e., there is no guidance in the ICF manual about how to interpret and manage the bi-directional arrows in the ICF model that links the different components. To analyze co-occurrence and relations, a graphical model with a visualization network will be used in this study to view the connection between ICF as a roadmap to understand the associations between different aspects of human functioning, not provided by the current ICF classification system. Graphical models have been a useful tool in earlier studies with ICF to visually view the dependence structure of health aspects among individuals with a chronic health condition (38, 39).

Aim

The study's aim was to use the ICF classification system to describe how professionals in healthcare, habilitation, and school document problems with everyday life functioning at body, activity, and participation levels for children who completed brain tumor treatment.

Research Questions

How are the ICF codes identified in documents distributed within and across the services of healthcare, habilitation, and school?

How are the identified ICF codes distributed within the different ICF components: body function, body structure, activity/participation, and environmental factors?

How do the identified ICF codes co-occur and relate to each other within and between the components body, activity, participation, and environment?

MATERIALS AND METHODS

Design

This study used a retrospective multi-method design.

Approach

Overall, the study used a deductive content analysis approach (40) directed by the ICF. The ICF categorizes health information into four interacting components: body function (b), body structure (s), activity and participation (d), and environmental factors (e). The component body function (b) and body structure (s) comprise physiological and psychological functions of systems and anatomical construction of the body. The component activity and participation (d) comprise aspects of functioning from individual and societal perspectives. The activity and participation component includes two constructs: activity and participation. Activity describes the execution of a task or action of an individual, and participation describes the involvement of an individual in a life situation. The environmental factor component (e) addresses the various environments in which the individuals live and conduct their lives and the physical, social, cultural, and political features of those environments.

Each component of the classification can be categorized at four levels, ranging from ICF chapter (a letter accompanied by zero digits, indicating the lowest level of detail) to ICF code numbers with detailed definitions (a letter plus four digits indicating the highest level of detail). An example of this is within the component body function (b, which is the lowest or first level of detail), the first chapter describes *Mental functions* (b1, which is the second level). *Energy and drive functions* describe global mental functions (b130, which is the third level), and further the *Motivation Mental functions* describe the incentive to act; the conscious or unconscious driving force for action (b1301, which is the fourth or highest level of detail).

This study investigated the abilities of an individual to perform tasks or actions independently separately from their participation in life situations. The rationale is that individuals who lack the ability to perform tasks independently can nonetheless participate independently in life situations. The ICF manual (p.20 Swedish version, 2021) suggests four alternatives for ICF users who prefer to separate activity and participation when applying the activity/participation component of the ICF. The alternatives are: (a) define certain domains as activity and others as participation with no overlap, (b) as in alternative (a) and allowing overlap, (c) define all specified codes as activities and use first and second levels as participation, or (d) use both activity and participation codes in all domains. This suggestion is further elaborated in Appendix 3 of the ICF manual (41). Alternative (a) was applied in this study. As suggested in Appendix 3 of the ICF manual (41), the first four domains of the activity/participation component (e.g., learning and applying knowledge, general tasks and demands, communication, and mobility) were defined as activity and instead of "d" like in domain, these chapters were assigned an "a" like in activity. For the subsequent six domains (e.g., personal care, domestic life, interpersonal relationships, important life areas, and societal and civic life), p (participation) was used, rather than d (domain).

Setting

Pediatric oncology departments serving urban and urban–rural areas in central Sweden provided access to medical records for children treated for brain tumors. Yearly these hospitals serve about 50 children (aged 0–18 years.) diagnosed with a primary brain tumor. The pediatric oncology departments provide surgical removal of the tumor to the extent possible, plus adjunct chemotherapy, and radiotherapy. Municipal hospitals deliver some types of chemotherapy, manage acute complications (e.g., neutropenia), and monitor children for persistent and late onset treatment-related complications (e.g., imagines). Child and youth habilitation focus on rehabilitation of the skills of the child. University hospitals link the children with municipal hospitals, habilitation services, and mainstream and/or special schools depending on the needs of children and where they reside. In total, two University hospitals, four municipality hospitals, and five habilitation services were involved in this study.

Participants

Convenience sampling was used to recruit children of either sex and diverse ages with various types of brain tumors and other clinical characteristics. Children who received care at either of the two participating pediatric oncology departments were eligible if (a) they had been diagnosed with a brain tumor between the ages of 5 and 15 years and (b) completed a neuropsychological assessment about 1-year after ending treatment for their brain tumor.

Procedure

Verbal and written information about the study was provided to eligible families by the consultant nurse for pediatric brain tumors at participating University hospitals. The nurse also asked for permission to share contact information for families interested in learning more about the study with the first author (A-CB), who telephoned the families and provided additional information about the study and answered their questions. After taking time to reflect on the requirements of the study, parents and children (age 15 years and older) signed the consent forms and mailed the documents and information about the schools of the child to the first author.

The heads of the involved hospitals and habilitation services facilitated the access of the author to the electronic healthcare records of the child, where documentation about the child by various healthcare professionals (e.g., nurses, physicians, and psychologists) was found. One hospital provided printed copies of the health records of the child. Participating children were linked to 19 schools during their education. Principals at these schools provided printed copies of documentation about the child by school professionals (e.g., teachers, special education teacher, and school-nurse).

Data Extraction

The first author extracted data from the records of children between May 2018 and March 2019; each extraction was dated. The extracted data included the date of the documentation document source (service), the profession of the documenter, and the text that described problems regarding the function of children in everyday life. Data were extracted from the first neuropsychology assessment performed by the children around a year after the treatment completion. A problem was defined as a perceived difference between the present and desired state of functioning of the child (42) at the time of documentation. Time periods covered by the documents of interest ranged from 2.7 to 10.4 years (mean 5.1 years). In total, the extracted data comprised 847 pages and 182,014 words.

Data Coding

The extracted text (units for analysis) was linked to ICF codes. The coding process was guided by a modified version of ICF-linking rules described in eight steps (36). The *first rule* highlights the need to require good knowledge of ICF fundaments. The first author was initially a novice user of the ICF classification system but became familiar with coding during the analysis through close mentorship and regular monitoring by two of the authors (MG and MB), who have extensive knowledge of the ICF and experience linking data to its codes. The *second rule* is that meaningful segments of text should be linked to the most precise, that is, the highest level of detail possible for relevant ICF codes. In this study, all documents were read through several times to become familiar with the content. If several problems appeared in an extracted text segment, that segment was divided into several meaning units with one problem per unit. The first author labeled each unit with word(s) relating to the problem and then linked the word(s) to the highest level of detail possible for the relevant ICF code. Problems related to body function/structure were linked to b1–b8 and s1–s8 codes. Problems related to activity in the activity/participation component were linked to Chapters a1–a4. Problems related to participation were linked to p5–p9. Lastly, the text related to environmental factors was linked to e1–e5. **Table 1** shows an example of the coding process.

The *third rule* state that if a meaningful concept is not explicitly named in the ICF manual but can be related to the ICF code "other specified," this should be avoided when possible. The *fourth rule* describes that when a lower level ICF code could not be found you should avoid using "unspecified categories" and instead use a higher level of ICF code. This was used when an explicit ICF code for the problem could not be found, but the chapter level was clear. The *fifth rule* states that when a meaningful concept cannot be linked to a specific ICF code of category, it was assigned as "not definable." *Rules six* (assigning meaningful concepts to personal factors), *seven* (assigning meaningful concepts that cannot be found in ICF to not covered), and *eight* (assigning meaningful concepts referring to a diagnosis to a health condition) were not used, as personal factors or diagnosis were not the focus of the present study.

Problems related to the text segments with equivocal links or an ambiguous link to an ICF chapter or code were marked and discussed by the first author and the last (MB) author until they agreed on the most suitable ICF chapter and code. A second

TABLE 1 | Examples of the coding process.

Meaning unit	Identified meaning of the problem	ICF chapter	ICF codes
Otherwise have diffuse abdominal pain during the last week	Pain	b2 Sensory functions and pain	b280 sensation of pain
Difficult to undertake activities	Undertake activities	a2 General tasks and demands	a230 carrying out daily routine
Phone call with the mother: Child expressed school not being fun and having no friends	No friends	p7 Interpersonal interactions and relationships	p750 informal social relationships
Special support needed during lessons, does not work among all the teachers in school	Educational support	e3 Support and relationships	e330 People in position of authority

rater (MG), familiar with ICF and coding data to ICF, reviewed about 10% of the coding among a randomly selected data from all the participants. When discrepancies were identified, the data segments were discussed and agreements regarding the most relevant codes were made among the authors (A-CB, MG, and MB).

Statistical Analysis

Frequencies of ICF codes were calculated based on occurrences of text segments with specific codes in the document. To generate information about relations between co-occurring codes for the body, activity/participation, and environmental components, network visualization diagrams of the frequency with which codes co-occurred together were created. First, all ICF codes were retrieved from the research records of participants. RIS files were created for each participant and time-period (year) since the first neuropsychological assessment after ending brain tumor treatment. Then, these data and VOS viewer software (43) were used to create a code co-occurrence network visualization, wherein each node represents an ICF code. The size of a node indicates the number of occurrences of the code; larger nodes indicate greater frequencies. Nodes located closer to each other have a stronger relatedness in terms of co-occurrence than those further apart and are visualized as more central in the diagram. The links indicate co-occurrence of two or more codes and the thickness of the link denotes link strength, in this case, the number of co-occurrences between codes. Sets of closely related nodes form networks, which are indicated by different colors. Unique abbreviated ICF code labels were added to the visualization (see **Figure 2** for the list of abbreviations and complete code labels). The network visualization diagram was visually inspected (based on content) to identify and name frequently occurring patterns of codes based on the ICF components body function and structure, activity, participation, and environment.

RESULTS

Parents of 12 children were approached about the study. Of these, 11 returned signed informed consent forms. Two children whose parents consented were not enrolled—one was diagnosed prior to age of 5 years and the other had yet to have a post-treatment completion neuropsychological assessment. Thus, the study sample consisted of nine children, including four females and five males with a mean age of 6.8 years (range 5–11 years). Five children lived in rural areas and four in urban areas. Children were diagnosed with medulloblastoma (5), astrocytoma (3), or craniopharyngioma (1). Six of them had received surgery + chemotherapy + radiotherapy, two surgery + chemotherapy, and one surgery + radiotherapy. Their grades in school at the time of diagnosis and data collection are presented in **Table 2**. Given the small sample size and risk to privacy, the details are sparse.

TABLE 2 | Grade in school at diagnose and data collection.

Grade	Number of children
Grade in school at diagnose	
Pre-school	6
3rd grade	1
5th grade	2
Grade in school at data collection	
4th grade	2
5th grade	1
7th grade	1
8th grade	1
9th grade	2
1st yr. in high school	2

The overall result of reviewing records from nine included children, 4,543 problems linked to ICF codes representing both unique (mentioned once) and more common (mentioned repeatedly) problems were identified. The ICF codes were distributed among all, but one ICF Chapter: *s5 Structures related to the digestive, metabolic, and endocrine systems*. Within Chapters, 82 ICF codes were related to body function, 23 codes were related to body structure, 45 were related to the activity part, 22 codes were related to the participation part, and 26 codes were related to environmental factors. Some codes (154/4543) were only linked to chapter level as no code on the second level could be identified, and 69 codes were identified as not definable when being too diffuse to relate to any ICF code or to the study aim.

Distribution of Identified ICF Codes Within and Across Services

Within each service type (healthcare, habilitation, and school) and overall, the largest proportion of ICF codes were linked to body function. Codes linked to body structure represented the smallest proportion of codes per service and overall. The proportion of codes linked to activity was the lowest, and the proportion linked to participation was the most prominent within school documentation. Habilitation accounted for the greatest proportion of codes linked to environmental factors, see **Figure 1**.

Distribution of ICF Codes Within the Body Function, Body Structures, Activity/Participation, and Environmental Factors Components

The greatest proportion of problems linked to ICF codes was within the body function component (64%). Codes within the body structure component were sparse (4%). The proportion

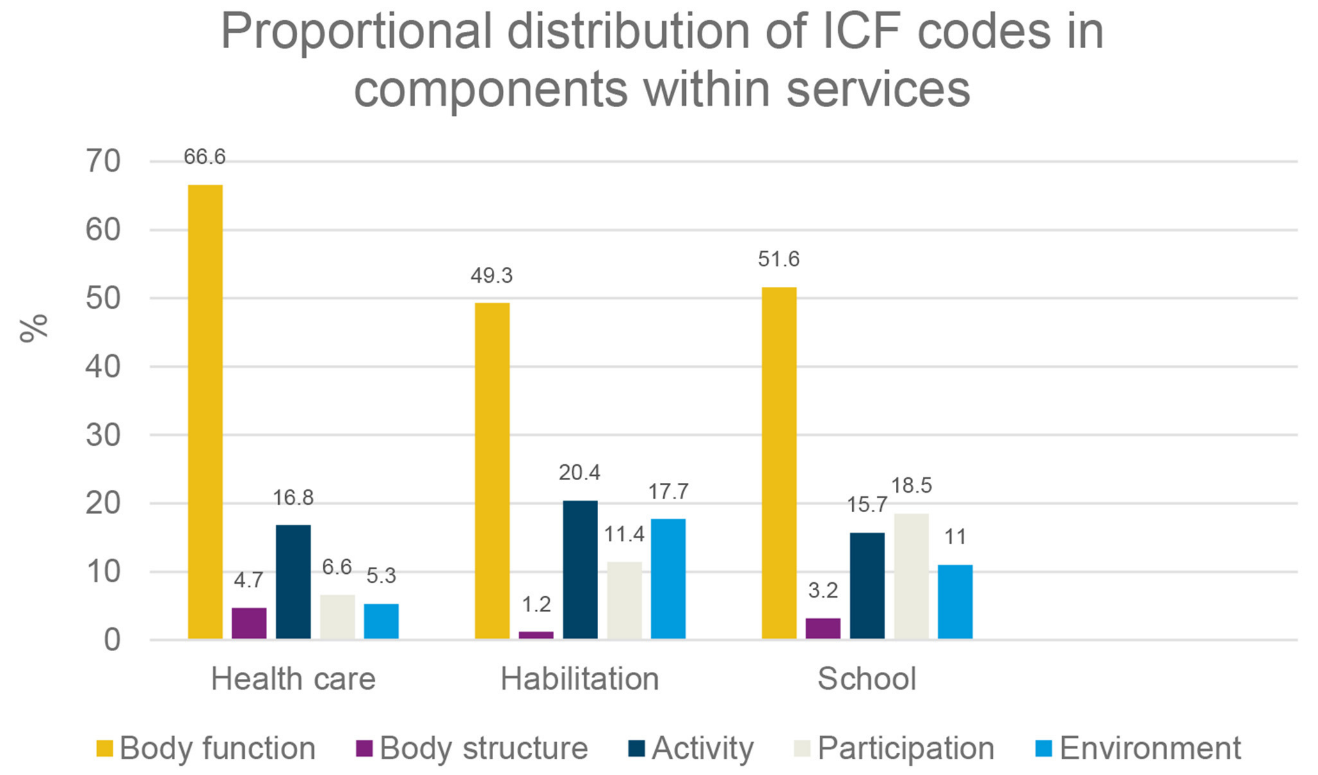

FIGURE 1 | Distribution of codes in the ICF components within services.

of codes within the activity component was modest (17%), as were codes within the participation part (8%) and in the environmental factors component (7%).

ICF Codes Within the Body Function and Body Structure Component

The highest proportions of problems linked to ICF codes within the body function component ($n = 2,882$) were found in Chapter b1 Mental functions (48%) followed by the Chapters of b7 Neuromusculoskeletal and movement-related functions (22%) and b2 Sensory functions and pain (13%). A considerable proportion of ICF codes were in Chapter b5 Functions of the digestive, metabolic, and endocrine systems (10%). Few codes were in Chapter b3 Voice and speech functions, b6 Genitourinary and reproductive functions, or b8 Functions of the skin and related structures.

Within Chapter b1 Mental functions, ICF codes *b126 Temperament and personality functions* and *b130 Energy and drive functions* were present in 9/9 cases. In Chapter b2 Sensory functions and pain, *b280 Sensation of pain* accounted for almost 50% of the codes and was found in 8/9 cases. Within Chapter b7 Neuromusculoskeletal and movement-related functions, *b730 Muscle power functions* had about 30% of the codes and was present in 7/9 cases. An example of the most frequently used body function codes within each chapter are presented in **Table 3**.

The body structure component had the lowest number of identified problems linked to ICF codes ($n = 193$). The largest proportion of ICF codes in this component were found in the Chapter s1 Structures of the nervous system (65%), followed by s7 Structures related to movement (17%) and s8 Skin and related structures (9%).

ICF Codes Within the Activity Part of Activity/Participation

The highest proportion of problems linked to codes within the activity component (Chapters a1 to a4; $n = 776$) was found in Chapter a2 General tasks and demands (41%) followed by a1 Learning and applying knowledge (31%). The proportion of ICF codes in Chapter a4 Mobility was moderate (21%) and the lowest proportion of ICF codes in Chapter a3 Communication (7%). Within Chapter a1 Learning and applying knowledge accounted for about 45% of the codes in *a166 Reading* and *a170 Writing*. The codes *a210 Undertaking a single task* and *a230 carrying out daily routine* displayed most of the identified codes within Chapter a2 General tasks and demands and were present in 8/9 cases. In Chapter a4 Mobility, the codes *a440 Fine hand use* (36%) and *a455 Moving around* (24%) accounted for the greatest proportions of codes.

TABLE 3 | Examples of most frequently used ICF codes within the chapters of Body function component.

ICF Chapter and number of codes within	ICF code	Number	Presented in number of cases
b1	*b126 temperament and personality functions*	$n = 103$	9/9
Mental functions	*b130 energy and drive functions*	$n = 380$	9/9
	b140 Attention functions	$n = 137$	7/9
	b144 memory function	$n = 177$	8/9
	b147 psychomotor functions	$n = 63$	6/9
	b152 emotional functions	$n = 63$	7/9
	b164 higher-level cognitive functions	$n = 93$	7/9
b2	*b210 seeing functions*	$n = 90$	9/9
Sensory functions and pain	*b280 sensation of pain*	$n = 188$	8/9
b3	*b310 voice functions*	$n = 23$	2/9
Voice and speech functions			
b4	*b450 additional functions of the respiratory systems*	$n = 29$	4/9
Functions of the cardiovascular, hematological, immunological, and respiratory system	*b455 exercise tolerance functions*	$n = 22$	2/9
b5	*b535 sensation associated with the digestive system*	$n = 58$	8/9
Functions of the digestive, metabolic, and endocrine systems	*b555 endocrine gland function*	$n = 43$	8/9
b6	*b610 urinary excretory functions*	$n = 14$	3/9
Structures related to the genitourinary and reproductive systems	*b620 urination functions*	$n = 16$	2/9
b7	*b730 muscle power functions*	$n = 188$	7/9
Neuromusculoskeletal and	*b735 muscle tone functions*	$n = 79$	5/9
movement-related functions	*b755 involuntary movement reaction functions*	$n = 128$	9/9
	b760 control of voluntary movement functions	$n = 73$	8/9
b8	*b810 protective function of the skin*	$n = 11$	4/9
Skin and related structures			

ICF Codes Within the Participation Part of the Activity/Participation

The highest proportion of problems related to ICF codes within the participation component ($n = 370$) were found in Chapter p7 Interpersonal interactions and relationships (46%), followed by the Chapter p8 Major life areas (35%). ICF codes found in Chapter p5 Self-care accounted for 16% of the codes in participation, and the code *p550 Eating* was present in seven of nine cases. The ICF code *p820 School education* was the most frequently documented code (32%) and seen in eight of nine cases.

ICF Codes Within the Environmental Factors Component

The largest proportion of problems linked to the ICF codes within environmental factors ($n = 322$) was found in Chapter e3 Support and relationships (45%), followed by Chapters e1 Products and technology (17%), e2 Natural environment and human made changes to the environment (14%), e4 Attitudes (14%), and e5 Services, systems, and policies (10%). In Chapter e2 one ICF code related to "other specified" (e298 Natural environment and human-made changes to environment) despite recommendations not to use other specified occurred 15 times. The ICF code *e310 Immediate family* was the most frequently occurring code within environmental factors (21%) and was present in all cases. The ICF code *e330 People in position of authority* was also frequently documented (18%) and was present in seven of nine cases.

The Relation of ICF Codes Within and Between ICF Components

The RIS files created for building network visualization diagrams resulted in 193 unique ICF codes and since proportionally fewer (p) participation codes occurred more than 10 times, a network visualization diagram based on all p-codes and their linkages to b-, a-, and e-codes was created (**Figure 3**). The final network visualization diagram (**Figure 2**) is based on the codes that occurred at least 10 times. The diagram displays two clusters of networks: one of these clusters is comprised of blue nodes and links, and the other by orange nodes and links. The color signifies nodes and links that tend to co-occur, that is the clusters of problems that, as indicated by the thickness of links, likely share an underlying cause. Nodes in the center of the diagram tend to relate to both clusters as both blue and orange links to these nodes. Central nodes tend to be large since the codes occur frequently and have many links to both the blue and orange cluster. Here, the central nodes seem to be the body function codes *b130 energy and drive functions*, *b144 memory functions*, *b180 experience of self and time functions*, *b280 sensations of pain,* and *b755 involuntary movement reaction functions;* the

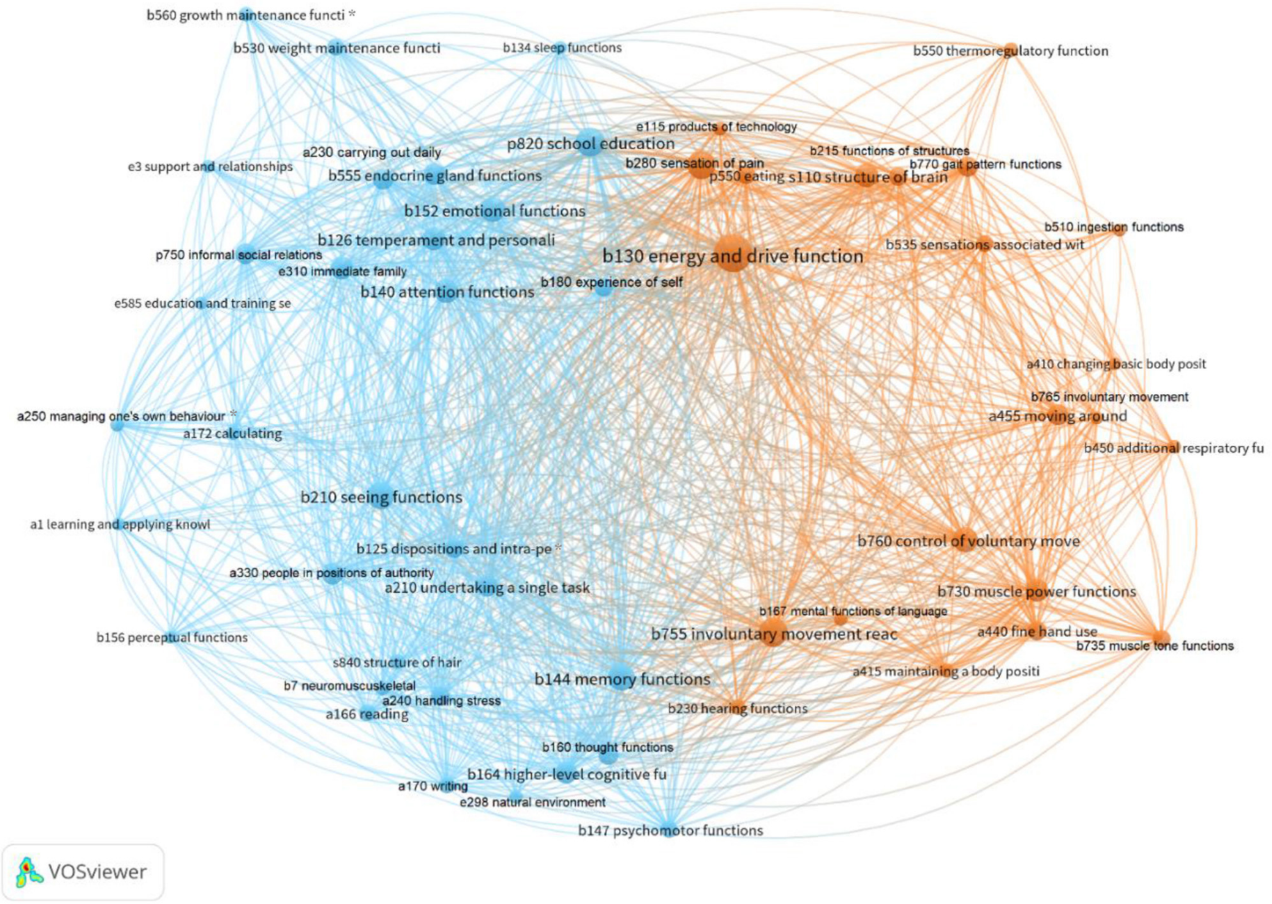

FIGURE 2 | Network visualization diagram within and between the ICF components. ICF- codes with labels (shortened), co-occurrence threshold = least 10 occurrences, No. of codes = 54, No. of clusters = 2. Blue cluster codes; b134 sleep functions, b125 dispositions and intra-personal functions*, b126 temperament and personality functions, b140 attention functions, b144 memory functions, b152 emotional functions, b180 experience of self and time functions, b210 seeing functions, b530 weight maintenance functions, b560 growth maintenance functions*, b730 muscle power functions, b750 motor reflex functions, b760 control of voluntary movement functions, a166 reading, a170 writing, a172 calculating, a210 undertaking a single task, a240 handling stress and other psychological demands, a250 managing one's own behavior*, a330 Speaking, a350 conversation, p750 informal social relationships, p820 school education, e250 sound, e298 natural environment and human-made changes to environment, other specified, e310 immediate family, e330 people in positions of authority, e585 education and training services, systems, and policies. Orange cluster codes; b130 energy and drive functions, b230 hearing functions, b280 sensation of pain, b510 ingestion functions, b535 sensations associated with the digestive system, b550 thermoregulatory functions, b730 muscle power functions, b735 muscle tone functions, b755 involuntary movement reaction functions, b760 control of voluntary movement functions, b770 gait pattern functions, a410 changing basic body position, a415 maintaining a body position, a440 fine hand use, a455 moving around, e115 products and technology for personal use in daily living. *ICF codes included in the old version of ICF-CY.

Participation code *p820 school education*, and the environmental factors code *e330 people in position of authority*. Note that no activity (a) code is central. A common theme of the central nodes seems to be information processing.

The nodes in the blue cluster (see **Figure 2**) can be characterized as related to cognition and managing school tasks. The network shows that problems in body function related to sleep, seeing, weight, and growth maintenance (*b134, b210, b530, b560*) and personality functions (*b125, b126, b152*) tend to co-occur with problems with attention, memory, and experience of self and time (*b140, b144, b180*) and to problems in basic learning and reading, writing, and calculating (*a166, a170, a172*). Problems related to sleep and seeing also link to carrying out tasks in school (*a210*), managing stress (*a240*), and managing behavior (*a250*). In addition, problems in speaking, conversation, social relationships (*p750*) and education (*p820*) is in this network. The orange cluster also includes problems concerning support and relationships (*e3*) within and outside school.

The cluster of orange nodes in the network can be characterized as illustrating the co-occurrence of problems related to using movements in everyday life and regulating sensations such as hunger, temperature, and pain. A central problem is energy level (*b130*). Problems related to using movements in everyday life and regulating sensations tend to co-occur with problems related to pain and hearing (*b230, b280*), problems with movement related functions (*b730, b735,* *b755, b760, b770*), problems with mobility functions (*a410, a415, a440, a455*), and problems with metabolic functions (*b510, b535, b550*). Needing equipment/assistive technology in daily life (*e115*) seems to be linked to the orange network.

Few participation problems were documented in the records; thus, these problems do not appear as nodes in a network visualization based on at least 10 occurrences of a code. Therefore, another network visualization (see **Figure 3**) was created based on the participation (p) codes that occurred at least once. Three networks of co-occurring problems were identified: blue, pink, and yellow. Again, nodes with a central position are more prominent, tend to be linked to all or several of the identified networks, and perhaps greatly influence the participation of children in everyday life. Central participation (p) nodes seem to be participation in basic interpersonal interactions, informal social relationships, eating, and school education. The common theme is social interaction and relationships. See **Figure 3**.

As seen in **Figure 3**, the blue cluster in the network contains four relatively larger nodes (informal social relationships, interpersonal interactions and relationships, school education, and eating); the common theme seems to be informal relationships outside family/home. Three of these nodes (informal social relationships, school education, eating) frequently co-occur and thus have strong links to each other. The pink cluster seen in **Figure 3** contains eight nodes whereof two are larger, basic interpersonal interactions and complex interpersonal interactions; these nodes also have frequent links to the central node interpersonal interactions in the blue cluster. This pink cluster contains nodes for formal relationships, family relationships, engagement in play, and looking after one's health; the common theme seems to be problems with relationships within the family. A common theme of the pink cluster of nodes in **Figure 3** seems to be participation in formal/organized activities. The yellow cluster in the network in **Figure 3** contains five nodes that are less central in the diagram, indicating lower strength of their relatedness to the overall network. School life and related activities and recreation and leisure are relatively large nodes that also are linked to the pink network. The nodes representing caring for body parts and dressing are smaller.

DISCUSSION

Long term effects of brain tumor treatment concern not only body function but also the performance of activities and participation in everyday life activities. Therefore, problems on all these levels must be analyzed as patterns of problems based on relatedness and co-occurrences to obtain a comprehensive view.

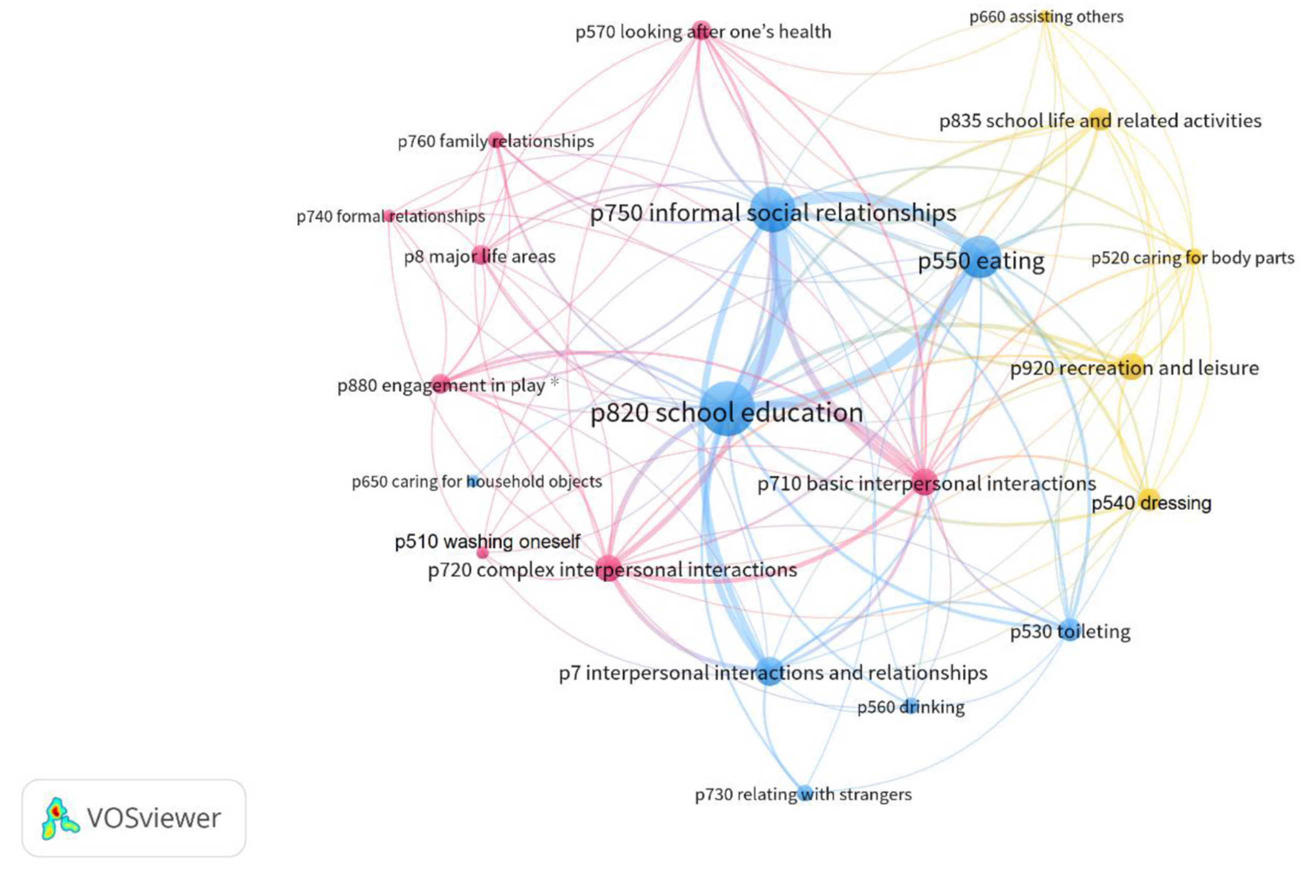

FIGURE 3 | Network visualization diagram between the participation codes. ICF p codes with labels, co-occurrence threshold = least 1 occurrence, No. of codes = 21, No. of clusters = 3. *ICF codes included in the old version of ICF-CY.

This study reveals that, irrespective of service type, professionals involved in services for children who completed brain tumor treatment focus their documentation regarding problems of the child on body function aspects (physical and psychological).

Linkages between body function focused problems and performance of everyday life activities are somehow invisible in the records. This invisibility is because co-occurrences are not explicitly documented, which obstruct the development of a comprehensive bio-psycho-social understanding of the problems that children experience following treatment for a brain tumor. To address the co-occurrence of problems, we linked information in the various service records to ICF codes and used the coding to generate network visualizations. The results confirm the ICF classification system as a useful tool for coding information in records to inform a more comprehensive understanding of children's problems and their need for support following treatment for brain tumor. ICF manual in its current form still do not provide users with guidance on how body, activity, and participation codes co-occur and are related to each other. Although the previous child and youth version of ICF (ICF-CY) now is completely merged into the ICF classification, this study started out by using the ICF-CY for identifying codes for analysis. Noten et al. (44) noted that the ICF in its current form does not cover child-specific codes to the same extent as ICF-CY. The codes identified were therefore in a *post-hoc* analysis compared to ICF (2021). The comparison revealed that four codes identified in ICF-CY (b125 disposition and intrapersonal functions, b560 growth maintenance functions, a250 managing one's own behavior, and p880 engagement in play) were not found in the new merged version of ICF. Three of these codes occurred so frequently (more than 10 times) that they appear in the network diagrams (b125, b560, a250). Therefore, in the analysis, the four ICF-CY codes were kept although not seen in the merged ICF version. This approach illuminated relations and co-occurrences between body function, activity, and participation codes. The visualizations provide some information, but still additional contextualization of what codes stands for within a certain population is needed to obtain a comprehensive view of everyday function.

Findings from this study reveal that most of the documented problems (80%) were found in healthcare records, which may not surprise, as healthcare bears the main responsibility for the medical follow-up of the child after ending brain tumor treatment. On the other hand, habilitation, and school play critical roles in assisting the children to maximize their functioning in everyday life and their quality of life. Long-term follow-up of children treated for brain tumors and other malignant conditions is guided by medical protocols and evidence-based recommendations (45), where the main focus of which are medical outcomes (e.g., endocrine function, cardiac function, linear growth, and weight category). Guidelines regarding comprehensive assessment and, moreover, intervening to support the functioning of the child in everyday life are lacking. Children typically meet a physician and a neuropsychologist at certain timepoints after ending cancer-directed treatment. Depending on the treatment exposures and identified healthcare needs of the child, a multiprofessional assessment is done, and a rehabilitation plan with interventions and goals is generated with regular re-assessments and revision of the plan as indicated (45). Guidelines in congruent long-term follow-up remain a vision and are not yet fully implemented at childhood cancer centers throughout Sweden.

Habilitation contributed 11% of the documented problems. Of note is that two of nine children in the study did not have access to the habilitation service, which partly explains the low proportion of problems documented by habilitation. However, 9% of the documented problems were derived from school records, and all of the children in the study attended school, which is mandatory (26). The limited documentation by school personnel could be due to the use of standardized educational plans where documentation of regular evaluations and adjustments are not mandatory (46). Previous studies have found that school professionals avoid documenting psychosocial issues to protect the personal integrity of children and their guardians (30). Thus, this information tends to be exchanged orally between colleagues (47).

Problems documented in habilitation and school were mostly linked to body function codes, and terms used by healthcare were adopted by professionals providing habilitation and educational services. This tendency is problematic; in that, the support provided in habilitation should be based on the needs of children for support in everyday life functioning, which is not the focus of the healthcare professionals (48). Schools focus on promoting and supporting the educational and social development of the child to reach the educational goals and become independent individuals (24). The multidimensional approach that should be seen in the school context was partly confirmed by the ICF codes linked to activity, participation, and environment, even if they were sparse. Yet, problems linked to body function codes dominated in school documents. To support a comprehensive approach to understanding the needs of children and developing interventions to maximize their overall health and daily functioning, the ICF classification may help professionals across services to broaden their perspectives on the health of the child and collaborate to assure that children are offered the comprehensive array of services they need (49).

Problems linked to codes from the chapter of mental functions (b1) in the body function component were frequently mentioned and problems linked to the ICF code *energy and drive functions (b130)* were noted for each participant. Prior studies have identified "cancer-related fatigue" as a common problem for children who completed brain tumor treatment and the association between fatigue and problems performing daily activities (12, 50, 51). Studies have also concluded that fatigue is associated with problems regarding aspects of cognitive functioning, such as slow processing speed, mental health problems, such as depressive symptoms (52, 53), and problems with social interactions (53). Within the chapter on mental functions, other ICF codes to which problems were linked concerned personality functions. Personality functions have been highlighted earlier in research regarding these children described having a low self-esteem, worse mood, and lower level of stress tolerance (50).

Even though they had completed treatment, most of the children (8/9) had documented problems linked to *pain* (*b280*). This finding is consistent with prior studies, which found that pain from headache is distressing for children post-treatment for brain tumors (50, 54, 55). Problems linked to motor functions (b7) presented in all nine children: poor muscle tone, balance disturbances, and poor coordination of movements occurred frequently. These motor function problems are highlighted in previous studies (56, 57), as causing limitations in everyday life activities for brain tumor-treated children. Motor function problems affect the ability of children to play with friends during school breaks and leisure time activities. The current study identified documented problems with *informal social relationships (p750*), which includes socializing with friends. This is consistent with prior studies, which found that children treated for brain tumors have problems in making and maintaining friendships and lack the capacity to engage in social activities in everyday life (50).

Most of the children (8/9) had problems linked to *school education (p820*), including attending regularly, organizing, and learning subjects within the educational program and reaching curriculum goals, which prior studies also found among cancer-treated children (58, 59). The present study also identified documentation of problems with specific aspects of learning and applying knowledge (a1) and with general tasks and demands (a2). This implies that the children had problems learning to read, write, calculate, and perform tasks, which is also highlighted in previous studies (60) and tend the treated children to perform poorly academically (50) and need special education support to a greater extent than other children (61).

Problems linked to environmental codes were rare. This lack may be explained by the framing of environmental problems as explanations for problems with the functioning of the child. Identified environmental problems tended to relate to the *immediate family (e310*). The family is the primary source of support for children; thus, the unit and each of its members are affected by the diagnosis of the child in various ways across the cancer trajectory (62). Parents may be overprotective, feel sympathy for the child, and experience difficulties with discipline and setting limits and consistent expectations for the behavior of the child (63). Children must receive needed support to maximize their adaptation and thus the ability to function in their environments, including within school. Professionals representing various services must collaborate around the child and their family. They need knowledge and skills about relating assessments of the problems of children to body functions, activity performance, and specific everyday challenges with functioning in the school and/or family environments. Such knowledge and skills in how to link different types of information are necessary in order to utilize the available environmental support with the aim to enhance functioning in everyday life activities (64).

The environmental problems identified by professionals also tended to be documented without a clear description of co-occurrences and relations between problems and primarily relate to body functions. This situation is problematic problems concerning functioning in an everyday context require developing and implementing environmental adaptations targeted toward problems on the body and activity levels. Such environmental adaptations are probably the main focus in participation interventions (65).

A comprehensive view of problems of children and needs for support to maximize functioning can be explicated in networks based on frequency, links based on co-occurrence, and centrality. Identifying such networks might be one solution toward unraveling the content of arrows between ICF components as shown in **Figures 2**, **3**. Here, the network analyses are attempts to illustrate that problems tend to occur in networks, with some types of problems co-occurring more frequently and having stronger links to each other. In addition, some problems are more central in a network (more links to other nodes, that is, codes for problems), and some are more peripheral (fewer links).

Central body level problems seem to be *energy and drive functions (b130)*, *memory functions (b144), experience of self and time (b180)*, *sensations of pain (b280)*, and *involuntary movements (b755)*. Central problems related to participation were *informal social relationships (p750)* outside home, *family relationships (p760)*, *basic interpersonal interactions (p710)*, *and school education (p820).* These identified problems are in line with what prior studies have identified as common problems seen in children treated for brain tumor (19, 63, 66, 67). However, the prior studies did not explicitly relate these common problems to each other. In the current study, these central problems seem to be related to the ICF codes for most of the other documented problems. The central position of these problems (nodes) also indicates that they are important for the two identified networks of problems where the blue network concern cognition (body level) and managing school tasks (activity level), and the other identified orange network seems to be related to moving around in everyday life (activity level) and metabolic function (body level). In clinical practice, professionals need to identify the networks of the problem of the child or an influential (dominant) cluster within the network as targets for interventions to support the child and maximize functioning in everyday life. Based on prior professional experiences and the results of prior studies (68–70), the collaborative problem solving (CPS) model might be one way to support the identification of the network of problems of an individual child and potential targets for interventions that address the multiplex of problems comprising a network or an influential cluster within that network. An initial step in applying the CPS model is to identify several problems and then potential explanations for those problems (71). For example, healthcare professionals might not readily link problems of a child with body function detected in healthcare to problems with performing activities in habilitation or to activity performance or participation in school or family life. Rather what is explicitly documented as a problem within one service can be seen as an explanation to a problem within another service. The differences in how problems and goals may be documented in healthcare, habilitation, and school services are illustrated in **Table 4** in relation to the CPS model, containing the steps problem, explanation, goal, and method (42).

TABLE 4 | Problems identified as targets for intervention by organizations serving the child.

Problem	Explanation	Goal	Method
Pediatric oncology Fatigue (energy level b130) as a treatment-related complication	Brain damage, long lasting side effect that may disappear with time	Not tired	Medication
Habilitation Seldom physical active, difficulties with staying on task (a210)	Acquired brain injury caused by brain tumor and treatment	Perform more physical activities, less tired	Training program, medication, and psychosocial support
School Seldom attend lessons, (p820), difficulty to finish school tasks (a230), do not reach curriculum goals (p820). Difficulty performing mathematical operations (a172)	Tiredness as side effect of treatment School activities not adapted to length and time points of alertness	Finish school tasks, reach curriculum goals	Setup opportunities for activities requiring less motor activity in breaks Adapt schedule, length of tasks and instruction to level of alertness

In conclusion, ICF codes identified from documentation in the records of the child, mainly focused on the problems related to body function aspects. For a comprehensive view of the functioning and participation of the child in everyday life, documentation should focus on problems related to activity limitation and participation restrictions, and their relations to body function and environmental characteristics. However, ICF does not provide guidelines for how to assess how ICF codes within and between its components relate to each other. Therefore, to support the functioning and participation of the child in everyday life, networks of problems related to body function, activity, participation, and environment must be identified. One way of doing this might be to use the CPS model.

Limitations

This study focused on clusters of ICF-linked problems in everyday life, documented in records from healthcare, habilitation, and school for children after ending brain tumor treatment. The frequency of occurrence of ICF codes has been measured without qualifiers (from no to complete problem), that could have provided information on the severity of the problems. Using qualifiers is also recommended but was not possible due to the type of documents analyzed. To use written texts in the records means that some degree of interpretation has been done at the timepoint of professionals' documentation and may not reflect the everyday life context of the child (37). Frequencies of problems were calculated but not their impact on the everyday life of the child beyond the service settings. A weakness is the lack of two coders to establish the extent to which the identification of documented problems and linkages to ICF codes are reliable. That is replicable across reviewers and additional coders for some portion of the records is a means to enhance the reliability of the data extraction and coding process. Strategies to enhance the reliability of these processes and the validity of the results in this study included continuous dialog within the research group (MB and MG) where the senior researcher (MG) has expertise in applying the ICF. The author (A-CB) has expertise in the healthcare of children treated for brain tumor, and collaboration with habilitation and school. Alternatively, their prior research and clinical experiences may have unintentionally biased the results.

The strength of a co-occurrence network visualization is the graphical presentation of information about relatedness of codes (38, 44). Nonetheless, there is still a loss of information about the context in which the codes co-occur. In addition, depending on technical choices and the established cut-off set for the number of nodes in the visualization, the relatedness of nodes is not reflected with perfect accuracy in its two-dimensional presentation. Therefore, the conclusions that can be drawn from the visualization are limited and may not be upheld with different cut-points or larger sample sizes. Consequently, network visualizations are best used to generate hypotheses or provide additional support for expert judgments (72). This study represents feasibility testing of the use of network visualizations to identify clinical patterns that are important for planning comprehensive support to address the full array of problems with functioning in everyday life experienced by children treated for brain tumors.

Clinical Implications

The results from this study provide an opportunity for professionals in healthcare, habilitation, and school to reflect on what domains require attention when meeting the child in context. Most children who survive treatment for a brain tumor will go on to require life-long healthcare monitoring for co-morbid medical conditions attributable to their treatment exposures and to experience problems with functioning in everyday life. Healthcare follow-up concerns evidence-based screening for body problems. Relatively little attention is given to the activity and participation of the child in everyday life. The environments where the child operates also matter and should be assessed. The results of the extraction and analysis of documentation by services supporting children treated for brain tumor highlight that these services differ in their goals for the child, which may not be communicated within and among the services to provide a comprehensive view of problems of the child to address via collaborations. Implications also include that the use of the ICF classification system is feasible in interdisciplinary settings, even though its application is complex and time-consuming for those who lack familiarity. The patterns of relationships between ICF codes presented in the network visualization diagram could enhance understanding the problem complexity in the heterogeneous group of children treated for brain tumors.

DATA AVAILABILITY STATEMENT

The data sets presented in this article include personally identifying information that present risks to confidentiality and cannot be shared without the expressed consent of the children/their parents. Therefore, we do not include an email address where requests for the data sets can be sent.

ETHICS STATEMENT

This study was given formal approval by the Ethical Board in Linköping, Sweden (Dnr 2017/475-31). The participation in the study was voluntary, and parents and children were assured confidentiality. Given the small sample size and risk to privacy, the details about the study sample are sparse. The participants were also informed that they could withdraw from the study at any time without impact on the ordinary care or education of the child.

AUTHOR CONTRIBUTIONS

A-CB, MG, and MB involved in conceptualizing and finalizing the manuscript. SS involved in analyzing and drafting the manuscript and in language review. KE involved in conceptualizing the study and partly involved in the coding process. SC involved in analyzing the data mainly network visualization diagrams and drafting the manuscript. All authors contributed to the article and approved the submitted version.

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REVIEW
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ICF Linking and Cognitive Interviewing Are Complementary Methods for Optimizing Content Validity of Outcome Measures: An Integrated Methods Review

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Content validity is a fundamental requirement of outcome measures. After reviewing operational needs and existing definitions, content validity we as defined as: the extent to which a measure provides a comprehensive and true assessment of the key relevant elements of a specified construct or attribute across a defined range, clearly and equitably for a stated target audience and context. ICF linkage rules from 2002, 2005, and 2019 have provide increasingly clear processes for describing and evaluating content of outcome measures. ICF Core Sets provide international reference standards of the core constructs of importance for different health conditions. Both are important as reference standards during content validation. To summarize their use as reference standards, the following summary indicators were proposed: (1) Measure to ICF linkage, (2) Measure to (Brief or Comprehensive) Core Set Absolute Linkage, (3) Measure to (Brief or Comprehensive) Core Set Unique Linkage, (4) Core Set Representation, and (5) Core Set Unique Disability Representation. Methods to assess how respondents engage with content are needed to complement ICF-linking. Cognitive interviewing is an ideal method since it used to explore how respondents interpret and calibrate response to individual items on an outcome measure. We proposed a framework for classifying these responses: Clarity/Comprehension, Relevance, Inadequate response definition, Reference Point, Perspective modification, and Calibration Across Items. Our analysis of 24 manuscripts that used ICF linking for content validation since updated linking rules were published found that authors typically used linking to validate existing measures, involved multiple raters, used 2005 linking rules, summarized content at a concept level (e.g., impairment, activity, participation) and/or use core sets as a reference standard. Infrequently, ICF linking was used to create item pools/conceptual frameworks for new measures, applied the full scope of the 2019 linking rules, used summary indicators, or integrated ICF-linking with qualitative methods like cognitive interviews. We conclude that ICF linkage is a powerful tool for content validity during development or validation of PROM. Best practices include use of updated ICF linking rules, triangulation of ICF linking with participant assessments of clarity and relevance preferably obtained using cognitive interview methods, and application of defined summary indicators.

Keywords: ICF, linking, content validity, PROM, cognitive interviewing, methods, outcome measures

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INTRODUCTION

The issue of content validity of health outcome measures is the most critical, and most neglected area of clinical measurement science. Content validity is important for all health outcome measures and is especially complex to measure for patient-reported outcome measures (PROM) since how potential respondents interact with items depends on a variety of factors related to the respondent e.g., age, language, culture, lifestyle, life experience, health; and factors related to the PROM e.g., content, clarity, and comprehensiveness. Development of methods for content validation support more rigourous development of new PROM and evaluation of existing PROM. Progress in different aspects of content validity and ICF linking has been evident in recent years. For this reason, an integrated narrative review that focuses on methods for using ICF linking in content validation is one way to bring together emerging work with a view to greater clarity and rigor in content validity research.

The purposes of this paper are:

1. To describe previous content validity definitions and propose a more comprehensive operational definition
2. To discuss how ICF linking can be used to support content validation
    a. To provide simple indicators that can be used to summarize how PROM items codes relate to ICF and relevant ICF Core Sets
3. To describe how cognitive interviewing complements ICF linking
    a. To provide summary indicators for describing sources of potential errors or cognitive dissonance as respondents interpret and respond to PROM instructions or items
4. To describe, through a structured review process, how ICF linking has been used in the development or evaluation of item pools for PROM since the updated 2016 ICF linking rules were published.

CONTENT VALIDITY DEFINITIONS

Content validity has been defined by multiple authors with varying elements. We located published definitions of content validity and listed below some of the key existing definitions. This is not an exhaustive list of all known published definitions but illustrates that there is some shared vision of what constitutes content validity in prior literature, but also that definitions differ in their focus on relevance, range, clarity, and representation of the construct as key elements of content validity. Based on core constructs from different definitions and methodologies used to assess content validity we have constructed an operational definition (**Table 1**).

TABLE 1 | Definition of content validity.

The definition of content validity "*the extent to which a measure provides a comprehensive and true assessment of the key relevant elements of a specified construct or attribute across a defined range, clearly and equitably for a stated target audience and context*"

1. The degree to which elements of an assessment instrument are relevant to, and representative of the targeted construct, for a particular assessment purpose (1)
2. The degree to which an instrument has an appropriate sample of items for the construct being measured (2)
3. Whether or not the items sampled for inclusion on the tool adequately represent the domain of content addressed by the instrument (3)
4. The extent to which an instrument adequately samples the research domain of interest when attempting to measure phenomena (4)
5. The extent to which a scale or questionnaire represents the most relevant and important aspects of a concept in the context of a given measurement application (PROMIS consensus) (5)
6. The degree to which a sample of items, taken together, constitute an adequate operational definition of a construct (6)
7. The degree to which the content of an instrument is an adequate reflection of the construct to be measured (7)
8. The extent to which a subject's responses to the items of a test may be considered to be a representative sample of his responses to a real or hypothetical universe of situations which together constitute the area of concern to the person interpreting the test (8).
9. Whether or not the items sampled for inclusion on the tool adequately represent the domain of content addressed by the instrument (3).

Ideally content validity is well-attended to during development of a PROM since content validity requires careful conceptualization of the construct and potential domains during item generation and preliminary testing (**Figure 1**). Basic science, theory, and quantitative or qualitative empirical studies on the experiences of people living with impairment or disability can inform item generation (9). Developers often use or adapt items from pre-existing PROM. Clinical experts can provide expert knowledge of the health condition mechanisms and impacts and are ideally suited to judge whether a PROM addresses the nature and range of health manifestations of a given health condition, or the attribute being assessed. Social media scraping and observational studies of behavior can also inform the item generation but are less commonly used than methods involving patient/expert interviews or surveys. The International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Board of Directors produced a report on "Patient Reported Outcomes (PRO) Content Validity Good Research Practices" that emphasized the importance of qualitative approaches to item generation (10). It stated that important steps include: having a framework, coding system and training of coders to optimize the rigor of moving from qualitative interviews to PROM items. The PROMIS group (5) emphasized that understanding content validity includes: (1) specifying the concept the scale is intended to represent; (2) scaling the concept's various components and items; and (3) defining the PRO measure's intended purpose, the

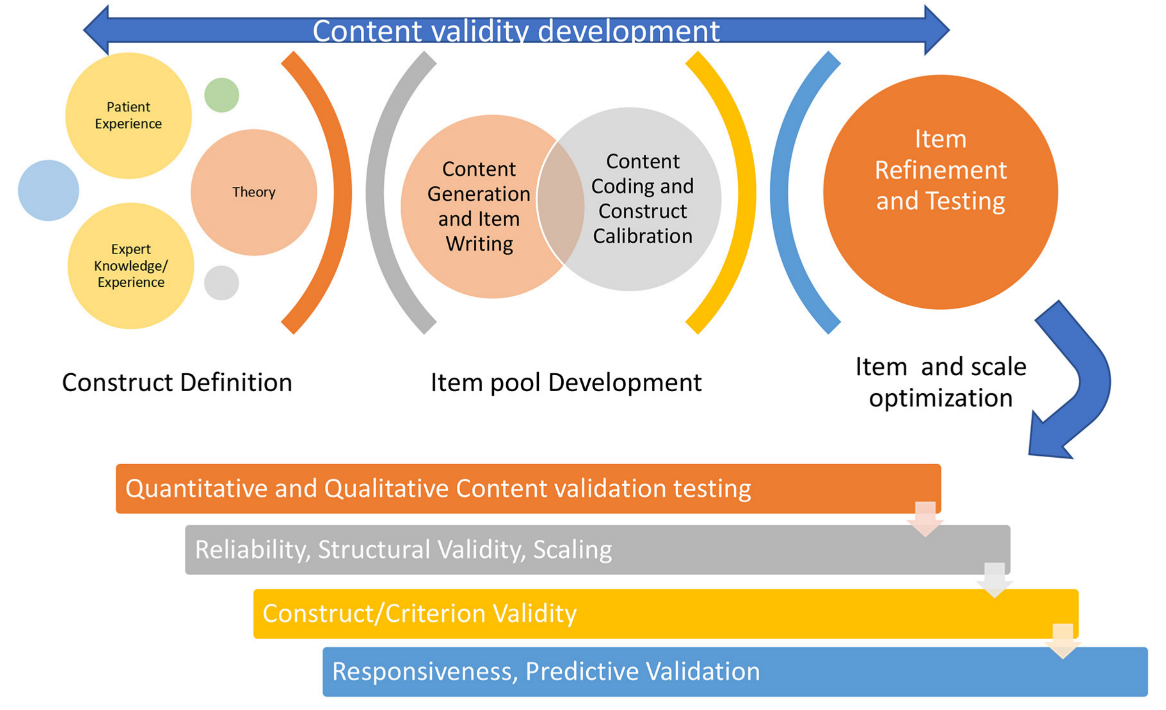

FIGURE 1 | Content validation is a key foundation when developing and evaluating PROM.

opinions of patients about whether the item is relevant to them and the clarity of how the item is framed.

It is a responsibility of the instrument developer to develop/test items that are representative of the target construct/attribute and that are relevant for a wide array of users. Items should cover a sufficient range, be equitable and generalizable. It is important to consider differences due to gender, culture, age, differing levels of health literacy, and factors that might affect how a construct manifests or how an item measures the intended construct. Yet these issues are often underexplored and vaguely reported during content validation. Achieving the best pool of item is a challenging and iterative process. While **Figure 1** suggests a sequence, the ordering of steps, optimal number of iterations varies, and processes can vary at each state. Consultation with the target population, clinical experts and method experts can be used to refine definitions of the construct, target audience and the item pool. In our experience it is important to include both quantitative and qualitative methods during development of items. The patient perspective is the most important one since PROMs represent the patient view and give patients a voice in outcome evaluations. Experts in clinical measurement methods and clinical experts can contribute insights that are unique and complementary to that provided by patients.

The investigation of content validity often occurs, or is extended, after a PROM is made available for public use. This is important since content validity may have been insufficiently reported by the original developers, can vary by target audience or be different across different contexts/cultures. A clear operational definition of content validity and tools to assess content validity can facilitate rigorous evaluation of existing PROMs and can inform what methods are needed to assess aspects of content validity. For example, COSMIN suggested 10 criteria for evaluation of content validity: 5 are allocated to relevance, one to comprehensiveness and 4 to comprehensibility (11).

Content validity of PROM is dependent on the item pool being rich, diverse, and yet specific to the intended construct. Item generation processes can use patient interviews, other PROMs, and expert opinion as sources. In some cases, developers start with a pre-defined construct and define items that fit within that construct. In other cases, the patient and expert opinions are used to define a model or definition of the construct being measured, before proceeding to item generation. Content must be interpreted and classified in a way that leads to specific items and a structure (unidimensional or multiple subscales). Content validity indices use survey methods and percentage indicators to summarize how respondents rate the relevance of items (4, 6, 12, 13). Clinimetric methods consider importance and frequency ratings as indicators of relevancy (14, 15). Some authors use qualitative approaches, to explore relevance and ease of comprehension during development (10, 16–18). It is likely that integration of multiple methods is needed to determine whether items represent the spectrum, context, and features of the intended construct, since different methods have strengths and limitations. Unfortunately, many developers fail to report how qualitative interviews or opinions directly led to generation of items. Common areas that are under-reported are how the construct was defined, how the subcomponents of that construct were defined and how the items were generated to reflect the appropriate dimensions and weighting of elements of that construct. Methodologists have made some steps toward clarifying methods, such as those reported by the COSMIN group (7, 11). ICF linking rules which provide a framework and method for describing and classifying content about functioning, disability and health are an important tool for PROM developers and evaluators (19–25).

Psychometric studies of PROM often focus on quantitative measurement properties like reliability, structural or construct validity and responsiveness. As a result, systematic reviews of PROM often fail to address content validity or find it lacking for existing PROM. However, investigating psychometric properties of PROM that have not been adequately subject to content validity is problematic. Items with poor clarity contribute to random error which limits reliability and makes it more difficult to detect true changes (responsiveness) or real relationships between variables (construct validity). Proof of reliability does not mean that the intended construct intended is being measured, it only means that scores are stable. Analyses like factor analysis or Rasch analysis are likely to demonstrate poor model fit if content validity is inadequate. Therefore, content validity should be considered an essential prerequisite for investigation of psychometric properties.

Failure to establish content validity can have negative consequences on health research since inadequate content validity undermines the validity of the conclusions. We may fail to detect treatment effects if PROM do not capture the elements that the treatment is targeting. Conversely, if a PROM assesses different constructs than intended, this can lead to false conclusions about the mechanisms of action of an intervention. Limited content validity can impede the progress of health research by confounding our understanding of phenomena, allowing inaccurate attribution of causation, failing to identify effective interventions, or accepting interventions based on flawed assumptions.

For all the reasons above greater attention to the methods of content validity is important for health research. The focus of this integrative review is to focus on the use of ICF linking to describe the content of PROMs and how it is complemented by exploring how patients interact with content using cognitive interviewing.

ICF LINKING AND SUMMARY INDICATORS

Icf provides a conceptual framework that considers body structure/function (impairments), activity (limitations) and participation (restrictions) (26). These interacting domains of health can be modified by personal and environmental factors (27). ICF also provides a hierarchical coding system where body structure (s), body function (b), disability (d), and environmental (e) factors codes can be used to describe the aspects of disability, functioning and health that are affected using a common language. Like any language, ICF can support an unlimited number of applications. Clinical measurement research is just one of the many uses of ICF linking. ICF linking was defined in 2002 (28) and has been refined in 2005 (21) and 2019 (22) in update publications (published online in 2016). See **Table 2** to review the progression of these linking rules.

The linking rules updates build on each other, while maintaining a consistent approach. Consistent across each version are rules stating that people should have content knowledge to classify content and that content should be linked as specifically and precisely as possible within the ICF hierarchical classification system. In some items, this result in codes that are broad, even at the chapter level, if the item being evaluated is posed at a very broad level. In other cases, a very specific code may be assigned, at a 3rd or 4th level, if an item has a narrower focus. Greater specificity is indicated by codes with more numbers that reflect deeper level codes and more specific code definitions. In the 2005 update the rules around how to deal with content that is difficult to code including unspecified, undefined, and global terms like quality-of-life were clarified. In 2019 there were additions to the rules to focus on the perspective taken (Appraisal, Needs, or dependency), which is an important aspect of a PROM since it focuses on the cognitive evaluation requested within an item. A substantial clarification in the 2019 update was how to deal with response options (coded as Intensity, Frequency, Duration, Confirmation or agreement, Qualitative attributes). This was an important addition since older ICF linking studies usually ignored response options. Response options are central to how patients are asked to calibrate their responses. Therefore, the 2019 linking rules have important additions that can provide more detailed description of PROM content validity.

The volume of ICF codes can be unwieldy, which may act as a barrier to usage in many applications of ICF. To address this barrier, ICF Core Sets have been developed through a rigourous process of international consensus informed by research evidence and patient/expert experiences and priorities (29, 30). The process by which the Core Sets were developed includes literature review, patient surveys and expert surveys, culminating in an international consensus conference that achieves agreement on the most salient content for health conditions based on the discussion and voting of a multidisciplinary international group who can envision many different applications and who represent many unique perspectives. Core sets have now been established for many conditions in 7 different domains covering different health conditions and contexts (https://www.icf-research-branch.org/icf-core-sets). Given that a comparison gold standard is elusive when evaluating PROMS, ICF Core Sets provide an important reference standard for the most salient content for PROM addressing functioning, disability, and health. ICF linking can be particularly useful for disease-specific PROM where there are relevant Core Sets since they act as an international reference standard for that health condition. Core sets and ICF linking are less suited for categorizing abstract concepts like emotions/attitudes, life experience, PROM that explore a single construct (e.g., pain or sleep) or concepts not covered by ICF.

A challenge that we experienced in interpreting ICF linking was how to summarize the large volume of information from our raw mapping code lists that often contain many items and codes.

TABLE 2 | Evolution of ICF linking rules developed by Cieza et al. (23).

2002 linking rules (23)

1. Before one links health-status measures to the ICF categories, one should have acquired good knowledge of the conceptual and taxonomical fundament s of the ICF, as well as of the chapters, domains, and categories of the detailed classification, including definitions
2. Each item of a health-status measure should be linked to the most precise ICF category
3. If a single item encompasses different constructs, the information in each construct should be linked
4. All constructs of the item to be linked have to be highlighted (e.g., bold)
5. The response options of an item are linked if they refer to additional constructs
6. If the content of an item is not explicitly named in the corresponding ICF category, then the "other specified" option at the third and fourth coding level of the ICF classification is linked. The additional information not covered by the ICF classification is documented. Two special cases are to be distinguished within this rule:
   a) When the 'other specified' option in the two-level classification is not available, then the 'other specified and unspecified' option is linked. The additional information not covered by the ICF will be documented
   b) When the content of an item is not explicitly named in the corresponding ICF category, but at the same time is included in the ICF-category, then the item is linked to this ICF category, and the additional information not explicitly named by the ICF is documented
7. If the content of an item is more general than the corresponding ICF category, then the code of the higher level is linked
8. If the content of an item is more general than any ICF category but otherwise the item specifies by examples partial aspects of the concept contained in one or more ICF categories, then the "unspecified" option of the ICF classification is linked (Code 99 for the second coding level, Code 9 for third and fourth coding levels). As statement or part of an item will be considered an example when it is introduced with "e.g.," appears between parenthesizes, is introduced with "for example," or with "such as"
9. If the information provided by the item is not sufficient for making a decision about which ICF category the item should be linked to, this item is assigned nd (not definable)
10. If an item is not contained in the ICF classification, then this item is assigned nc (not covered by ICF)

Linking rules updated in 2005 (21)

1. Before one links meaningful concepts to the ICF categories, one should have acquired good knowledge of the conceptual and taxonomical fundaments of the ICF, as well as of the chapters, domains, and categories of the detailed classification, including definitions
2. Each meaningful concept is linked to the most precise ICF category
3. Do not use the so-called "other specified" ICF categories, which are uniquely identified by the final code 8. If the content of a meaningful concept is not explicitly named in the corresponding ICF category, the additional information not explicitly named in the ICF is documented
4. Do not use the so-called "unspecified" ICF categories, which are uniquely identified by the final code 9 but the lower-level category
5. If the information provided by the meaningful concept is not sufficient for making a decision about the most precise ICF category it should be linked to, the meaningful concept is assigned nd (not definable)
   Special cases of this rule:

a. Meaningful concepts referring to health, physical health or mental (emotional) health in general, are assigned nd-gh, nd-ph, or nd-mh (not definable-general health, not definable-physical health, not definable-mental health), respectively. Meaningful concepts referring to quality of life in general are assigned nd-qol (not definable-quality of life)

6. If the meaningful concept is not contained in the ICF, but it is clearly a personal factor as defined in the ICF, the meaningful concept will be assigned pf (personal factor). Personal factors are defined in the ICF as follows: "The particular background of an individual's life and living and comprise features of the individual that are not part of a health condition or health states. These factors may include gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience (past life events and on current events), overall behavior pattern and character style, individual psychological assets and other characteristics, all or any of which may play a role in disability at any level"
7. If the meaningful concept is not contained in the ICF and it is clearly not a personal factor, this meaningful concept is assigned nc (not covered by ICF)
8. If the meaningful concept refers to a diagnosis or a health condition, the meaningful concept will be assigned hc (health condition)
   Note some specific rules for health status instrument clarified rules on linking of response items and examples within items were included in this paper in a separate list.

2019 linking rules published online in and in print (22)

1. Acquire good knowledge of the conceptual and taxonomical fundamentals of the ICF, as well as of the chapters, domains, and categories of the detailed classification, including definitions before starting to link meaningful concepts to the ICF categories
2. Identify the purpose of the information to be linked by answering the question What is this piece of information about? or What is this item about? The answer to these questions will help to identify the main concept(s) most relevant to be linked to the ICF
3. Identify any additional concepts contained in the piece of information in addition to the main concept(s) already identified in the previous step
4. Identify and document the perspective taken on within a certain piece of information when linking it to the ICF (Appraisal, Needs, or dependency)
5. Identify and document the categorization of the response options. Take into consideration the most frequently used approaches as listed in **Table 3** (Intensity, Frequency, Duration, Confirmation or agreement, Qualitative attributes). Note: this rule applies only to instruments, questionnaires, assessments, or tests that contain response options
6. Link all meaningful concepts, the most relevant and additional ones, to the most precise ICF category
7. Use "other specified" or "unspecified" ICF categories as appropriate
   At the end of the chapter, and at the end of each embedded set of third- or fourth level ICF categories, there are categories with the final code number 8 for "other specified" and 9 for "unspecified""8" is to be used when the concept is not contained within any of the other specific categories at the respective level of a chapter. The additional information is documented after the ICF code "9" is used when the concept to be linked fits within a given chapter but there is not sufficient information at hand to assign it to a specific ICF category
8. If the information provided by the meaningful concept is not sufficient for making a decision about the most precise ICF category, assign the concept to nd (not definable)
   Concepts referring to health in general, physical health or mental (emotional) health in general, are assigned nd-gh, nd-ph or nd-mh (not definable-general health, not definable-physical health, not definable-mental health), respectively, as well as to disability in general (nd-dis), functioning (nd-func), or a child's development (nd-dev)

(Continued)

TABLE 2 | Continued

9. If the meaningful concept is not contained in the ICF but is clearly a personal factor as defined in the ICF, assign the meaningful concept to pf (personal factors)
10. If the meaningful concept is not contained in the ICF, assign this meaningful concept to nc (not covered)
    Further specifications: Meaningful concepts referring to a diagnosis or health condition are assigned to nc-hc (not covered-health condition). Meaningful concepts referring to quality of life or life in general are assigned nc-qol (not covered-quality of life)

Therefore, we proposed simple summary statistics (**Table 3**) that can be used to augment other descriptive analyses such as mapping items to chapters, mapping codes to a theoretical framework, or mapping items to ICF conceptual domains. The defined set of indicators are a set of simple summary indicators that quantify the extent to which items can be coded to ICF, linked to the core sets, and represent the core sets. Recognizing that a common shared goal of ICF and some PROMs is to describe disability, a summary indicator that focused on disability content was also proposed (**Table 3**). We have used these indicators and found them to be helpful in describing or comparing PROM (31–33).

COGNITIVE INTERVIEWING EXPLORES HOW RESPONDENTS INTERACT WITH CONTENT

Cognitive interviewing is a semi-structured interview process that explores how individuals understand, mentally process and respond to survey instructions, items and response options; and whether an individual perceives the items/measure as reflecting the intended construct or attribute being assessed (17, 34–36). Whereas, ICF linking is designed to describe and classify content, cognitive interviews are designed to explore how respondents interact with the content. Thus, they are complementary methods. Cognitive interviewing uses a semi-structured qualitative interview with think aloud and probing approaches to explore how potential respondents understand, calibrate, and respond to instructions and items on a PROM. More detailed description of these methods has been described in textbooks (17) and manuscripts (10, 17, 34, 35, 37–40).

Cognitive interviewing is ideally suited to PROM content validation since it explores the four cognitive actions involved in a response to PROM items: respondents must understand the meaning and intent of the question, they must be able to retrieve accurate information about a past or present status (rationale) or gauge their current feelings (emotional), make a judgment as to how their experience or feelings fit with the question posed, and choose an appropriate answer/response option that reflects their cognitive calibration process. Cognitive interviews also explore whether an individual perceives that the overall pool of items reflect the intended construct or attribute being assessed (15).

Cognitive interviews can generate a large amount of descriptive information that complements the large volume of information obtained from ICF linking. Therefore, we developed a guide and classification system for classifying potential sources of confusion or cognitive dissonance as respondents interpret and calibrate their response to items on a PROM. Qualitative think aloud and probing approaches are used to explore how potential respondents, content experts or measurement experts interpret the meaning of instructions, items, and responses options, and then how they calibrate their responses to items (16, 17). Sources of response error or cognitive dissonance are then classified as listed below [see web (41) or **Appendix 1** for full details]. In brief, this method classifies findings from the qualitative interview into summary statistics that describe the extent to which the following issues were identified.

Clarity/Comprehension

Refers to when the terms/words used in an item or response are ambiguous or incorrectly interpreted by respondents.

Example: "*downhearted and blue*" is used for depressive symptoms but is easily misinterpreted.

Relevance

Refers to when an item is not relevant to respondents (e.g., task not possible or important in their circumstances).

Example: "*Washing your hair*" not relevant to bald men.

Inadequate Response Definition

Refers to when response options provided are: 1. not mutually exhaustive or have missing options, or 2. are not matched to the questions posed.

Example: Question asks how important something is, but the response options are about frequency.

Reference Point

Refers to when respondents have difficulty calibrating their responses to an item because their reference points have changed (e.g., response shift) or the item has unclear reference boundaries (e.g., time interval or context). Includes when respondents are unable to recall information needed to calibrate their response.

Example: "*How much have you improved*?"; respondents are unclear and may not recall prior health status (recall bias) … since when?

Perspective Modifiers

Perspective modification occurs when items are interpreted differently by respondents based on a personal factor, life experience or environmental factor.

Example: "*Can you do your recreational activities*?"- can be very different based on activities they do.

Calibration Across Items

Refers to when the response to one item is modified by the patient's response to a previous item.

Example: "*What is your pain at its worst*?" Respondents may score it based on what they scored for other items.

TABLE 3 | ICF linkage summary indicators.

ICF linkage summary indicators

Raters can describe the content of an outcome measure using the instructions/training and established linking rules (21–23) and any further updates established by the ICF branch to select the ICF codes that best represent the content of items/measures. This content coding can then be summarized by the following indicators that compare the item/test codes to the ICF or its relevant subset Core Sets

These indicators summarize codable content. Only codes are counted; "not codable" codes are reported as defined by ICF linking rules but are not included in the summary indicators below. It is useful to describe the number of codes and the distribution, e.g., by chapters or domains (structure, function, activity, participation, personal factors, environmental factors, health conditions) in addition to the summary terms below. These are intended to be descriptive summary that can be used to compare items/measures and their relationship to ICF overall to core sets but should be used in combination with other descriptive strategies to fully describe or compare measures in terms of content validity v

Measure to ICF linkage: This is the percentage of items from a measure that can be linked to ICF codes. This represents the extent to which content of a measure can be expressed in ICF codes

$$= \frac{\text{The number of items linked to at least 1 ICF code}}{\text{Total number of items on the measure}} \times 100\%$$

Measure to (brief or comprehensive) core set absolute linkage: This is the percentage of items from a measure that could be linked to ICF codes that appear on a relevant Brief or Comprehensive Core Set

$$= \frac{\text{Number of linked to a code(s) appearing in the CoreSet}}{\text{Total number of items on the measure}} \times 100\%$$

Measure to (brief or comprehensive) core set unique linkage: This is the percentage of items from a measure that could be linked to unique ICF codes and represents the extent to which the items of a measure represent different content from the core set. Once an item is coded to a core set item, additional items that code to that same code are not counted again

$$= \frac{\text{Number of item that are linked to Unique codes in Core Set}}{\text{Total number of items on the Scale}} \times 100$$

Core set representation: This is the percentage of core set codes that are covered when the measure's items are linked to ICF codes. This represents the extent to which the entire scope of content defined by the core set is represented on the measure

$$= \frac{\text{Number of unique ICF codes from the measure that appear in the CoreSet}}{\text{Total number of codes in the (Brief or Comprehensive) CoreSet}} \times 100\%$$

Core set unique disability representation: This is the percentage of unique core set disability codes that are covered when the measure's items are linked to ICF codes. For Patient-Reported Outcome (PROs) Measures that were designed to measure disability, it can be important to determine the extent to which they measure this aspect of content. This represents the extent to which the disability codes defined by the core set are represented on the measure. Once an item is coded to a core set disability code, additional items that code to that same code are not counted again

$$= \frac{\text{Number of unique (d)codes from the measure that appear in the Core Set}}{\text{Total number of disability codes in the (Brief or Comprehensive) CoreSet}} \times 100\%$$

STRUCTURED REVIEW OF CURRENT APPLICATION OF ICF LINKING IN PROM CONTENT VALIDATION

In the authors experience, ICF linking is a valuable way to code and map PROM content, and ICF core sets are valuable reference standards for evaluating content validity. To understand how ICF linking methods have used recently, we used a structured review to identify papers where ICF linking was reported in content validation (using search terms for ICF linking and content validity). We searched using Google Scholar and PubMed starting in January 2016 and ending in August 2021. We chose this timeframe to coincide with the 2016 online publication of updated linking rules that became available in print in 2019. Our goal was to establish the most current content validity research practices not to provide a comprehensive review of all studies using ICF linking. Our inclusion criteria were peer-reviewed published studies that used ICF linking to develop or evaluate items from a PROM for the purpose of content validation. Exclusion criteria: studies that used ICF linking for other purposes other than examination of content validity of PROM item, 2. when ICF linking was used to code open ended responses from PROM, 3. papers that used ICF linking to validate Core Sets not outcome measures and 4. Theses, abstracts, conference presentations, or non-peer reviewed papers. From these papers we extracted information about whether the authors used ICF linking process to inform development of items for a new measure or validation of an existing measure, which version of linking rules were used, and how data were coded and summarized. We also extracted whether ICF linking was used alone, in combination with cognitive interviewing or in combination with other methods for assessing content validity.

The findings are summarized in **Table 4**. We found that ICF linking has been used in a wide variety of disciplines and health conditions to assist with the development of a new PROM or validate the content validity of an existing PROM. More frequently it has been used to assess the content validity of an existing PROM, that in creation of new PROMs. Most commonly multiple raters perform the linking procedures, and there was a mixture of 2005 and 2019 rules cited. In studied citing 2019 rules, many did not report all aspects of the 2019 linking rules as findings, particularly lacking were reports of perspective and response options. Most often the data was interpreted by focusing on how the codes fell into different conceptual domains (e.g., impairment, activity, participation concepts) or ICF chapters; and summarized in charts that organized the complete set of raw codes. Some authors did use the ICF core sets as reference standards typically stating what percentage of the items appeared on the core set. The complete set of indicators that we proposed which quantify how codes relate to ICF with specific definitions was used in 1 study by our group (33) and picked up by one other research group (61).

TABLE 4 | Recent use of ICF linking in content validation.

References	Tool/construct	Stage	Linking	Synthesis/ analysis	Other methods/notes
Lu et al. (33)	35 PROM identified by SR for total shoulder arthroplasty	EMCE	1 + LC 2005 2 + OM	RCM, CD, PL+, DSI	Definition of constructs e.g., QoL/health status
Roe et al. (42)	13 candidate PROMS for a shoulder core domain set	EMCE	2 + LC, LRR 2019 2 + OM	RCM, RCC, PL	Used perspective and response option rules
Osborne et al. (43)	Behavioral Assessment Screening Tool (BAST), a measure of behavioral disruptions after traumatic brain injury	IDIR	2 + LC LRR 2016 1OM	RCM, CD, RCC, PL	Use of conceptual model of construct
Wikström et al. (44)	Abilitator: work ability PROM	IDIR	2 + LC 2016 1OM	RCD, RCS, PL	7 stage mixed methods with iterative development and consultations described
Elvrum et al. (45)	Bimanual Fine Motor Function (BFMF) hand function	EMCE	2 + LC 2005 2OM	CD, RCC	Qualifiers capacity and performance were considered in the content
Carter et al. (46)	Leeds Foot Impact Scale in people with psoriatic arthritis	EMCE	2 + LC, LRR 20xx 1OM	CD, PLQ	Listed concepts not linkable in ICF
Ballert et al. (24)	41 participation measures that addressed at least three disability chapters of the ICF	EMCE	+LC 2019, 2 + OM, SS	CD, RCC, RO	Reported perspective
de Moraes et al. (47)	The Brachial Assessment Tool (BrAT) and the Impact of Brachial Plexus Injury Questionnaire (IBPIQ)	EMCE	2 + LC, LRR 2016 2 + OM, SS	RCM, RCC, CD	Did not report perspective and response options
Manchaiah et a. (48)	14 hearing loss PROMS	EMCE	2 + LC, LRR 2005, LM 2 + OM, SSS	RCM, PLC, PL	Personal factors coded with a different system; not codable reported
Darzins et al. (49)	Personal Care Participation Assessment and Resource Tool (PC-PART) and FIM (functional independence measure)	EMCE	2 + LC 2005 2 + OM	CD, RCM, RCC	Codes to 2nd level, ICF; FIM codes were extracted from published linking results; narrative comparative synthesis, informed by scenarios and discussion
Lassfolk et al. (50)	Spinal Function Sort and Functional Capacity Evaluation	EMCE	2 + LC, LRR 2016 2 + OM	CD, RCC, RCS, PL	PROM compared to performance tests
Oner et al. (51)	PROM and clinician-based outcome measures for spinal trauma	EMCE	2 + LC 2005 2 + OM, SS	RCM	Measures included if cited in at least 5 articles
Gutierrez et al. (52)	Military Concussion Readiness Inventory for Dizziness and Balance	IDIR	2 + LC 1OM	CD, RCM	Used formal consensus and other processes to inform development
Osborne et al. (43)	Pediatric Evaluation of Disability Inventory-Computer Adaptive Test (PEDI-CAT	EMCE	2 + LC, LRR 2014, LM 1OM	CD, RCC	Reported not linkable constructs; focused on links to chapters
Schiariti et al. (53)	42 PROM aligning with the ICF Core Sets for children and youth with cerebral palsy	EMCE	2005 2 + OM, SS	RCM, RCS	4 stage process to go from 80 + measures to 25
Burgess et al. (54)	8 upper limb activity measures for 5- to 18-year-old children with bilateral cerebral palsy	EMCE	1LC, 2016 2 + OM, SS	CD, RCC	Where publishing linking was found it was used; where no published data done by team, COSMIN used is synthesis; analysis of not codable items
Hammond et al. (55)	British English DASH	EMCE	Unclear linking process	RCS	Cross-cultural validation, Rasch
Janssen et al. (56)	32 PROMS for gout	EMCE	2 + LC 2016 2 + 2 + OM, SS	RCM, CD, RCC (in appended files)	did not link health concepts to the "other specified" or "unspecified" ICF categories; high content validity was assigned when ≥75% of the health concepts of the PROM were included on the ICF core set; used COSMIN criteria for content validity; did review of psychometric properties

(Continued)

TABLE 4 | Continued

References	Tool/construct	Stage	Linking	Synthesis/ analysis	Other methods/notes
Alam et al. (57)	Development of a PROM for abdominal surgery	IDIR	2 + LC 2005 1OM	RCM	Conceptual framework then Qualitative interview content linked to create outcome measure framework for item bank for CAT and standard PROM
Fresk et al. (58)	Test Instrument for Profile of Physical Ability	EMCE	2 + LC 2016 1OM	CD, RCM, RCS, RO	
Nund et al. (59)	27 Swallowing Outcome Measures for Head and Neck Cancer	EMCE	2 + LC, LRR 2005 2 + OM, SS	RCM, CD, RCC	
Lassfolk et al. (50)	26 migraine, tension-type headache, and cluster headache	EMCE	? raters 2 + OM, SS	CD, RCM, RCC, PL	Coded to 2nd level not the most specific
Papelard et al. (60)	Activities and participation in patients with systemic sclerosis	IDIR	1LC 1OM	CD, RCM, RCC	Core set developed then questionnaires items created
Wong et al. (61)	The quality of life in neurological disorders (Neuro-QoL)	EMCE	1OM 2 + MC LRR 2002/2005	CD, RCC, DSI	Used the ICF linking indicators developed by MacDermid; attributed development to student author who used

Stage: IDIR, Instrument Development Item Refinement; EMCE, Established Measure Content Evaluation.
Linking Process: Single linking coder, 1LC; 1 primary linking coder with calibration or checking process, 1 + LC; 2 or more linking coders, 2 + MC; Linking reliability reported, LRR; Year cited for linking rules, 1 PROM assessed, 1OM; 2 + PROM compared, 2 + OM; SS, systematic search used to identify measures.
Analysis: ICF linking Raw Code Map/Table, RCM; Concepts distribution (impairment, activity, participation, personal, and environmental factors), CD; ICF-linking Raw code comparison to Chapters, RCC; ICF-linking Raw code comparison to Core Set, RCS; Percentage of items linked to ICF/Core Set, PL; Defined Summary Indictors of linkage (MacDermid system), DSI.
Other: CI, Cognitive interviewing; CAT, computer adaptive test.

DISCUSSION

This integrated narrative review illustrated the complexity of content validity, provides an operational definition, illustrates how ICF linking has been used to support description/mapping, and how cognitive interviewing complements ICF-linking. This review indicated the need for more consistent use of recent ICF rules, clear definitions of cognitive interview findings and better summary statistics to characterize findings of content validation. We provided definitions/classification to summarize sources of cognitive dissonance/interpretation errors derived from cognitive interviewing and simple statistics to summarize the results of ICF-linking to improve the consistency and interpretability of these methods in future content validity studies.

Ideally, content validity is integrated throughout development of a PROM and capitalizes on the knowledge and life experience of potential respondents, clinicians, and measurement experts. All will provide useful insights into how items and the entire PROM can be improved. In the past there was an overreliance on clinician experts in the PROM development process. The importance and methods for patient engagement improved as clinimetric methods evolved. Usually, the instrument developer/team defines a core construct needed in a PROM, and through patient engagement determines the item pool that represents that core construct, which is refined iteratively. ICF linking and qualitative methods should be considered as essential when developing PROM that address functioning, disability, and health. Our scoping review indicates that in most cases ICF linking has been used to evaluate PROMS already in use. This likely reflects the developing standards in content validity methods which were enhanced after many PROMS were already developed. This explains the need for retrospective content validation. The challenge in retrospective content validation is that "the horse is out of the barn" and changing an existing PROM can result in improvements, but also has downsides from version confusion and compromised data comparability. Less often ICF linking has been used to develop the conceptual framework for a construct that will be measured in a new PROM. This is ideal since it builds a strong foundation for the PROM. The emerging use of ICF linking during development indicates progress in awareness and implementation of formal methods for conducting, and reporting, content validity during PROM development. In our experience not all journals are interested in publishing content validation work done prior to establishing the final version of a PROM since they see this as preliminary work. However, given the importance of content validity it is important that these processes be documented. Further content validation is substantial piece of research and deserves a fulsome peer review and scientific discourse before PROMs are finalized.

Based on this narrative review we defined content validity as "*the extent to which a measure provides a comprehensive and true assessment of the key relevant elements of a specified construct or attribute across a defined range, clearly and equitably for a stated target audience and context.*" The definition is intended to be both conceptual and operational. It contains elements that can be assessed by different methodologies, including ICF linking. Concept mapping (62), qualitative description (63–66), content validity indices (6, 10, 12, 13, 36, 67–70), relevance surveys, focus groups, expert panels as examples of methods that might be used as part of the content validation process. These methods were not explored in this paper. The array of methods that inform content validity indicate that full rigorous evaluation of content validity should be possible with existing methods.

Validity is focused on whether a measure provides a true score. Although there are different types of validity, in the case of content validity "true" means that the items reflect the construct or attribute being measured "*Comprehensive, balanced*" and "*the key relevant elements of a specified construct or attribute*" focus on whether items provide a balanced assessment of the most relevant, important, or salient aspects of the attribute/construct being measured. Balance also refers to the emphasis placed on different aspects of the phenomenon, since the weighting of items should be directly proportional to how much those components contribute to the target construct. This is reflected in how many items are allocated to specific aspect of the construct being measured, and how that is reflected in score. For example, different PROM assess upper pain and disability differently based on how they weight pain and function. The Patient-Rated Wrist Evaluation weights 5 pain items (ICF code b278014) and 10 disability items at 50% and attributes this weighting to consultations with experts and the defined construct of this PROM (71, 72). The subscales are considered separately as subscales to separate these constructs (although often combined in a total score). The Disability, Arm, Shoulder Hand (73) PROM has 2/30 questions relate to pain and 3/30 that relate to other symptoms; these are summed and all items weighted equally in the total score. In these 2 examples the importance placed on pain is different and during content validity it might be considered if this is proportional to how important pain is to potential respondents with upper extremity conditions. ICF linking can be used to describe content of items, but also to summarize how content is weighted by assessing how often a specific code appears in relation to the total number of items. These aspects of content validation will support future structural validity of the PROM. If a subdomain is important, it may require multiple items. For example, since pain is a primary reason for seeking healthcare, it is often important to explore different dimensions of pain (ICF code b2780). These nuances would require multiple items that address different contexts in the stem (e.g., pain while doing an activity), perspectives, or dimensions e.g., frequency vs. intensity. With the updated ICF linking rules some of these nuances could now be reflected as perspective or response differences. There is a tension in "right-sizing" PROM since being comprehensive and minimizing respondent burden are conflicting goals. ICF linking can be used to help identify areas of overlap in content where efficiencies might be achieved is item reduction is needed.

Validity is tool, context, purpose, and population specific. The extent to which PROM items measure "*clearly and equitably for a stated target audience and context*" emphasizes the importance of considering personal factors like literacy, culture, language, gender, and socioeconomics of potential respondents on any PROM when developing or evaluating items. These differences can be explored in a variety of ways. Since ICF is a universal language embedded within a social view of health and functioning, it can be used as a start point to consider how items that are evaluating functioning might differ across contexts. Once an item is linked, the next question can be–would this aspect of functioning be similar for different populations, genders, or age groups? For example, the item "driving a car" is an item on the commonly used Neck Disability Index, but is also commonly left missing (74). People who cannot afford a car, who lived in countries where women are not allowed to drive cars, or who had their driving license taken away due to medical or age-related issues cannot answer this question. The NDI like many PROM was developed in North America where driving a car might be frequently mentioned as a problem for patients with neck pain. If the developers and used ICF in their thinking and item development, they might have taken a broader view. In ICF, d475 Driving falls under mobility (Chapter d4), and is defined as "*Being in control of and moving a vehicle or the animal that draws it, traveling under one's own direction or having at one's disposal any form of transportation appropriate for age, such as a car, bicycle, boat or animal powered vehicle.*" An ICF lens would have considered driving is often accomplished other ways outside of North America, and that the need to be the driver to achieve mobility across distances is far less important in some societies. Therefore, the functional intent of this item and the aggravation to neck conditions might be fulfilled by e d470 Using transportation- "Using *transportation to move around as a passenger, such as being driven in a car, bus, rickshaw, jitney, pram or stroller, wheelchair, animal-powered vehicle, private or public taxi, train, tram, subway, boat or aircraft and using humans for transportation.*" This illustrates how an ICF lens and ICF linking can prevent content validity problems that manifest later as missing items or flaws that show up during cross-cultural validation or psychometric studies. In our example, failure to take a broader functional view made the wording of an item on "driving" unnecessarily discriminatory.

An important addition to the 2019 linking rules that enhances the description of PROM focuses on item perspective and the response options. The added clarifications about how to link the perspective (appraisal, needs, or dependency) and response options (intensity, frequency, duration, confirmation or agreement, qualitative attributes) provides much better description of the nature and range of the assessments achieved by the items on a PROM. This aligns with the aspect of the content validity addressed in the definition by "across a defined range." Clarity on the range where measures are accurate, whether it is a PROM or a biophysical tool, is important to avoid floor or ceiling effects. Floor/ceiling effects, interval level scaling (Rasch analysis) and factor analyses which might fall under structural validity provide more detailed assessment of the range and scoring metrics of a PROM. However, these assessments typically take place after PROMs are developed so it is important that content validity be thoughtfully designed and evaluated to support structural validity. The consequences of inadequate attention to content validity during development of a PROM is non-response, poor performance of the item in structural validation (factor analysis, Rasch) or other psychometric analyses.

Prior to the recent update which described how to assess perspective as part of ICF linking we had developed another process for describing perspective. We started by deciding whether items required rationale decisions e.g., how often do you do something, are you capable of performing, what is your pain intensity; or an emotional response e.g., satisfied with ability, fear of an event or outcome. Rationale decisions depend on calibrating past experiences, whereas emotive decisions reflect a current feeling that occurs in the moment of calibration. The perspectives identified in the refined ICF Linking Rules are the descriptive perspective (e.g., refers to the ability or the extent of a problem or difficulty a person experiences in performing a certain activity or task), appraisal (e.g., refers to the extent to which personal expectations and hopes have been achieved), and the perspective of needs or dependency (e.g., refers to how much assistive devices are needed to perform certain activities or tasks). Descriptive and appraisal definitions have overlap with the rationale and emotional definitions we used with ICF linking to describe health outcomes (75) and reflect some shared thinking about how to describe perspective in these independently developed perspective classifications. ICF linking of perspective is important since this can have a large impact on what construct is being measured. People with the same level of ability can have very different levels of satisfaction with their ability, and people with different levels of ability can achieve the same level of functioning using assistive devices. Understanding these nuances is important in understanding health outcomes, and particularly important in rehabilitation where both remediation and adaptation are important parts of the treatment process. In this study our scoping review confirmed that few authors have considered perspective as an important issue in item validation. The recent updates to the linking rules are important improvements that may facilitate greater attention to perspective and response options in future research.

The development of core sets has been invaluable for content validation and our review of methods in published studies indicated that use of the core sets as reference standards is emerging. The process of achieving international consensus on Core Sets makes them ideal reference standards. We found that authors using ICF-linking in content validation often created maps comparing the items on a PROM to the core set, in a large table. This is an important 1st step for looking at the congruence between items and the core set. Some use percentages to reflect this congruence. However, the ways these percentages were calculated was not consistent, which limits comparability across studies. The summary indicators we proposed which describe how to calculate indices of the linkage between PROM items and Core Sets provide consistent indicators that could be compared across studies or used to compare instruments within a study. For example, when we compared 2 similar elbow pain and disability PROM the summary indicators illustrated the high level of concordance in content between the two PROM (31). Conversely, when we used the indicators to compare different PROM used in total shoulder arthroplasty we found the summary indicators reflected very different profiles across PROM (33). We found that combining different approaches enhances the value of ICF-linking. For example in our shoulder arthroplasty outcomes study we explored how authors conceptualized measures as function or quality of life, which revealed a lack of clarity in conceptual frameworks and definitions (33). Our review of methods used by others indicated that it is common to augment ICF linking with other methods of content description such as conceptual definitions or codes for personal experience factors.

The strengths of ICF linking are the consistency and benefit of using a common language which provides a system to move from items to content codes. ICF linking provides detailed coding for content description. However, there are also gaps in what ICF linking provides in terms of content description, especially since not all PROM focus only on what ICF was designed to cover with respect to functioning, disability, and health. Some concepts are not definable by ICF (personal factors, emotions, abstract constructs, life experiences). For example, concepts like safety, fear of movement, happiness, optimism, negative thinking, prior life trauma and other constructs may not be ideally suited to ICF linking if they are not easily framed as an aspect of functioning. The most recent linking rule update provided clarity on how to code some non-specific or not definable item content assigning health in general, physical health or mental (emotional) health as not definable-general health, not definable-physical health, not definable-mental health (nd-gh, nd-ph, or nd-mh), respectively. Global content on disability in general (nd-dis), functioning (nd-func), or a child's development (nd-devdo) can be coded in a general sense as falling in these domains, even though not specifically definable (coded). While this allows for a code to be assigned, generic codes are not very helpful in content validation, especially when comparing different PROMs since the detail of the construct is lost. However, ICF does provide wide coverage of content and no single classification system could be expected to cover every potential thing that humans would want to measure in health research. The most recent linking rule update enhanced how ICF linking characterizes PROMs while maintaining the structural integrity and focus of the classification system. Although ICF recognizes that personal factors are important, these are not coded/classified. Others have add classification frameworks to address life experience (76) within PROM validation. However, no agreed upon classification for personal factors exists for content validation.

We propose that cognitive interviewing is the ideal complement to ICF linking in terms of providing a more comprehensive assessment of content validity. That is because whereas ICF linking focuses on content, cognitive interviewing focuses on how patients interpret and calibrate responses to that content. Together they provide a powerful assessment of what is being assessed by an outcome measure. Cognitive interviews were usually performed in person prior to the pandemic since it is useful to observe how the participants behave as they complete PROM items or as they "talk aloud" through their thinking. Since the pandemic many adaptations to research have been necessary, and video/web technologies can be used for cognitive interviews or other qualitative methods. As in other qualitative methods, probing in ways that encourage people to reveal their cognitive processes is a skill that is essential to optimize the quality of the information acquired. The processes involved in cognitive interviewing can produce a large volume of information and communicating the detail while also summarizing it to reveal key themes can be challenging. For this reason, we developed the Sources of *Cognitive Dissonance Classification System* comprised of definitions and a classification framework that were shared in this paper. Although ideally ICF linking and cognitive interviewing are used together, we did not find many papers where this occurred. This may be because researchers are not using both techniques together, and because they are reporting these findings separately in different manuscripts. We specifically focused on ICF linking in our search strategy and may have missed isolated cognitive interview studies. Since cognitive interviews and ICF linking are substantive pieces of work they may be published separately by some authors to ensure adequate attention to the rich information acquired. However, the integration of the findings across these two methods may be lost in separate publications. In such cases, authors need to ensure that the integration of these different studies into decisions about the final construction of a PROM or decisions about content validity of existing PROM is documented in manuals or other subsequent publications.

Content validation like many other aspects of instrument validation, often requires that multiple methods and studies be interpreted together when making decisions about PROM development or improvement. For example, we combined perspective classification portrayed in radar plots, ICF-linking table of raw codes, ICF concept description in a radar plot and ICF linkage indicators and their concordance with presenteeism core sets (32) to investigate the content of presenteeism (work disability) PROM. We found that most items mapped to a few ICF related work codes since work disability/presenteeism PROM focus on one specific type of participation. However, we were able to distinguish differences in PROMs by examining their perspectives, structures, and response options. Although this work was a preliminary step, gaps remain in our understanding of the content validity of presenteeism scales since conceptual frameworks that clarify the scope and components of the construct, content validity indices and qualitative studies are still lacking. This emphasizes that content validation is a process, not an event.

Overall, no single method or study is likely to give a full assessment of content validity. ICF linking is an important method in content validation which has many strengths, especially for health conditions where core sets have been developed and the focus of the PROM is on symptoms and functioning. It provides a rich content description language which can be used to describe item content and map PROMs to core sets and conceptual frameworks; and allows comparisons to be quantified within or across PROMs/studies. The major gap which remains after linking is how do patients engage with that content? That is best addressed though qualitative methods, preferably cognitive interviews, which are designed to explore how PROM items are understood and calibrated. While content validity has been under addressed in the literature, a common theme across existing studies is that humans, their contexts, and experiences are highly variable, and this is important to consider when designing or improving existing PROM. Methods for summarizing content validity findings in ICF linking and cognitive interviewing, as proposed in this paper, are helpful for analysis and scientific discourse about PROM content validity.

Although this paper provides insights into current content validation methods it is not a comprehensive of all methods that can be used. For example, quantitative methods like content validity indices (6, 10, 68, 70, 77, 78) (a survey method), concept/content mapping (62), mapping to consensus core sets (79), theoretical models other than ICF, clarification of conceptual models/construct definitions (80), or qualitative methods other than cognitive interviewing (69) were not explored in this paper. Given the array of appropriate methods that could be used in content validation, a prescriptive approach to content validation might lead to narrow thinking. Rather, a thoughtful and rigorous analysis of content validity using multiple methods is needed. Since our focus was ICF linking for content validation, we did not explore the many other uses of ICF linking including other types of work that have secondary impacts on what health constructs should be measured. Some of these related types of research include studies include studies that: code the disability experience (76), describe how the literature addresses disability (81), describe symptoms experienced by people living with different health conditions (63), or report the PROM used in clinical research within an ICF framework (33). Although we reviewed recent content validity papers to assess what methods are being currently used, we did not capture older papers, some of which were landmark papers that led thinking in this field. That is because wanted a snapshot of current content validation methods. We may have missed papers since some authors may have used terms that were not included in our search terms. Despite these limitations, our conclusion based on the retrieved sample of 24 recent studies is clear–there is wide variation in how ICF linking is used and the full spectrum of ICF linking rules and summary indicators are rarely reported by authors. While progress has been achieved on content validity methods, there is a need for full use of the updated linking, rules, better use of summary measures of content validation finings (as proposed in this paper), clear integration of qualitative and quantitative findings and more extensive reporting and public discourse on content validity during development of new PROM or modification of existing PROM.

AUTHOR CONTRIBUTIONS

The author confirms being the sole contributor of this work and has approved it for publication.

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SUPPLEMENTARY MATERIAL

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Linking Free Text Documentation of Functioning and Disability to the ICF With Natural Language Processing

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Background: Invaluable information on patient functioning and the complex interactions that define it is recorded in free text portions of the Electronic Health Record (EHR). Leveraging this information to improve clinical decision-making and conduct research requires natural language processing (NLP) technologies to identify and organize the information recorded in clinical documentation.

Methods: We used natural language processing methods to analyze information about patient functioning recorded in two collections of clinical documents pertaining to claims for federal disability benefits from the U.S. Social Security Administration (SSA). We grounded our analysis in the International Classification of Functioning, Disability, and Health (ICF), and used the Activities and Participation domain of the ICF to classify information about functioning in three key areas: mobility, self-care, and domestic life. After annotating functional status information in our datasets through expert clinical review, we trained machine learning-based NLP models to automatically assign ICF categories to mentions of functional activity.

Results: We found that rich and diverse information on patient functioning was documented in the free text records. Annotation of 289 documents for Mobility information yielded 2,455 mentions of Mobility activities and 3,176 specific actions corresponding to 13 ICF-based categories. Annotation of 329 documents for Self-Care and Domestic Life information yielded 3,990 activity mentions and 4,665 specific actions corresponding to 16 ICF-based categories. NLP systems for automated ICF coding achieved over 80% macro-averaged F-measure on both datasets, indicating strong performance across all ICF categories used.

Conclusions: Natural language processing can help to navigate the tradeoff between flexible and expressive clinical documentation of functioning and standardizable data for comparability and learning. The ICF has practical limitations for classifying functional status information in clinical documentation but presents a valuable framework for organizing the information recorded in health records about patient functioning. This study advances the development of robust, ICF-based NLP technologies to analyze information on patient functioning and has significant implications for NLP-powered analysis of functional status information in disability benefits management, clinical care, and research.

Keywords: natural language processing, clinical coding, disability evaluation, international classification of functioning disability and health, electronic health records, artificial intelligence, functional status, ICF

INTRODUCTION

A person's functioning requires a multifaceted picture of the complex interactions between the person and the world around them. The International Classification of Functioning, Disability and Health (ICF) (1) conceptualizes these interactions as between health condition(s), body structures and functions, activities and participation, and both environmental and personal contextual factors of a person. In order to fully capture the multifactorial nature of functional outcomes and a person's experience of their functioning, providers primarily turn to free text documentation in the Electronic Health Record (EHR) (2–4). While the flexibility of free text presents a barrier to standardization in the EHR, limiting comparability across patients and opportunities for data-driven learning in modern health systems (5), the expressivity of natural language is the key to capturing the nuances of functioning as it is experienced in the life of the patient (6). For example, two patients reporting moderate limitations in walking may experience them in entirely different ways: One may describe arthritic stiffness in their knees that causes manageable discomfort in navigating employment in an office, while chronic low back pain of another patient makes their hiking hobby no longer viable. These differences in experience, which inform both therapeutic interventions and the perception of the patient of their own functioning, are difficult to capture in standardized instruments but can be easily described in natural language.

How to navigate the tradeoff between flexibility in clinical documentation and standardization for comparability and learning? We explored the use of natural language processing (NLP) systems, grounded in the ICF, to index and organize information about functioning and disability in free text clinical records, enabling a measure of standardization without sacrificing the details of the patient experience. NLP can be used to identify, organize, and retrieve information from free text documents for use in clinical decision-making and research (7, 8). NLP shows growing promise for capturing and analyzing information on functioning: Kukafka et al. (9) developed an early system for coding rehabilitation discharge summaries to identify activities including eating, dressing, and toileting, and NLP has since been used for a variety of purposes, including locating functional status documentation in oncology notes (10), identifying potential wheelchair use (11), and detecting functional outcomes of geriatric syndrome (12). We have previously developed NLP methods to identify activity mentions describing mobility functioning in clinical notes (13–15) and to link these activity mentions to the Mobility chapter of the Activities and Participation domain of the ICF (16).

This study investigated NLP methods for automatically coding documentation of key domains of functioning to the ICF and evaluated their performance on coding medical records associated with claims for federal disability benefits submitted to the U.S. Social Security Administration (SSA). We adapted our previous work on Mobility information to expand to information from the Self-Care and Domestic Life chapters of the Activities and Participation domain of the ICF. Together with Mobility, these domains align with the majority of Activities of Daily Living (ADLs)—fundamental activities frequently considered in therapeutic patient assessment, such as dressing, hygiene, eating, and ambulation—(17, 18), and account for 11 of the 18 items in the Functional Independence Measure (FIM)—a tool for assessing the degree of independence of a patient, commonly used in assessing rehabilitation outcomes (19). Thus, NLP methods to automatically identify activities in these three ICF chapters have significant potential for use in clinical information systems.

The remainder of this article is organized as follows: In the Materials and Methods section, we describe the medical records we analyzed from SSA disability benefits claims and present the NLP methods used for linking information about patient function in these records to relevant categories in the ICF. The Results section presents our experimental findings and analysis of successes and challenges in coding clinical data with the ICF. The Discussion section outlines implications from our work, including challenges for applying the ICF in coding clinical notes, opportunities for NLP impact in the SSA disability adjudication process and in broader clinical information systems, and limitations of the study.

MATERIALS AND METHODS

Our study involved the development and evaluation of machine learning-based statistical models for linking descriptions of Mobility, Self-Care, and Domestic Life functioning in free text clinical documentation to relevant categories in the ICF. While we considered an automated assignment of the qualifier component of ICF codes out of scope for this study and used two-level classification categories for the output of our NLP systems, we referred to this process as *ICF coding* to align it with prior literature on automated medical coding systems. We used the term *functional status information* (FSI) to refer to information

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Abbreviations: HER, electronic health record; FSI: functional status information; IAA, inter-annotator agreement; ICF, International Classification of Functioning, Disability, and Health; NLP, natural language processing; SSA, U.S. Social Security Administration.

about patient functioning, including specific observations in activity mentions.

Data Sources and Use of the ICF

Our primary data source for this study was free text medical records collected by SSA in the process of adjudicating federal disability benefits claims. During the adjudication process of a claim of an individual, SSA may obtain records from prior medical encounters of that individual in order to collect medical evidence related to the disability claim. These records are reviewed by expert adjudicators at SSA to identify appropriate evidence to support the claim decision, such as impairment history and severity, relationship to work requirements, etc. The volume of these records is substantial, with each claim having potentially hundreds or thousands of pages of associated medical records, presenting a significant opportunity for NLP methods to assist in evidence review by automatically identifying relevant information.

We used two types of medical documents in the study. (1) Consultative Examination (CE) reports are written by a medical expert commissioned by SSA to examine a claimant in-depth as part of the claim adjudication process. (2) EHR data are provided directly to SSA by health providers pursuant to a disability benefits claim. Both types of documents are frequently submitted to SSA as faxed or scanned documents and thus require Optical Character Recognition (OCR) to convert them to text for NLP analysis. All documents used in this study were converted to text using the Nuance OmniPage^{TM} (now Kofax OmniPage Ultimate^{TM}) OCR software.

We selected the ICF, and the Activities and Participation domain in particular, as our framework for identifying functioning information in these documents. We chose the ICF due to its role as an internationally recognized coding system for functioning, and our familiarity with it (6, 15, 16). SSA assesses function as part of the claim adjudication process, including assessment of residual functional capacity for individuals applying for disability benefits, examining both physical and mental function. We identified the Mobility, Self-Care, and Domestic Life chapters of the ICF as being most relevant to this process and the types of functioning documented most frequently in the data we reviewed. As noted in the Introduction, these chapters are also closely aligned with commonly used ADL measures and the FIM, making them particularly relevant types of information to study for a broad range of information needs in rehabilitation. We used the title case in this article to refer to Mobility, Self-Care, and Domestic Life information, as defined by the ICF, to distinguish from the more general uses of these terms.

Document Collections for Annotation

We identified two sets of medical documents from SSA to annotate for Mobility, Self-Care, and Domestic Life FSI. Both datasets for annotation were drawn from adult disability benefits claims with a decision issued in 2016–2018, primarily related to musculoskeletal, neurological, or mental impairments.

Following our prior work on analyzing Mobility information (15), we identified 300 CEs likely to contain descriptions of Mobility functioning. We ensured that each CE corresponded to a different claimant in order to control for cross-document correlation from an individual claimant.

An additional 350 documents were then selected to annotate for Self-Care and Domestic Life information. The documents were selected from the same overall set of claims as the Mobility documents, but we ensured that the specific claims used in annotation were disjoint between the two datasets. As the concepts of Self-Care and Domestic Life are highly intertwined and often discussed together in clinical notes—e.g., eating (Self-Care) and preparing meals and cleaning (Domestic Life)—we chose to annotate for these chapters jointly (referred to in the remainder of the article as "Self-Care/Domestic Life"). Annotated documents included both CEs and EHR data; no two documents of the same type were included for any individual claimant.

SSA Document Collection for Computational Language Modeling

A further set of 65,514 documents collected by SSA was used for machine learning of statistical models of clinical language as used in the SSA setting (as detailed in the "Text representation with word embeddings" section below). Many documents included in this collection included notes from multiple clinical encounters during the history of a patient with a particular healthcare provider. Each "document" was thus much longer on average than a single clinical note, with a median document length of 3,476 words. These documents were sampled by SSA separately from the documents used for annotation, using a broader set of criteria to enhance the diversity of the data: adult claims adjudicated based on musculoskeletal, neurological, or mental impairments, with a decision issued during 2013–2018, drawn from multiple states around the U.S. We confirmed that no documents selected for Mobility or Self-Care/Domestic Life annotations were included in this collection.

Annotation Process

Annotation of SSA documents for FSI regarding Mobility and Self-Care/Domestic Life was performed in a multistage process, illustrated in **Figure 1**. Mobility information was annotated using guidelines developed in previous work (15); we adapted this existing process to develop new guidelines for Self-Care/Domestic Life information. We developed the annotation guidelines *via* an iterative process among the annotators (JCM, PSH, MS, and RJS), involving team annotation and discussion to refine a schema for representing Self-Care/Domestic Life information and develop clear guidelines for how to annotate for it in free text. After guideline development, the annotators jointly annotated a small set of documents (50 for the new Self-Care/Domestic Life guidelines, and 16 to further validate the existing Mobility guidelines in SSA data), and Inter-Annotator Agreement (IAA) was calculated (IAA values are reported with other dataset statistics in the Results section). Following standard practice in annotating for text spans (20, 21), we calculated IAA using the F-1 measure. Disagreements were then resolved by joint meetings among the annotators to produce a final consensus version of the jointly annotated documents. Finally, each individual annotator annotated a further set of

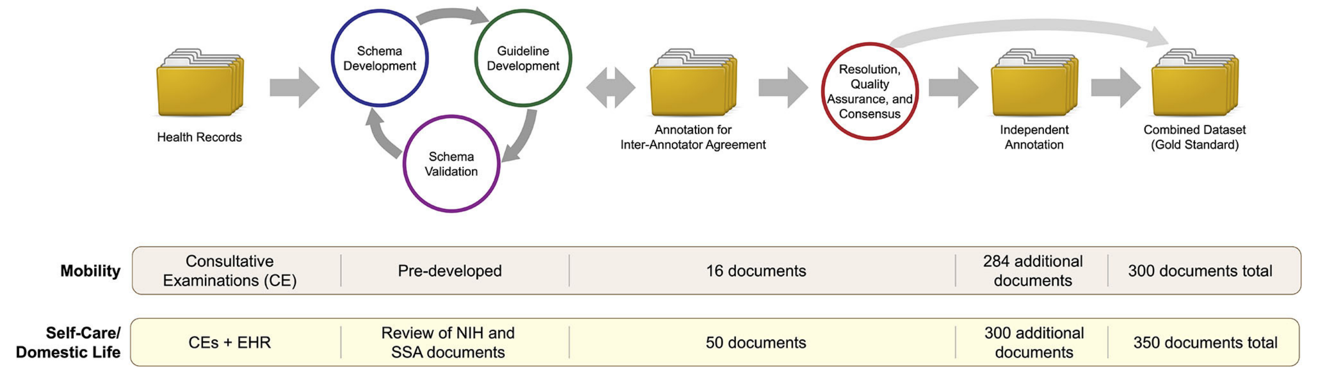

FIGURE 1 | Flowchart illustration of the annotation process. Data sources and document counts are provided for Mobility and Self-Care/Domestic Life annotations separately.

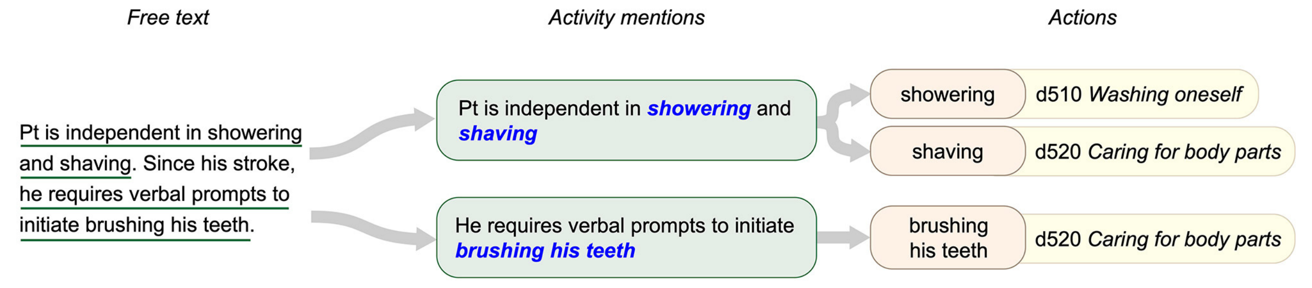

FIGURE 2 | Structure of annotations for functional status information. Free text is annotated to identify activity mentions describing specific observations. Each activity mention may include one or more Action components, which can be mapped to second-level ICF categories.

documents independently, which were then combined with the consensus annotations to produce the final "gold standard" annotated corpus.

When annotating a document, the first step in our process was to identify *activity mentions*, which we operationalized as self-contained spans of text describing the functioning person's within the scope of the relevant ICF Activities and Participation chapters. Within each activity mention, we then identified each distinct *action* referred to, operationalized as a distinct activity defined by one of the ICF categories within the relevant chapters of the two-level ICF classification (or activity of similar granularity not specifically captured in the ICF, e.g., "do household chores"). These categories are represented using the ICF format of the letter *d* (indicating the Activities and Participation domain), followed by three digits: a one-digit chapter identifier and a two-digit category identifier (e.g., d450 indicates the *Walking* category in Chapter 4 *Mobility*). We referred to these as *second-level categories* to distinguish them from the more specific subcategories in the detailed classification (e.g., d4501 *Walking long distances*).

Each of the identified action components (which we denote with a capitalized *Action* for the remainder of this article, for clarity) within an activity mention was then assigned the second-level ICF category best representing the activity described. We excluded the "other specified" and "unspecified" ICF categories, such as d598 *Self-care, other specified* and d599 *Self-care, other unspecified,* from use in annotation due to their ambiguity. In cases where an Action component referred to an activity for which no specific ICF category was appropriate (e.g., "doing household tasks"), or when multiple categories could apply (e.g., "denies difficulty with ADLs"), a label of "Other" was used. **Figure 2** provides an illustrated example of Self-Care/Domestic Life activity mentions, including one with two Action components.

The focus of annotation was on observations or descriptions of specific, volitional activities performed by the patient within the specific domains of interest. We, therefore, excluded the following types of information about functioning: (1) hypothetical statements (e.g., "her sleep is better if she takes medication"); (2) education given by the provider (e.g., "The patient educated on how he can attempt to dress his lower body in bed"); and (3) references to habitual activity in the context of work duties (e.g., "his job at the hotel involves doing laundry and cleaning guest rooms").

Patient Engagement in Medication Management and Non-Pharmacological Therapies as Categories of Self-Care

The documents reviewed for Self-Care/Domestic Life guideline development included frequent discussions of active engagement of patients in the therapeutic process, including adherence to

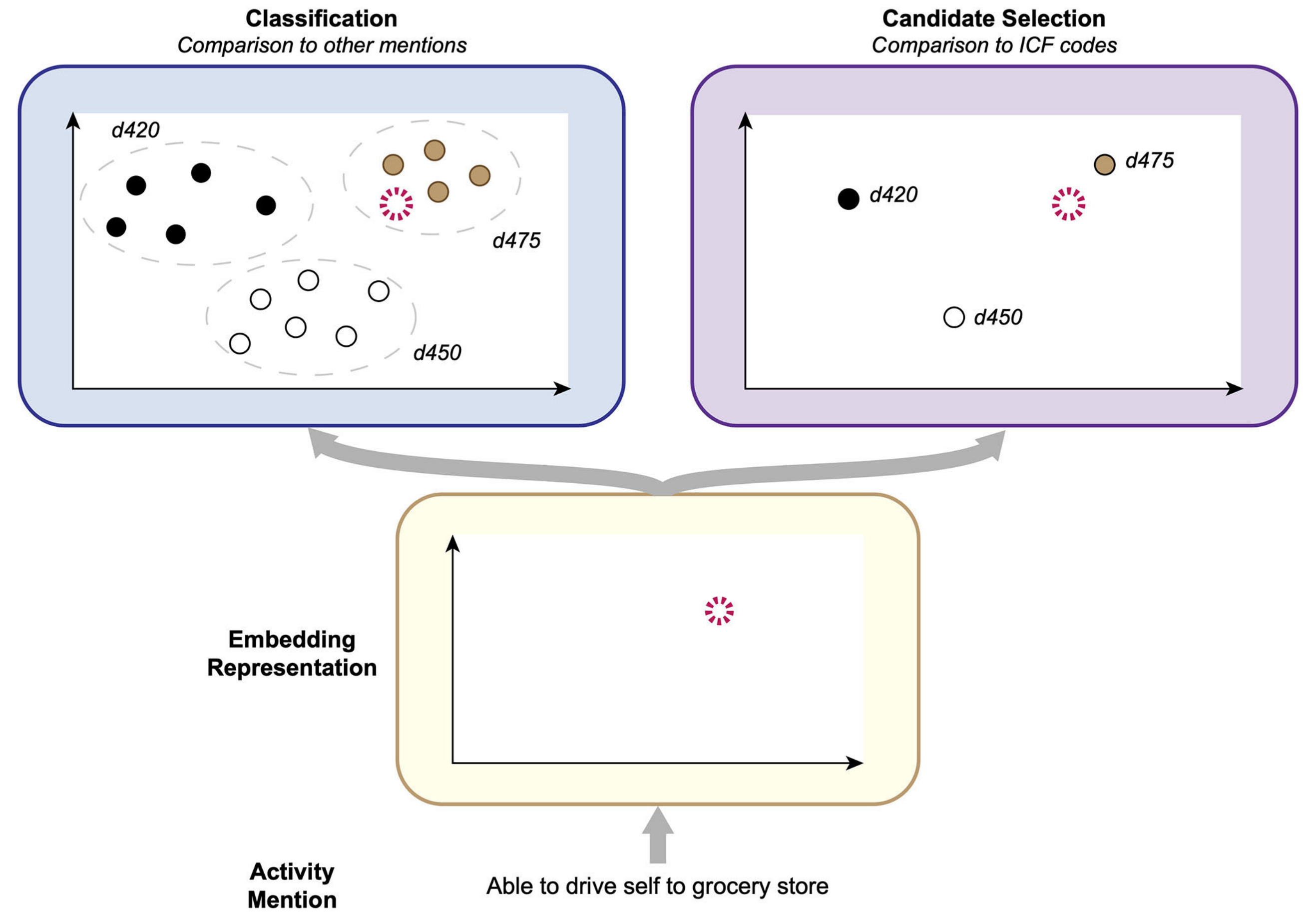

FIGURE 3 | Conceptual illustration of the ICF coding process. Given an activity mention, an embedding representation of the report is calculated and then compared with other activity mentions, in Classification; or available ICF categories, in Candidate Selection.

medication management regimens and participation in non-pharmacological therapies. While these mentions provided valuable evidence of distinct kinds of patient engagement in self-care, they were not reflected by ICF categories more specific than d570 *Looking after one's health*. To more accurately capture—and differentiate between—these frequent topics, we added two additional Action labels based on codes in the Systematized Nomenclature of Medicine Clinical Terms set (SNOMED CT). We used *Manage medication* (SNOMED CT code 285033005) to refer to anything related to compliance with medications such as the ability to store medications, obtain medications, take the medications, etc. This label also included the mismanagement of medication (e.g., forgetting to take prescribed medications). We used *Therapy* (SNOMED CT code 709007004) to refer to attending or, otherwise, engaging in non-pharmacological therapies, such as addiction treatment programs, physical therapy, occupational therapy, cognitive behavioral therapy, psychological therapy, and anger management. We did not use these labels to annotate the therapeutic interventions themselves, which are out of the scope of the ICF. Thus, while a mention of a patient attending physical therapy was annotated as a *Therapy* activity mention, a mention of a physical therapy appointment with no indication of whether the patient attended or not did not provide evidence of self-care and was not annotated.

Methods for Automated ICF Coding

We experimented with two strategies to develop computer methods to automatically assign ICF categories to Mobility and Self-Care/Domestic Life activity mentions. In our prior work (16), we explored a variety of methods for ICF coding, including both *classification*—identifying the group of samples a given activity mention is most similar to—and *candidate selection*—identifying which ICF category a given activity mention is most similar to—approaches, for Mobility information only. In this study, we evaluated the best-performing classification and candidate selection models from this prior work on the SSA datasets we developed for Mobility and Self-Care/Domestic Life. Our overall process is illustrated in **Figure 3**.

Text Representation With Word Embeddings

Given an activity mention, we calculated a numeric representation of the text using word embedding features. In word embedding models, each word and phrase is represented mathematically using a vector of n real numbers—frequent values for *n* include 100, 300, and 768—with the property that words that are similar in meaning generally have similar numeric representations (22). These models are fundamental resources for modern NLP methods. Our prior work demonstrated that word embedding features alone were more informative for ICF coding than features indicating the presence and/or frequency of specific words (referred to as *lexical features*) or combined embedding and lexical features (16); we, therefore, used word embedding features alone in this study. We experimented with two methods for word embedding:

- In *static* embeddings, each unique word is represented by a single vector. Thus, for example, every occurrence of the word *patient* is represented within the model using the same set of real numbers. We used FastText (23), a commonly used method that integrates sub-word information into embedding learning to better capture morphological patterns.
- In *contextualized* embeddings, each word is represented by a single vector conditioned on the context it appears in; thus, the word "cold" in "patient described cold symptoms" and "applied a cold pack" is represented using different vectors of real numbers for each case. This provides additional context sensitivity in how the model represents text content. We used BERT (24), a recent embedding model that has rapidly become the *de facto* standard for text representation in NLP.

The parameters of both static and contextualized embedding models (i.e., the values used to represent words and phrases) are typically estimated prior to their usage in any specific NLP task (e.g., our ICF coding application), based on a large sample of natural language (referred to as a *corpus*). Different corpora may be chosen for different purposes—e.g., estimating an embedding model using the text of PubMed abstracts provides useful representations for analyzing scientific literature while using the text of clinical notes provides more useful representations for clinical applications. We, therefore, experimented with multiple corpora to estimate our word embedding models (referred to in machine learning as *model training*); each of which reflects different tradeoffs between corpus size and representativeness for the target task. These corpora are summarized in **Table 1**.

For static word embeddings, we experimented with three clinical corpora for training embedding models. In each case, document texts were broken down into individual words (tokenized) with the spaCy software (25), and the following processing steps were applied to normalize out aspects of the text irrelevant to our language modeling goal: all words were converted to lowercase, all numbers were normalized to "[NUMBER]", all URLs were normalized to "[URL]," and all dates and times were normalized to "[DATE]" and "[TIME]," respectively. The FastText software (version 0.2.0) was used with the skipgram algorithm, 300-dimensional embeddings, and all other settings at default to training embeddings on the following three corpora:

- **MIMIC**: Approximately 2 million free text notes are included in the publicly available Medical Information Mart for Intensive Care (MIMIC) critical care database, version 3 (26). Notes are associated with admissions to ICU units of Beth Israel Deaconess Medical Center in Boston between 2001 and 2012 and are commonly used for language modeling in clinical NLP research.
- **NIHCC**: Over 63,000 free text notes from 10 years of Physical Therapy and Occupational Therapy encounters in the Rehabilitation Medicine Department of the NIH Clinical Center were collected and used for calculating word embedding features in our previous work (16).
- **SSA**: Over 65,000 free text notes associated with disability claims processed by SSA within a 5-year period (as described in the "SSA document collection for the language modeling" section above).

TABLE 1 | Free text corpora used to train word embedding models for text representation.

Training corpus	Number of notes	Number of words (approx.)	Data description
MIMIC	2,083,180	497 million	Critical care admissions (26). Most commonly used corpus for language modeling in clinical NLP.
NIHCC	63,605	11.8 million	Physical therapy and occupational therapy encounters, used in our prior work on coding Mobility information to the ICF (16).
SSA	65,514	664 million	Clinical data associated with disability benefits claims submitted to SSA. New in this study.

MIMIC-III was used to train both FastText and BERT models; NIHCC and SSA were used for FastText embeddings only.

Contextualized embedding models require significant computing power to train on new data, and pre-trained models are typically used to generate text features. We used the clinicalBERT model released by Alsentzer et al. (27), which was trained on MIMIC clinical notes and produces 768-dimensional word embeddings.

Action Oracle

As illustrated in **Figure 2**, activity mentions are complex statements, including multiple pieces of information. Thieu et al. (15) define sub-components of activity mentions, including (1) a source of Assistance—typically a device, person, or structure in the physical environment used in activity performance; (2) a Quantification—an objective measure of functional performance, such as distance or time; and (3) one or more specific Actions being performed, which correspond to defined activities in the ICF Activities and Participation domain. For example, the activity mention "Pt ambulated 300' in a clinic with a rolling walker" which includes the Action component "ambulated," the Assistance component "with a rolling walker," and the Quantification component "300'." Action components are annotated with the second-level ICF categories, which the NLP systems described in this study are designed to assign.

Prior work on extracting activity mentions from the free text (13, 14) did not include extraction of the Action sub-components. However, as NLP methods for functional status information continue to develop, more complex models that reflect the semantic structure of activity mentions will be needed. We, therefore, evaluated the ICF coding models in this study in two settings: (1) an *Action oracle* setting, in which both an activity mention and the location of an Action component within it (i.e., where, in the text span of the activity mention, the Action is found) are input to the ICF coding model; and (2) a non-oracle setting in which only the activity mention is provided (reflecting the technologies so far developed for extracting activity mentions).

Classification

In classification approaches, a mathematical representation is calculated for each activity mention using word-embedding features, and a predictive model is trained to assign an ICF category to each Action component based on its similarity to previously observed samples labeled with each ICF category. We adopted the best-performing classification model from our prior work (16), a Support Vector Machine (28) using a word embedding features as input. Given an input activity mention, we calculated its embedding features in one of four ways:

- **Static embeddings, no Action oracle**: the activity mention is represented by averaging the word embeddings of each word in the mention.
- **Static embeddings, with Action oracle**: two averaged embeddings are calculated: (1) the averaged embedding for the words in the Action component; and (2) the average of other all words in the activity mention. These are concatenated, i.e., combined into a single, longer vector, to produce the final representation.
- **Contextualized embeddings, no Action oracle**: the activity mention is represented as the averaged context-sensitive embeddings for each of its words.
- **Contextualized embeddings, with Action oracle**: as the contextualized embeddings of words in the Action component already reflect information about the full activity mention, we averaged the embeddings of Action component words only.

Candidate Selection

In the candidate selection approach, an embedding representation is calculated for each activity mention and is then compared to embedding representations of each of the available ICF categories to identify which category the given mention is most similar to. We adopted the best-performing candidate selection model from our prior work (16), consisting of a Deep Neural Network (DNN) that operates as follows:

1. The model takes as input an activity mention embedding and embedding representations of the ICF categories that could be assigned to it (i.e., all Mobility categories or all Self-Care/Domestic Life categories).
2. These embeddings are all fed into a DNN to calculate new embedding representations of the candidate ICF categories, conditioned on this specific activity mention.
3. The conditional ICF category embeddings are compared with the activity mention embedding using the cosine similarity measure, and the category with the highest similarity is chosen as the model output.

Embedding features of activity mentions were calculated using the strategies described in the "Classification" section. Embedding representations of ICF categories were calculated as the averaged embeddings of each word in the definition of the category presented in the ICF, using both static and contextualized embeddings. For the "Other" label, the following definitions were used: "Mobility other or unspecified" for Mobility, and "Self-care or domestic life other or unspecified" for Self-Care/Domestic Life. For the added *Therapy* and *Manage medication* labels, we used the names of the corresponding SNOMED CT codes ("Ability to manage medication" and "Compliance behavior to the therapeutic regimen," respectively). Further details of the model are presented in (16). Following our prior work, we used a 3-layer DNN with hidden layer size 300 when using static embedding features without the Action oracle, a 3-layer DNN with layer size 600 when using static embeddings with the Action oracle (to match the dimensionality of the concatenated activity mention and Action component embeddings), and a 1-layer DNN with layer size 768 when using BERT embedding features (for which vector dimensionality does not change with the Action oracle).

Experimental Procedure

Prior to machine learning experiments, each dataset was split at the document level into training data, for training the machine learning models, and test data for evaluating them. Test documents were sampled to include at least 20% of the samples for each ICF category. Statistical significance testing was performed using the bootstrap resampling method with 1,000 replicates, which is commonly used to analyze performance metrics in NLP research (29, 30).

Development Experiments

Training data were further split into 10-fold for development experiments to select the best word embedding method for classification and candidate selection approaches. For development experiments, cross validation was used; models were trained on 9-fold (90% of the training data) and evaluated on the held-out 10th fold, and this process was then repeated to evaluate on each of the 10-fold, with model performance being averaged across the folds to calculate final values. Model performance was calculated using the F-1 score (20), calculated as the harmonic mean between precision (positive predictive value) and recall (sensitivity). F-1 score was calculated for each ICF category in each dataset and averaged across categories to calculate macro F-1. The embeddings producing the highest macro F-1 on the development experiments were chosen to use for the main experiments.

Main Experiments and Model Evaluation

Once final word embeddings were chosen, an additional classification and candidate selection model was trained for each of the Mobility and Self-Care/Domestic Life datasets, using all of

TABLE 2 | Datasets of documents annotated for functional status information, drawn from U.S. Social Security Administration disability benefits cases.

	Mobility	Self-Care/Domestic Life
Number of documents annotated	289	329
With activity mentions	251	285
Total activity mentions	2,455	3,990
Including at least one Action	2,323 (94.6%)	3,866 (96.9%)
Total number of Actions	3,176	4,665
Training set size (documents / Actions)	203 / 2,361	229 / 3,350
Test set size (documents / Actions)	45 / 815	56 / 1,315

Separate sets of documents were annotated for Mobility (ICF Activities and Participation Chapter 4) and Self-Care/Domestic Life (ICF Activities and Participation Chapters 5 and 6).

the training data. These models were then evaluated on the held-out test documents, with performance measured using F-1 for each individual ICF category, and overall performance calculated as macro-averaged F-1 score.

RESULTS

Annotated Datasets

Table 2 presents the overall statistics of the two SSA datasets annotated for functional status information. Several of the documents selected for annotation were omitted after conversion to text with the OCR software due to failures in the OCR conversion, resulting in a total of 289 documents annotated for Mobility, and 329 documents annotated for Self-Care/Domestic Life. The majority of documents were found to contain descriptions of the target types of functioning: 251/289 (87%) of Mobility documents and 285/329 (87%) of Self-Care/Domestic Life documents contained at least one activity mention pertaining to the relevant ICF chapters. Each activity mention could contain zero, one, or more than one Action component; a total of 3,176 Actions were annotated for Mobility and 4,665 for Self-Care/Domestic Life. Only 132 Mobility activity mentions (5.4% of the total) and 134 Self-Care/Domestic Life activity mentions (3.4% of the total) were found to not contain any specific Action components. Inter-annotator agreement (IAA) was found to be 0.778 F-1 for Mobility and 0.695 F-1 for Self-Care/Domestic Life, comparable to IAA calculated in our previous study on annotating Mobility information in clinical reports (15). ICF coding annotation has previously been found to yield high agreement for resources and goals as well as specific problems (31). The two datasets are described in greater detail in the following sections.

Mobility Dataset

A total of 12 unique second-level ICF categories were used for annotating Mobility information; **Table 3** lists the frequency of each of these categories in the annotated dataset, together with the “Other” category. Of the categories in the Mobility chapter, only d480 *Riding animals for transportation* was not observed in the annotation process. d465 *Moving around using equipment* was excluded from annotation, as the use of equipment was annotated using Assistance components of Mobility activity mentions; d455 *Moving around* was used instead. The most frequent categories were d450 *Walking* (23% of Actions), d410 *Changing basic body position* (17.6% of Actions), and d415 *Maintaining a body position* (16% of Actions). Only d420 *Transferring oneself*, d435 *Moving objects with lower extremities*, and d460 *Moving around in different locations* were observed fewer than 100 times. A total of 123 samples (3.9% of Actions) were found that could not be mapped to a single appropriate second-level ICF category. These included Actions, which could map to multiple categories, such as “The patient is able to ambulate in the hallway and stairs” (which can refer to both d450 *Walking* and d460 *Moving around in different locations*), and Actions, which were too vague to map to any specific categories, such as “The patient cannot manage/negotiate stairs.”

Self-Care/Domestic Life Dataset

Thirteen distinct second-level ICF categories (seven from Chapter 5 *Self-Care*, six from Chapter 6 *Domestic Life*) were used in data annotation, together with the added labels of *Manage medication* and *Therapy* and the “Other” category. **Table 4** lists the observed frequency of each of these labels in the dataset. The most frequent category was d570 *Looking after one’s health*, accounting for 43.6% of the samples by itself. Five categories (d530 *Toileting*, d560 *Drinking*, d610 *Acquiring a place to live*, d650 *Caring for household objects*, and d660 *Assisting others*) occurred fewer than 100 times. A total of 175 samples were found that could not be mapped to a single appropriate second-level ICF category, such as “The patient is independent with ADLs” (which includes multiple Self-Care activities).

Automated ICF Coding

Development Experiments: Identifying the Best Word Embeddings

Figure 4 illustrates the results of development set experiments to identify the best word embedding features to use for coding Mobility and Self-Care/Domestic Life mentions. We evaluated MIMIC, NIHCC, SSA, and clinicalBERT embedding features for both classification and candidate selection approaches, with and without the Action oracle.

For the Mobility dataset, embeddings trained on the NIHCC and SSA corpora achieved highest development set performance both with the Action oracle (F-1 = 0.696 for both NIHCC and SSA) and without (NIHCC = 0.553, SSA = 0.541, difference not significant at *p*-value = 0.9, bootstrap resampling). NIHCC embeddings were statistically significantly better than the next best clinicalBERT features (F-1 of 0.553 vs. 0.531; *p*-value = 0.025) without the Action oracle, while SSA embeddings were not significantly different from clinicalBERT (F-1 of 0.541 vs. 0.531; *p*-value = 0.17). We, therefore, took NIHCC embeddings as the best-performing features for classification experiments on the Mobility test set.

TABLE 3 | ICF category descriptions and frequencies for Mobility dataset (3,176 samples total).

Mobility category	Description	Frequency	% of all samples	Training samples	Test samples
d450	Walking	730	23.0%	559 (77%)	171 (23%)
d410	Changing basic body position	560	17.6%	419 (75%)	141 (25%)
d415	Maintaining a body position	508	16.0%	385 (76%)	123 (24%)
d440	Fine hand use	319	10.0%	247 (77%)	72 (23%)
d430	Lifting and carrying objects	244	7.7%	167 (68%)	77 (32%)
d475	Driving	215	6.8%	165 (77%)	50 (23%)
d445	Hand and arm use	163	5.1%	104 (64%)	59 (36%)
d455	Moving around	147	4.6%	99 (67%)	48 (33%)
Other	Mobility-related activities for which no specific ICF category could be identified	123	3.9%	96 (78%)	27 (22%)
d470	Using transportation	103	3.2%	80 (78%)	23 (22%)
d460	Moving around in different locations	55	1.7%	34 (62%)	21 (38%)
d435	Moving objects with lower extremities	5	0.2%	4 (80%)	1 (20%)
d420	Transferring oneself	4	0.2%	2 (50%)	2 (50%)

Categories are ordered by frequency in the dataset. Sample count and relative distribution between training data (203 documents, 2,361 samples) and test data (45 documents, 815 samples) are given for each category. Descriptions given are the preferred name of each category in the ICF.

TABLE 4 | ICF category descriptions and frequencies for Self-Care/Domestic Life dataset (4,665 samples total).

Self-care/domestic life category	Description	Frequency	% of all samples	Training samples	Test samples
d570	Looking after one's health	2,032	43.6%	1,496 (74%)	536 (26%)
Manage medication	Ability to manage medication (SNOMED CT code 285033005)	520	11.1%	359 (69%)	161 (31%)
d540	Dressing	353	7.6%	268 (76%)	85 (24%)
d520	Caring for body parts	312	6.7%	228 (73%)	84 (27%)
d640	Doing housework	297	6.4%	205 (69%)	92 (31%)
d630	Preparing meals	222	4.8%	165 (74%)	57 (26%)
Other	Self-Care/Domestic Life activities for which no specific ICF category could be identified	174	3.7%	127 (73%)	47 (27%)
Therapy	Compliance behavior to therapeutic regimen (SNOMED CT code 709007004)	143	3.1%	103 (72%)	40 (28%)
d620	Acquisition of goods and services	142	3.0%	101 (71%)	41 (29%)
d510	Washing oneself	121	2.6%	90 (74%)	31 (26%)
d550	Eating	102	2.2%	57 (56%)	45 (44%)
d560	Drinking	82	1.8%	60 (73%)	22 (27%)
d660	Assisting others	79	1.7%	46 (58%)	33 (42%)
d650	Caring for household objects	40	0.8%	24 (60%)	16 (40%)
d530	Toileting	29	0.6%	15 (52%)	14 (48%)
d610	Acquiring a place to live	17	0.3%	6 (35%)	11 (65%)

Categories are ordered by frequency in the dataset. Sample count and relative distribution between training data (229 documents, 3,350 samples) and test data (56 documents, 1,315 samples) are given for each category. Descriptions given are the preferred name of each category in the ICF.

For the Self-Care/Domestic Life dataset, SSA embeddings achieved highest development set performance both with the Action oracle (SSA F-1 = 0.785 vs. NIHCC F-1 = 0.764; p-value = 0.031) and without (SSA = 0.631, NIHCC = 0.594; p-value = 0.015). We, therefore, took SSA embeddings as the best-performing features for Self-Care/Domestic Life classification experiments.

Under the candidate selection approach, clinicalBERT features significantly ($p \ll 0.001$) outperformed all other embeddings on both datasets. We used clinicalBERT embeddings as the best-performing features for test set candidate selection experiments.

Main Experiments

Figure 5 shows the overall performance of classification and candidate selection experiments on the Mobility and Self-Care/Domestic Life test sets. Classification models consistently outperformed candidate selection ($p = 0.041$ for Mobility without Action oracle; $p \ll 0.001$ for Mobility with Action oracle and both settings of Self-Care/Domestic Life). This is

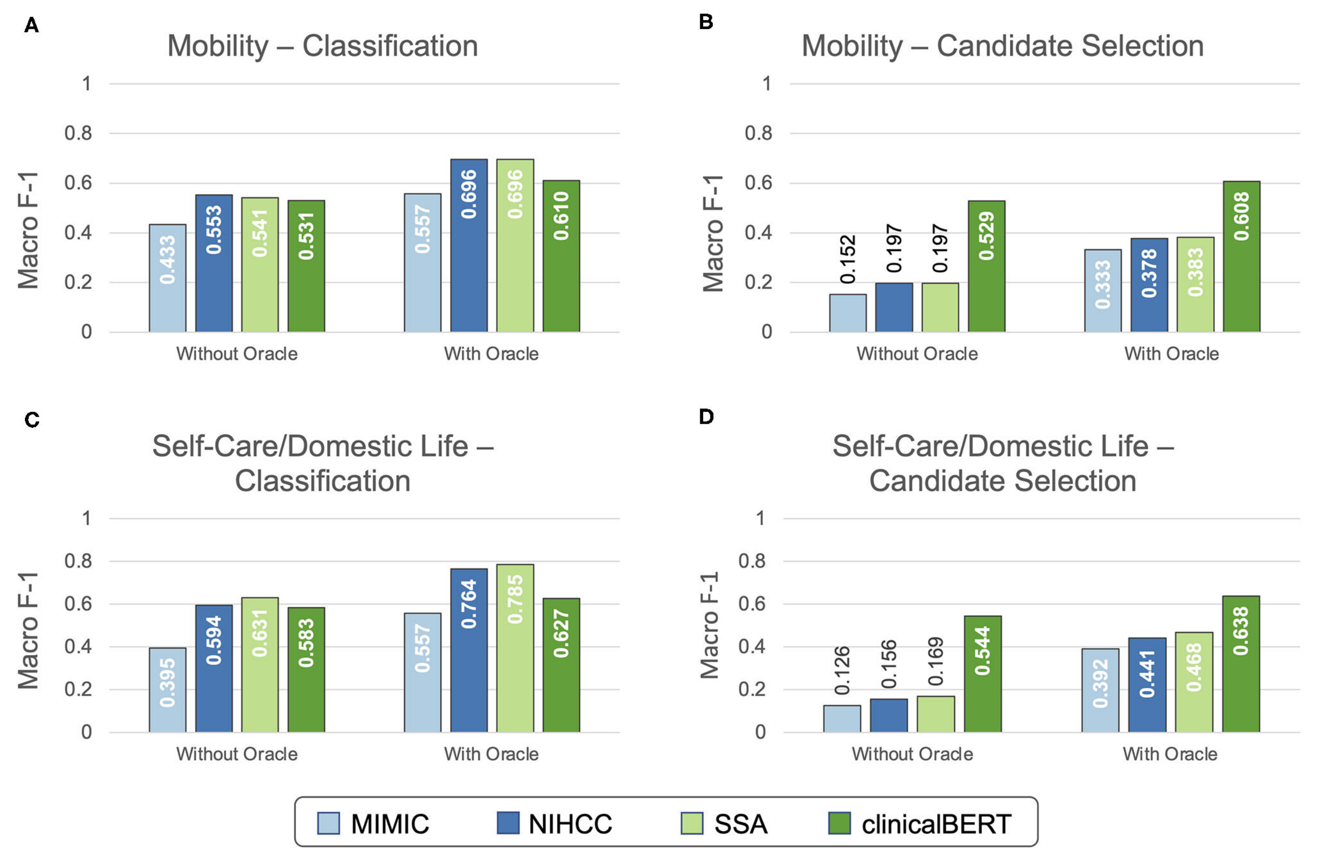

FIGURE 4 | Development experiment results for selecting word embeddings. Development set performance (macro-averaged F-1 with 10-fold cross validation) is shown using each embedding strategy for both Mobility **(A,B)** and Self-Care/Domestic Life **(C,D)** data, using both classification **(A,C)** and candidate selection **(B,D)** approaches.

consistent with our prior findings of comparable or slightly lower performance for our candidate selection model on Mobility data from physical therapy encounters (16). The Action oracle significantly ($p \ll 0.001$) improved performance in all cases, clearly demonstrating the value of building NLP systems to extract the Action components of activity mentions.

We further analyzed performance on each individual label in the Mobility dataset (shown in **Figure 6**) and the Self-Care/Domestic Life dataset (shown in **Figure 7**). Performance generally trended with the frequency of the label—i.e., both classification and candidate selection performance was best for the most frequent categories and gradually degrades for less frequent categories. We did not observe any categories where our classification or candidate selection models showed a clear advantage; rather, our classification models tended slightly higher than candidate selection on almost all categories. Exposing the position of an Action component within an activity mention to the model (i.e., using the Action oracle) improved performance on almost all categories, with most of the largest gains on rare categories; e.g., an F-1 gain of 0.25 (candidate selection) and 0.5 (classification) on d460 (21 samples) in Mobility data, and an F-1 gain of 0.3 (candidate selection) and 0.33 (classification) on d560 (22 samples) in Self-Care/Domestic Life data.

DISCUSSION

We have shown that rich and diverse information on Mobility, Self-Care, and Domestic Life is recorded in free text health records collected from health providers by SSA for disability benefits adjudication. We presented NLP systems to map this information to specific ICF categories using two paradigms: classification (comparing each sample to other, previously seen samples) and candidate selection (comparing a sample to ICF categories directly). Our experiments demonstrated that these systems show promising performance for enabling automated analysis of medical evidence through the lens of the ICF.

Our study also revealed limitations of the ICF as a practical tool for analyzing medical documentation. We discuss key insights from our annotation process in the following section and highlight the particularly complex case of ICF category d570 *Looking after one's health*. We further identify particular successes and challenges arising from our NLP experiments and discuss implications of NLP tools for functional status, aligned with the ICF or with another conceptual framework, in both the SSA use case of disability adjudication and broader applications in clinical care and research.

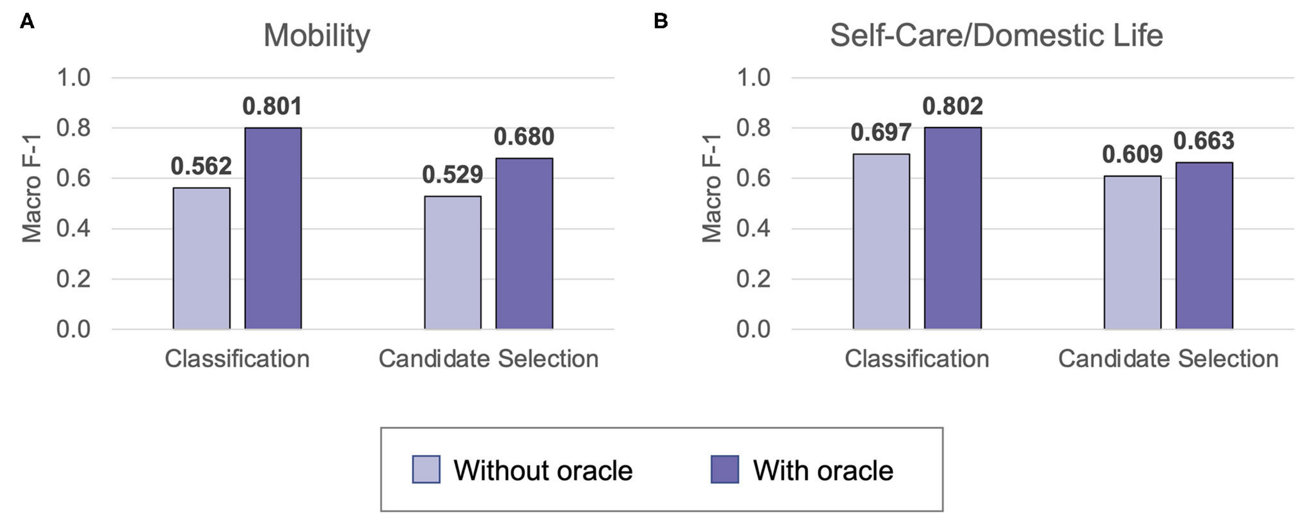

FIGURE 5 | The test set performance on automated ICF coding in Mobility **(A)** and Self-Care/Domestic Life **(B)** test sets. Performance is reported for the best classification (Mobility: NIHCC embeddings; Self-Care/Domestic Life: SSA embeddings) and candidate selection (both datasets: clinicalBERT embeddings) models.

FIGURE 6 | Automated coding performance for each distinct category in the Mobility dataset. Classification results are shown in **(A)**, and candidate selection results in **(B)**. Categories are ordered by descending frequency [illustrated in **(C)**].

Practical Limitations of the ICF for Mobility, Self-Care, and Domestic Life Information

Coding functional status information according to a standardized framework such as the ICF allowed us to identify what kinds of functioning are discussed in health records and to organize information on patient functioning for retrieval and analysis. The ICF, as the internationally accepted classification of human functioning, is an important touchstone for this work, and it allowed us to capture a broad set of information about functional activity in free text health records. However, some activity mentions we observed in practice did not align with the categories presented in the ICF, such as "managing stairs," "doing household tasks," and "cleaning." At the same time, other categories had significant overlap with one another in the expert annotation process, such as d450 *Walking*, d455 *Moving around*, and d460 *Moving around in different locations*. Category d465 *Moving around using equipment* was excluded entirely from annotation, as our information model represented assistive

FIGURE 7 | Automated coding performance for each distinct category in the Self-Care/Domestic Life dataset. Classification results are shown in **(A)**, and candidate selection results in **(B)**. Categories are ordered by descending frequency [illustrated in **(C)**].

equipment (Assistance component) separately from the action being performed (Action component); this category, therefore, reduced to d455 *Moving around*. Some activity descriptors were highly context dependent for selecting the appropriate ICF category; for example, we annotated "drinking" as d560 *Drinking* for the generic action of drinking but as d570 *Looking after one's health* when used to refer specifically to drinking alcohol (e.g., "He drinks two shots of whiskey a day"). Thus, while the ICF is clear and comprehensive for coding many Mobility, Self-Care, and Domestic Life activities, its use is often more theoretical than practical when applied to actual clinical reporting.

ICF Category d570 Is Overly Broad

The limitations of the ICF in practice were particularly clear for the Self-Care category d570 *Looking after one's health*. We found this category to be significantly overrepresented in our data (accounting for 43.6% of all observed Self-Care/Domestic Life actions) and extremely broad in practice. Category d570 was treated as referring to preventative measures (e.g., exercising, taking prescribed medications, etc.) a person does to, or for, themselves or will/plans to do in the future. We excluded from consideration interventions performed or planned by healthcare providers, the goals providers set for themselves, and descriptions of specific therapy sessions that were not directly related to Self-Care. With this operational definition, we coded d570 for information as diverse as:

- She exercises four to five times a week.
- Stretching, breathing techniques
- He drinks two shots of whiskey a day.
- She has had two suicide attempts in the past.
- He smokes a pack of cigarettes a day.
- Takes over the counter supplements
- He is compliant with treatment but remains symptomatic.
- I haven't gone to counseling, but I talk to my friend who is a preacher.
- He consumed caffeine one to two times a week.

Notably, we found category d570 in practice to include several social determinants of health, such as drug and alcohol use (also including misuse and abuse) and smoking status. In addition to the breadth of information, several activity mentions we coded with d570 required some level of inference on the part of the reader to understand the functioning described. For example, we annotated "I talk to my friend who is a preacher" in the example above as d570, because, in the context of referring to counseling, this can be understood as the patient establishing a connection and/or reaching for help to look after themselves. References to suicide attempts were also coded as d570 because of the detriment to the physical and mental health of the patient.

From a practical standpoint in the annotation process, activity mentions coded with d570 presented two further complications. While stated (or implied) reasons for a patient taking care of themselves or not were not generally included in annotating activity mentions, in some cases, they provided context to clarify whether an action was related to taking care of oneself or not. For example, in "her tendency to take a double shift, knowing that there will be a detrimental impact on her comfort and health status," the phrase "take a double shift" alone is not sufficient to determine a category of d570; including its effect on the health of the patient provides the necessary context to clarify that this is related to taking care of oneself. In addition, d570 was the

TABLE 5 | Examples for the related labels of ICF category d570, Manage Medication, and Therapy.

Category	Examples	Notes
d570	Her sleep varies and she never feels rested	Not annotated; these fall within the Body Functions domain of the ICF.
	She has had a previous suicide attempt	Suicidal actions are annotated as indicating risks to health.
	He drinks a six-pack of beer a day	Reference to alcohol consumption.
	Patient was well-nourished	Indicates the person is taking care of themselves.
	Her tendency to take a double shift knowing that there will be a detrimental effect on her comfort and health status	Significant context is needed to clarify the impact on self-care.
Manage medication	He is currently prescribed medication by his neurologist to slow down the progression of his symptoms	Not annotated; does not state whether the person is actually taking the medications or not.
	Pt is currently on medication: Prazosin at bedtime…	Medications the patient is currently taking; the medications themselves are not annotated.
	She takes Tylenol	Reason for medication not needed; the specific medication is annotated to clarify what action is being performed.
Therapy	He has had no psychiatric care and no history of psychiatric hospitalization	Not annotated; reference to therapeutic care the patient has not used.
	She had occupational therapy for a custom splint	Therapy for a particular purpose related to health.
	He was seeing a counselor for his drug addiction	Counseling for a particular purpose related to health.

Brief notes are provided for each example as to why it was or was not annotated as shown. Activity mentions are indicated using yellow highlights and Actions are indicated using underlines.

only category where negation needed to be captured as part of the Action component when it pertained to suicide or other self-harm, recreational drug, and/or alcohol use, or medication non-compliance.

In summary, we found that the ICF is not necessarily in line with the types of information providers record about Self-Care, and that category d570 was too broad to effectively represent the diversity of Self-Care activities described in the data.

Distinguishing Patient Engagement in "Therapy" and "Manage Medications" From Other Uses of d570

We took the step in this study of specifically distinguishing patient engagement in *Therapy* (non-pharmacological) and *Manage medication* as distinct Self-Care categories, separate from the broader d570 category. We found that clinical notes frequently provided detailed information on how patients were or were not engaging actively in specific therapeutic interventions and determined that separate categories would provide a more organized view of the self-care activities of the patient as a whole. We distinguished between adherence to regimens for managing medications, which are therapies that a licensed provider needs to approve (in contrast to over-the-counter products, such as multivitamins or alternative medicines, which we classified as d570), and participation in non-pharmacological therapies, such as addiction treatment programs, physical therapy, occupational therapy, cognitive behavior modification therapy, psychological therapy and/or counseling, and anger management. To provide concrete examples of these distinctions and further illustrate the complex scope of category d570, **Table 5** [drawn from our annotation guideline (32)] presents a selection of samples for each label, together with notes on why the information was or was not annotated as presented.

Overlap Between d570 and Other Domains of the ICF

The interactions between health conditions, body functions and structures, activities and participation, and contextual factors are at the heart of the biopsychosocial model of the ICF of human function. However, we found that, particularly for category d570, both its definition and our observations of it in practice overlapped significantly with other domains of the ICF, creating an additional challenge for aligning clinical observations to the ICF model. Terms used in the definition of d570, such as "ensuring," "appropriate level," "avoiding harm," and "being aware of the need," are more aligned with the b1 *Mental functions* heading in the Body Functions domain. At the same time, several examples we annotated as d570 included elements more in the domain of Personal Factors—these included references to work preferences, physical activity levels, etc. As the ICF does not currently classify Personal Factors, these elements cannot be classified separately from the activity of d570. However, alternative models can also inform approaches to representing these relationships in practice; for example, the Institute of Medicine's 1997 model (33) separates personal factors into biologic factors (less modifiable) and lifestyle and behavior factors (more modifiable) and represents them as transitional factors in the enabling-disabling pathway. This perspective provides a framework for viewing the activity of *Looking after one's health* as an outwardly observable act affected by internal processes, such as personal health behaviors and choices. Modeling these relationships thus represents an important area of further inquiry both in refining the ICF model and in developing information technologies to align clinical observations with it.

Implications for Updating the ICF

Our findings suggest specific ways in which the ICF could be updated to decrease overlap between codes and better align with practical clinical reporting needs. Specific recommendations supported by our analysis include: (1) Remove the term "walking" from the definition of d460 *Moving around in different locations* to reduce overlap with d450 *Walking*. (2) Explicitly distinguish between the general action of drinking liquids, represented by category d560 *Drinking*, and the specific case of drinking alcohol (which providers often refer to simply using "drinking" or "drinks," e.g., "his drinking habit" or "two drinks nightly"), which overlaps with d570 *Looking after one's health.* (3) Replace the broad category d570 *Looking after one's health* with multiple, more specific categories that reflect particular behavioral patterns, such as physical or cognitive exercises, substance use (ordered or disordered), or treatment compliance.

NLP Is a Promising Technology for Analyzing FSI in Clinical Free Text

Our experiments demonstrate that NLP technologies can help to organize FSI in free text portions of the medical record, making this information easier to find and use in decision-making processes. Our findings identify particular opportunities for future work on refining and expanding these technologies, and we further discuss the potential implications of these technologies in managing SSA disability programs, as well as individual patient care.

Successes and Challenges in Automated ICF Coding With NLP

The natural language processing systems developed in this work achieved high performance for the majority of Mobility and Self-Care/Domestic Life ICF categories. The Action oracle was the single largest factor in system performance—F-1 on Mobility codes increased by 0.22, on average, for classification and 0.15, on average, for candidate selection; increases for Self-Care/Domestic Life were smaller but still considerable at 0.11 average for classification and 0.05 average for candidate selection. The first step in further refining NLP methods for analyzing FSI must, therefore, be to include identification of Action components in the process of extracting activity mentions from text.

On a per-category basis, the best NLP models achieved high performance for most ICF categories. In Mobility, we achieved over 0.9 F-1 for five high-impact categories: d450 *Walking*, d415 *Maintaining a body position*, d475 *Driving*, d455 *Moving around*, and d470 *Using transportation* (d435 *Moving objects with lower extremities* is not included in this list as only one sample was present in the test set, limiting the reliability of performance evaluations for this category). In Self-Care/Domestic Life, we exceeded 0.9 F-1 for five common categories: d540 *Dressing*, d520 *Caring for body parts*, d630 *Preparing meals*, d620 *Acquisition of goods and services*, and d660 *Assisting others*. System performance was not strongly correlated with the frequency of the ICF categories, indicating that, in most cases, there is a clear separation between categories. However, many of the errors made by all systems were mispredictions of the most frequent labels (d450 *Walking* for Mobility, d570 *Looking after one's health* for Self-Care/Domestic Life); frequency effects are thus still an important issue to address in further refinement of NLP models for ICF coding.

Per-category performance was more consistent for Self-Care/Domestic Life than for Mobility, despite the higher skew of the Self-Care/Domestic Life category distribution; this may reflect greater issues of category overlap in the Mobility domain. In both Mobility and Self-Care/Domestic Life data, the *Other* category was a consistent challenge, reflecting its nature as a catch-all category for samples that could not be mapped cleanly to single categories in the ICF.

Potential Applications in the SSA Disability Adjudication Process

The process of adjudicating applications to the SSA for federal disability benefits was one of the motivating use cases for this study. The adjudication process includes the collection and review of highly heterogeneous medical evidence, frequently collected as free text or semi-structured documents, to identify whether a person meets the necessary criteria for determining disability. This is a sequential process, which involves identifying information related to functioning at multiple steps. Claimants may be allowed based on meeting specified medical criteria organized into different body systems (34), where musculoskeletal criteria refer to several aspects of Mobility, criteria for mental disorders involve multiple areas of daily functioning, and criteria for multiple body systems refer to adherence to treatment. Claimants will also often report on daily activities and routines to provide details of functional abilities and limitations relevant to the workplace. Functional assessment is also a regular part of the adjudication process to determine whether a claimant is able to work, including through Residual Functional Capacity assessments, which include physical assessments highly dependent on Mobility. Thus, NLP-based tools to extract information related to functioning and organize it according to a standardized framework, such as the ICF, could be of use at multiple points in the disability adjudication process (35).

Broader Implications of ICF Coding With NLP

Natural language processing systems like the ones developed in this study have significant potential for helping to advance both clinical research and patient care. Identifying and organizing the rich information on individual function currently locked away in the medical free text can unlock valuable details to enrich the understanding of researchers of rehabilitation outcomes, and highlight salient details of experiences of patients in clinical decision-making. Prior research on automated and semi-automated ICD coding systems using NLP methods provides an instructive example of how these approaches can streamline medical coding processes (36–38). The growing integration of the ICF into clinical and research settings, from primary care (39) and EHR implementation (40) to pediatric research (41), presents similar opportunities to smooth the adoption and practical use of ICF categories with NLP-based coding systems. Vreeman and Richoz (42) describe potential benefits to both clinical care and research from integrating the ICF and other standardized vocabularies into EHRs, and Bettger et al. (43) highlight the role of EHR data in providing key insights to advance quality measures, research, and policy for rehabilitation. NLP technologies for ICF coding can serve as a valuable method to leverage the ICF as a lens to study the rich information collected in EHR notes.

In patient care, further development of NLP technologies can facilitate the decision-making process in several ways. Manabe et al. (44) developed an interactive system for selecting ICF categories in the EHR for mental health care; combining such an approach with NLP-based analysis could enable context-sensitive ICF coding during clinical note entry, improving the depth of information entered and its alignment with the ICF. At a new patient visit, NLP analysis of previously entered notes could also be used to highlight past limitations the patient experienced and inform patient-provider communication. Beyond the clinical setting, the use of NLP technologies for social support programs (such as the SSA disability programs that motivated our study) can help to more rapidly identify and organize key information from an individual's history to inform benefits decisions. Developing and evaluating new NLP technologies targeting further use cases in clinical research and patient care is a key direction for future research with significant potential for impact.

Limitations

The SSA documents used in this study were a mix of clinical records sourced from healthcare providers around the U.S. and specialty records for consultations commissioned by SSA, pertaining to a disability benefits claim. These documents are thus not representative of EHR notes in most health systems. In addition, the population, who is the subject of these documents, consists of claimants for federal disability benefits due to work-related disability; this population is not necessarily representative of persons receiving rehabilitation care (or other care involving functional assessment) more broadly. From a practical standpoint, many of the SSA documents used exhibited severe noise from the OCR conversion process from scanned images to text. In our experiments, model design hyperparameters were not explored, nor were alternative classification or candidate selection methods, potentially limiting the F-1 measures we were able to achieve.

CONCLUSIONS

Valuable information about patient functioning is regularly recorded in the free text portions of the EHR. The expressivity of natural language allows for the documentation of rich details about the functional experience, from levels of functional limitations experienced in different contexts to the goals and priorities of the patient for their own functioning. While free text documentation is difficult to analyze with traditional methods, NLP technologies enable a powerful, semantically enriched analysis of functioning information without losing expressivity. We analyzed two datasets of clinical records pertaining to disability benefits claims submitted to the U.S. Social Security Administration, using the ICF to identify and organize documented information about Mobility, Self-Care, and Domestic Life functioning of claimants. We found a rich diversity of functional status information in SSA documents and developed NLP models to automatically code this information according to the ICF. Our models achieved strong performance across key types of Mobility, Self-Care, and Domestic Life activities, demonstrating promise for automatically organizing functional status information within the ICF framework for easier analysis and review. We identified several practical limitations of the ICF for coding clinical reports, particularly the overly broad formulation of the Self-Care category d570 *Looking after one's health*. The results of this study and the NLP technologies assessed have significant implications for deepening the analysis of free text EHR data through an ICF lens and will contribute to ongoing efforts to learn more from the EHR in rehabilitation.

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because they include identified medical information collected by the U.S. Social Security Administration for the purposes of adjudicating claims for disability benefits, and are not able to be shared. Requests for more information about the datasets should be directed to Julia Porcino, julia.porcino@nih.gov.

AUTHOR CONTRIBUTIONS

DN-G: conceptualization of the study, development of methodology, conducting experiments, data analysis, and the lead author of this manuscript. JC: development of methodology, data collection and annotation, and co-author of this manuscript. P-SH: development of methodology, data collection and annotation, and co-author of this manuscript. MS: development of methodology, data collection, and annotation. RJ: development of methodology, data collection and annotation, and statistical analysis. JP: project administration, development of methodology, data collection, and co-author of this manuscript. LC: acquisition of funding and project administration. All the authors contributed to this article and approved the submitted version.

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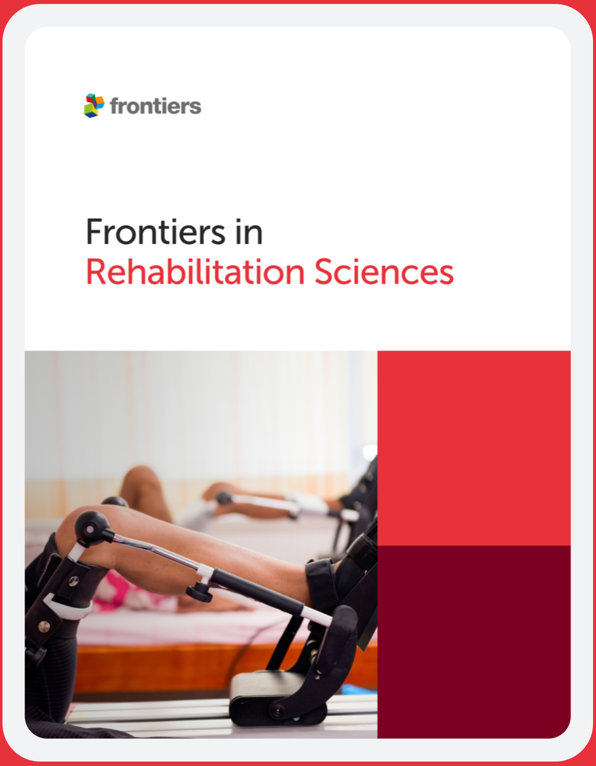

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